

UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

**The lived experience of engagement in occupations by older people during
the first year of widowhood**

by

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ABSTRACT

FACULTY OF HEALTH SCIENCES

Occupational Therapy

Doctor of Philosophy

**THE LIVED EXPERIENCE OF ENGAGEMENT IN OCCUPATIONS BY OLDER PEOPLE DURING THE
FIRST YEAR OF WIDOWHOOD**

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The world's population is increasing; whilst this implies improvement in health, for older people it may also imply more years spent in ill-health. A developing body of literature supports the role that remaining active and engaged in meaningful occupations can play in the maintenance of health and wellbeing at all ages. An understanding of how this can be supported is of importance. Whilst widowhood is a common experience; in older age it may be complicated by challenges resulting from increased age. The focus of this study was the experience of engaging in occupations by older people during the first year after spousal bereavement. A scoping review of the literature indicates the body of literature relating to occupation and bereavement to be small; in relation to older people this largely focuses on the development of skills to manage everyday occupations.

This study adopted a hermeneutic phenomenological approach to explore the lived experience for widowed, older people as they re-engaged in occupations and routines during the first year after the death of their spouse. Nineteen older widowed people were recruited with the help of the bereavement support teams at two hospices. The study took a longitudinal approach and participants were interviewed twice. The first interview took place approximately three months after they were widowed; the second at thirteen months.

A superordinate theme was identified, *recovering occupation*; this was underpinned by three sub-themes: *retreating to the familiar*; *taking stock*; and *revising occupation*. The study offers insight into the role played by occupation for the participants; and illustrates the challenges experienced and strategies adopted to facilitate engagement. The role of continuing bonds in this process is illustrated with evidence suggesting a novel form of occupational bond was developed. Implications for policy, health and social care practice; and the occupational therapy profession are considered.

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Academic Thesis: Declaration Of Authorship

I, Corinne Hutt Greenyer declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Title of thesis:

The lived experience of engagement in occupations by older people during the first year of widowhood

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signed:

Date:

Acknowledgements

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Chapter 1 Introduction

1.1 Introduction to the thesis

This thesis presents the findings and describes the process of completion of the investigation to explore the lived experience of engagement in occupations during the first year of widowhood for older people. The study was undertaken as part of doctoral study at the University of Southampton. The study followed a hermeneutic phenomenological approach (Van Manen, 1997) in order to explore recently bereaved older peoples' experiences as they began to resume engagement in everyday occupations. The concept of occupation is explored later in the thesis but in brief refers to the activities that people do which provide structure and meaning to their life.

This introductory chapter will provide background information about older peoples' experience of occupations and the implications of widowhood in order to explicate the contextual background for the study and justify the research question. It will also include a personal reflection by the author to explain her experience and interest in this topic and how this contributed to the development of this work. The chapter will conclude with an outline of the structure of the thesis.

1.2 Background to the study

The global population is ageing; this relates to an increase in both the median age of the population, and the number and proportion of older people in the population (ONS, 2015; WHO, 2002). The increase in birth rates after each of the World Wars and in the early 1960's combined with improvements in health across the population as a whole are argued to be behind these developments in the United Kingdom (ONS, 2015). Increases have seen the median age of the population rise to 40 years. In mid-2014 18% of the population were over 65 years of age; whilst 8% were aged over 75 years. The total number of people aged over 65 years has risen by 47% in the four decades leading to mid-2014. In the same period the percentage of people aged over 75 years has increased by 89% (ONS, 2015). The Kings Fund (2016) predicts that the 65-84 year old population will increase by 39% between 2012 and 2032; with the number of those aged over 85 years increasing by 106%.

These changes in the demographic makeup of the country are reflected across the globe (United Nations (UN), 2001). Although different countries may be at different stages in terms of the ageing of their population, the United Nations report World Population Ageing: 1950-2050 (2001) indicates the phenomena will not reverse. Increases in the expected length of life are understood to be due to improved nutrition and health (Royal Geographical Society, 2016). Chan et al (2016) challenge this however by suggesting that although the population is experiencing increased

longevity this does not necessarily reflect improved health; and may in fact suggest increased years spent in poor health. They propose that quality of life for older people should therefore be a priority.

Although the Kings Fund (2016) argue it is difficult to foresee the potential impact of these changes, there may be consequences for health and social care provision. Older people are considered more likely to experience physical and mental health symptomatology and chronic illness; and thereby incur greater costs in terms of health and social care (Clark et al, 2012). Furthermore, the increase in the older age population is likely to mean more older people will be living alone and require support to cope creating additional demand. The Kings Fund (2016) predicts that there will be a 60% increase in the number of older people with care needs by 2036.

In view of the increased number of older people in the population and the anticipated subsequent increase in demand for health and social care, there lies an imperative to identify means with which to effectively meet these changes with the finite resources available (Center for Disease Control and Prevention, 2007). Preventative measures to maintain the health and activity levels of older people must therefore be seen as a priority and integral to healthcare provision (Allen, 2008; World Health Organisation (WHO), 2002).

Recognising that maintaining active engagement with families and communities facilitates physical, mental and social wellbeing, WHO (2002) have promoted the concept of active ageing. This understanding is implicit in the International Classification of Functioning, Disability and Health (WHO, 2001). This is a model which, as well as considering health conditions and symptoms, incorporates environmental and participatory factors and acknowledges the intrinsic links between what people do and how they do it in relation to their health. The model considers opportunities and barriers to participation in activity and community.

A further priority in relation to older people, health and wellbeing must be to identify means to facilitate the independence of older people for as long as possible and to reduce or prevent disability (WHO, 2002). Hawley (2009) and Marcus-Varwijk et al (2016) identified that remaining independent in activities of daily living and social activities is a priority for older people and impacts on adherence to rehabilitation programmes following health crises and illness. Doble and Caron Santha (2008) proposed that participation in life and occupations which have personal meaning enhance health and wellbeing. This concept was further promoted in guidance published by NICE (2008; 2015) which considered the role of activity to enhance the mental wellbeing of older people.

The Well Elderly 2 study, a randomised controlled trial by Clark et al (2012) examined the efficacy of a programme aimed at maintaining skills to facilitate ongoing participation and engagement in

activity and occupation by older people. Using a previously tested model, known as Lifestyle Redesign®, the study involved implementation of a six-month intervention delivered in small group and individual sessions to older people living in the community, by occupational therapists. The intervention focused on supporting participants to identify, learn and rehearse strategies to overcome obstacles which prevented participation in everyday occupations and routines. Topics covered included energy conservation; joint protection; adaptation of activities; use of transportation; home and community safety; social relationships; coping with grief; and goalsetting. The outcomes measured pre- and post-intervention included perceived physical and mental health; depression; life satisfaction; and cognition. As in the original study, Well Elderly 1 (Clark et al, 1997), outcome measures demonstrated improvements which were maintained over 6 months.

Following the principles of the Lifestyle Redesign® programme and the Well Elderly 1 study (Clark et al, 1997) Mountain et al (2008) demonstrated the intervention transferred successfully to the UK. In a systematic review by Windle et al (2007) the Lifestyle Redesign® programme was deemed to provide the most robust evidence for health promotion for older people; and was used as the basis for the NICE Guidelines on occupational therapy and physical activity interventions to promote the mental wellbeing of older people in primary and residential care published in 2008 (NICE, 2008).

A literature review by Creek and Hughes (2008) considered the effects of occupation on health. They concluded that engagement in occupations impacts on health in both positive and negative ways. The positive benefits include expenditure of energy; social interaction and support; challenge and complexity; and perceived competence and achievement. Negative outcomes included the risk of pain and injury through overuse or sustained inactivity. Thus justifying the activity-based approach in the Lifestyle Redesign® programme.

The current study relates to widowhood in older age and the experience of participating in occupations following bereavement. Due to the disparity in life expectancy 50% of older women are widowed compared with 20% of men (Allen, 2008). Whilst most older widowed people cope with their changed circumstances with time; research has recognised there are significant physical, mental and social implications. Allen (2008) identified that whilst the majority of older people will have experienced bereavement; widowhood is especially challenging in terms of wellbeing. Bereavement and widowhood in particular can have significant impacts on health and wellbeing with spousal loss being associated with further secondary losses including loss of social networks. In addition to the health risks associated with ageing, widowhood can exacerbate health concerns and be a cause of loss of independence for older people. DiGiacomo et al (2013)

reported on potential physical and mental health implications for widows. Wilcox et al (2003) identified that self-neglect in relation to self-care activities such as meal preparation and eating, was notable for widows. Fitzpatrick et al (2001) and Allen (2008) identified that widowers were more likely to experience increased physical and mental health conditions during the first two years of widowhood; and that subsequently their opportunities for social interaction and support were markedly reduced which further exacerbated the risks to their health.

The transition to widowhood demands a revision of personal identity to widow or widower. In turn this is likely to demand a review of personal occupational identity. This term refers to the idea that what people do demonstrates to others who they are (Unruh, 2004; Christiansen et al, 2015). In older age occupational identity is subject to adjustment as how people spend their time changes; and is likely to change again in widowhood due to the secondary impact of bereavement resulting in changes to and reductions in social networks and health status. Changes in health and reduced opportunity to participate in activities which offer meaning may render the reconstruction of occupational identity challenging, and place the widowed older person at greater risk of health concerns.

Thus research and current Government drivers have identified the relevance of considering how older bereaved people spend their time and their experience of engaging in activities and occupations. Economic and health indications render this a pertinent topic for exploration. By exploring the lived experience of engaging in occupations findings from the current study will serve to elucidate and inform health and social care professionals, including occupational therapists, of the importance of “doing” for the longer term health and wellbeing of older widows and widowers.

1.3 Personal professional context

The following reflection on my professional experience and the journey to where the current study began is presented in the spirit of transparency (Lincoln and Guba, 1985). Completion of the study was underpinned by a phenomenological approach and it is acknowledged that the findings presented in this thesis reflect interpretations made of the data as understood through the lens of previous experiences and understandings.

My professional background as a mental health occupational therapist frequently exposed me to the potential impacts of loss. Working in both acute inpatient mental health units, community mental health and substance misuse services had afforded me opportunity to work with clients who experienced some form of loss as a result of their primary diagnosis. For clients with diagnoses such as schizophrenia, losses included loss of the future they had anticipated; and as their condition progressed a loss of skills, roles and relationships became more apparent. For

other clients some form of loss was the trigger to their mental health or substance difficulties. For these clients their primary loss might have been a bereavement, a broken relationship or unemployment. For most clients their primary loss led to a series of secondary losses which were often the focus of occupational therapy intervention. For people with schizophrenia or a substance misuse disorder this might involve support to develop new or compensatory skills to facilitate function; for people with depression or anxiety it might entail identification of strategies to enable them to resume the occupations they had ceased to engage in.

Opportunity to attend a bereavement counselling programme provided by CRUSE, a bereavement support organisation, provided me with skills to set up a specialist resource within the secondary mental health service where I worked at that time. This was a bereavement focused service but the experiences gained through this fed into my work with clients who were experiencing other losses. It began to appear that loss was a common concern and contributor to mental health issues. Recognition of this fuelled a nagging concern that I was looking for loss in all of my clients and that this might lead to neglect of other difficulties they were experiencing. Around that time Illott (1996) published a paper which spoke of the centrality of loss in occupational therapy practice; this provided reassurance about my experience. The CRUSE course had provided skills in talking with bereaved people; but the occupational therapy literature offered nothing in relation to praxis with clients who have experienced loss. Subsequently my work with clients relied on using a client-centred approach and implementation of practical measures to address their occupational needs. Professional practice illuminated the broad reach of loss in everyday life.

A move into Education provided further opportunity to explore the literature on bereavement whilst preparing lectures. In the interim period since this had last been explored attention had moved from Freud's argument that the bereaved must detach from the object of their loss which had rarely fitted with my clients' experiences, to one proposing maintenance of ongoing bonds and the dual-process model; both of which were a more effective fit with my practice experience. Still there was very little mention of loss and bereavement in the occupational therapy literature.

Opportunity to undertake doctoral study provided a chance to consider this further and to explore how loss impacts on participation in occupation. Whilst most of my professional practice had been with younger adults, exploration of the literature and reflection on my experience resulted in focusing on older people. Older people were potentially more likely to have an element of choice in how they spent their time and which occupations they engaged in; whilst younger people were more likely to have to engage in occupations such as employment. This thesis is the result of these experiences which have formed a thread through my professional

practice and will hopefully ultimately contribute to the limited literature available to the profession.

1.4 Structure of the thesis

The thesis is organised into seven chapters:

- Chapter one introduces the research project, provides information on the background to the study and the author's professional background and interest in the focus of the project. These serve to offer a rationale for the endeavour. The aims of the research and the research question which were developed are also presented.
- Chapter two presents the background to the study. This chapter covers three key areas: bereavement theory is discussed to provide contextual detail to the study. Although an everyday word occupation is understood in a specific way by occupational therapists and this is explained by examination of definitions used within the profession. The chapter concludes with a scoping review of the literature on occupation following bereavement.
- Chapter three describes and justifies the choice of a qualitative, interpretative phenomenological methodology to guide the structure and organisation of the study. The longitudinal study design, data collection and the approach taken to analyse the data are also explained.
- Chapter four provides a detailed explanation of how the study was conducted. The chapter is organised in three sections which describe the stages followed from preparation for data collection; data collection; and how the data collected was organised and analysed. This chapter also considers the ethical issues identified and how these were managed.
- Chapter five introduces the participants who took part in the study and presents the findings developed through the analysis of the data. A superordinate theme; three themes and nine sub-themes were identified and are explained in this chapter with extensive use of quotations taken directly from the interview transcripts.
- Chapter six identifies and discusses key issues drawn from each of the themes developed during analysis. These are explored in relation to theory and published literature drawn from a range of disciplines.
- Chapter seven concludes the thesis. This chapter includes consideration of the implications of the study and the findings to establish the contribution of the study; identifies the limitations to the study and proposes further research areas identified as a result of this study. The thesis concludes with a reflection on the process of completing the study.

The thesis includes a number of supporting appendices which are signposted throughout the main body of the document.

1.5 Terminology

The terms bereavement, grief and mourning are used interchangeably in the literature (Hoppes and Segal, 2010). For consistency the following definitions, taken from Parkes (2001) are used throughout the thesis:

- Bereavement – refers to the experience of loss
- Grief – refers to the complex reactions experienced following a loss
- Mourning – refers to the experience of processing grief; commonly understood to involve processes of adaptation

1.6 The research aim and question

The current study developed from a professional interest in loss and bereavement and the impact of this experience on occupation. The decision to focus on older peoples' experiences followed exploration of the literature on bereavement which indicated a paucity of research about older people despite acknowledgement that this group of people were more likely to have experienced bereavement (Allen, 2008). It is proposed that this study will provide a unique insight into the experience of engaging in occupations by older people during the first year after spousal bereavement. This focus is currently missing from what is already known about older people and spousal bereavement and so the study will make an original contribution to understanding in these areas.

The underpinning research question, aim and outcomes evolved from professional interest in issues such as what it would be like to have to do things alone for the first time? Did people do the same things in widowhood as before their bereavement? And recognition of the potential impact of traditional marital roles which may have been held by older people and how these might affect experience in widowhood.

The primary aim of the study was kept intentionally broad as it was recognised to be an exploratory study of an area which so far has not been investigated by occupational therapists.

The aim of the research was:

To explore the lived experience of participation and engagement in occupations during the first year following spousal bereavement.

The underpinning research question for the study was:

How is engagement in occupation perceived by older, bereaved spouses?

The study was undertaken with the following anticipated outcomes:

- Development of an understanding of the lived experience of engaging in occupations during the first year of widowhood in older age.
- Identification of how older people who are bereaved perceive their daily routines and activities.

1.7 Summary of the introductory chapter

This chapter has introduced the current study and contextual information from which and upon which it evolved. An overview of the potential role of engagement in occupations in older age and the relevance of this in widowhood has been presented to justify why it is appropriate to undertake the current study. The research question, aim and anticipated outcomes; and the structure of the thesis have been explained. The next chapter will provide an overview of bereavement theory; explanation of the concept of “occupation” and how it is understood for the purposes of this study; and present a scoping review of the literature on occupation and bereavement.

Chapter 2 Bereavement theory and literature review

2.1 Introduction

Chapter one of the thesis outlined the aim underpinning this research project; to explore the lived experience of engagement in occupation by older people during the first year of widowhood. Two areas of focus and understanding are key to this endeavour – occupation and bereavement. Both of these are deemed part of normal human experience (Oakley et al, 2002; Stroebe et al, 2007; Miliken et al, 2007) and provoke subjective responses and interpretations. In order to establish the context within which they are understood in this study exploration of the understandings of both concepts will form the basis of this chapter.

An overview of the development of bereavement theory forms the first part of the chapter; the second section will define and explain the concept of “occupation”, differentiating it from the more commonplace term “activity”; the chapter will conclude with a scoping review undertaken to investigate the literature on occupation following bereavement. This information is included to provide context for the study and thesis; and provides information regarding the pre-understanding of the researcher. As occupation forms the focus of the project it might be expected that this would be positioned first, however as concepts and themes from bereavement theory occur in the literature explored on occupation, the chapter will commence with a review of bereavement theory in order to provide a more fluent approach for the reader.

2.2 Grief and Bereavement

This section of the chapter will discuss understandings of grief and bereavement and how these have evolved. There are perhaps two key debates which have attracted significant attention in relation to bereavement – understandings of grief as a psychiatric condition requiring intervention or as a social construct; and whether the aim of grief is detachment from or maintenance of bonds with the deceased.

Klass (2014) discusses how attention moved around the end of the 19th century from a focus on the wellbeing of the dead to the wellbeing of the bereaved. Until this time the influence of the dead on the living was seen as normal experience; different religions and cultures guided communities to show respect to the dead as a means to appease their spirits and benefit from their benevolent power over the living. In Westernised cultures the dead were seen to provide moral guidance and reassurance; this culminated in the growth during the second half of the 1800s of the spiritualist movement in America and Britain (Klass, 2014). However as its popularity waned attention moved instead to focus on the bereaved; perhaps encouraged by the First World War and the large numbers of deaths which occurred as a result. Nevertheless Beischel et al

(2014) propose that significant numbers of bereaved people continue to seek contact with the deceased.

Freud's work *Mourning and Melancholia* (1917/1984) was published around the time when attention moved from the wellbeing of the dead to the wellbeing of the bereaved (Klass, 2014). Simultaneously it initiated the focus on grief as a health issue rather than a social issue. Until this time bereavement had been seen as a normal, albeit frequently stressful and challenging, life experience (Stroebe et al, 2007; Neimeyer et al, 2014). Freud's paper placed bereavement and grief within the realm of psychological experience and initiated debate which continues regarding the health implications of grief and whether intervention is required or even beneficial (Granek, 2010). Nevertheless it is now acknowledged that grief has emotional, behavioural, social, cognitive, physical and spiritual repercussions for the bereaved (Buglass, 2010; Hall, 2014); with emphasis on a return to previous levels of functioning (Zisook and Shuchter, 2001).

Despite the lack of widespread consideration of grief as a cause of significant and long-term distress until Freud's paper, it had formed the basis for earlier writers and researchers. These include Burton (1651) who wrote about melancholy caused by bereavement. Granek (2010) describes further references to grief including Rush, an American physician who although not claiming grief to be pathological described a range of symptoms and treatments. Shortly prior to the publication of Freud's work on grief, Shand (1914) also wrote about loss and grief in his text *The Foundations of Character* in which he described grief as sorrow and proposed it was relieved by sharing with others and social support, but worsened if kept hidden from others.

2.2.1 Freud's interpretation of grief

The publication of Freud's essay *Mourning and Melancholia* in 1917 is widely recognised as the basis for the development of modern bereavement theory. In it Freud argued that mourning necessitated the bereaved undertaking a process of grief work during which all previous memories and experiences shared with the deceased are brought to consciousness and examined. The purpose of this process, called decathexis, was to enable the emotion invested in each memory to be withdrawn, thus freeing up the individual to move on and develop new relationships (Freud, 1917/1984). This process came to be seen as an active process of "grief work" which must be completed in order to avoid potential future pathological repercussions (Stroebe, 1992; Granek, 2010). Freud acknowledged that often this was a lengthy, painful process, generally undertaken in fits and starts, due to the immense emotional energy required. Ultimately grief was seen to liberate the ego from its connection to the deceased through the sublimation of emotion into new projects and relationships ultimately resulting in disengagement from the deceased and the shared past, and re-engagement in life (Freud, 1917/1984; Granek, 2010).

As Freud's work continued to develop with the integration of incorporated object relations theory, the concept of sublimation of grief work was proposed. Simply, this relates to the continuation of a relationship to the deceased through the process of internalising aspects of the previous relationship whilst acknowledging the reality of the death; permitting the maintenance of an internalised representation, or image, of the deceased and allowing for ongoing interaction with that person (Klass et al, 1996). This would not be the outcome of the detachment that Freud is reported to have espoused. It must be acknowledged that Freud did not appear to advocate detachment be a complete severing of links with the deceased as has been portrayed. Significantly he stated that grief was not a condition requiring specialist intervention:

"although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on it being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful" (Freud, 1917/1984 page 252).

Freud's work on mourning developed out of his previous theoretical work, and was perhaps also influenced by the historical period in which it was conceived, notably during World War 1 when an acknowledgement of the impact of grief and loss was perhaps widely evident. During this period Freud also experienced several personal bereavements, most notably that of his daughter and his grandson. Freud's personal experiences of grief have been well documented and perhaps reiterate his conviction that detachment is not the outcome of mourning. In several quoted letters his acknowledgement that grief is ongoing is evident as is his recognition that he could not give up his emotional attachment to the deceased "way deep down I sense the feeling of a deep narcissistic injury I shall not get over" and "a loss not to be forgotten" (Gay, 1988).

It might be argued therefore that Freud's work on mourning was variously influenced by the period when it was produced; his personal experience of grief; and observations of the experiences of his patients. It is this last source that has attracted significant critique of his work. Grünbaum (1986) argued that evidence procured from therapeutic work with patients was insufficiently objective and liable to have been created through suggestion to the patient who placed the doctor in the position of expert. Whilst offering broad support for Grünbaum's critique Farrell (1986) proposed that despite this flaw in the reliability of his data Freud's work, to refute his work on this basis posed the risk of denying any validity in the experiences of his patients. MacCurdy (1922, cited in Dozois, 2000) had earlier described Freud's work as based on a small number of "clinically impure" cases; a fact acknowledged by both Freud in the introduction to *Mourning and Melancholia*; and Abraham who described Freud's work as descriptively accurate despite the fact it was based "on a small sample of Victorian Viennese" (Dozois, 2000, page 184).

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Despite this and subsequent to publication of *Mourning and Melancholia* grief began to be viewed increasingly as a pathological entity (Granek, 2010). This is an interesting development considering that Freud is acknowledged to not classify experience into normal and abnormal i.e. pathology, but viewed experiences as on a continuum along which everyone moved throughout life. His work did however promote the understanding that everyday events could have a psychological impact and it is on this premise that bereavement and grief came to be seen and studied primarily as a medical and psychiatric phenomenon (Granek, 2010).

Abraham, a contemporary of Freud, whilst acknowledging links between the two conditions differentiated further the concepts of mourning and melancholy. Mourning was argued to be specifically related to grief and bereavement, the purpose of which was to ultimately preserve a relationship with the deceased through introjection, rather than the internalisation proposed by Freud. Introjection required the bereaved to internalise an impression of the deceased allowing for the relationship to continue. Melancholy differed in that the affected individual was anticipated not to retain knowledge of the cause of their distress (Granek, 2010).

Deutsch, a contemporary of Freud, focused on describing the phenomenon of absent grief where the bereaved appear not to engage with grief work (Granek, 2010). Alongside chronic and excessive grief this came to be seen as a pathological phenomenon, preventing the individual from moving forward, and resulting in what would be described as pathological grief, described in psychoanalytic terms as potentially causing damage to the ego (Klass et al, 1996). It might also be likened to a defence mechanism with a self-protective aim adopted when ego-strength is felt to be inadequate to cope with the strong emotions experienced in grief.

The concept of complicated grief can thus be traced to both Freud's and Deutsch's work and was later reinforced by the work of Klein in the 1940's. In *Mourning and Melancholia* (1917) Freud's description of the preoccupation with the deceased, and experiences such as dreaming, ambivalence towards, and psychotic phenomena linked with the deceased may be clearly linked to the notion of pathological grief (Bradbury, 2001). Close attention to Klein's work however suggests her interpretation of grief and mourning are linked to normal child development (Granek, 2010) and was perhaps similar to the later work by Bowlby on attachment theory (Bowlby, 1998). Nevertheless Freud's interpretation of grief, although arguably based on unreliable evidence, on close investigation does in fact say more about more recent understandings of grief than is claimed. Despite referring to the notion of detachment, critics of his work in fact help to clarify other themes in his paper relating to ongoing bonds to the deceased and grief as pathology. Subsequently psychoanalysts commonly referred to grief as a pathological condition requiring intervention.

2.2.2 Grief as a psychiatric phenomenon

By the middle of the twentieth century bereavement was increasingly recognised as a psychiatric concern. One of the main proponents of this was Lindemann, an American psychiatrist who published a seminal paper on the role and necessity of grief work following his study of people bereaved as a result of a fire in a night club (Lindemann, 1944). This was the first empirical study of grief and in his paper Lindemann urged recognition of psychiatry as crucial to the recovery of the bereaved:

“the understandings of reactions to traumatic experiences whether or not they represent clear cut neuroses has become of ever increasing importance to the psychiatrist” (Lindemann, 1944, page 141).

His work also included identification of normal and abnormal grief symptoms, reinforcing the idea of grief as a pathological condition. This notion perhaps neglected the fact that the majority of people who experienced a bereavement coped without intervention by health professionals (Parkes, 2001; Schneider, 2000).

Lindemann’s work heralded the development of grief as an important area for psychological and psychiatric research which further reinforced the idea of it as a pathological experience. Research was used to investigate potential outcomes and appropriate interventions for the bereaved (Parkes, 1972; Granek, 2010). Identification of the symptoms and course of grief confirmed it as a condition which could be treated and cured by the medical profession, or more likely psychiatry (Granek, 2010). Lindemann’s work was taken up by other researchers, notably Marris (1958; 1986), but this period largely saw research focused on the identification of the symptoms and course of grief.

2.2.3 Grief as a process

In the late 1960’s Kubler-Ross (2014) undertook research with people who were dying and identified five stages common to the experience: denial and isolation, anger, bargaining, depression, and acceptance. Although her work was based on research with people who were dying it has come to be applied to the bereaved as well. Her work was perhaps the first to focus on the idea of grief as a process with specific stages to be worked through towards completion.

At a similar time a return to a more psychological approach was initiated by Bowlby in the 1960s. Bowlby working in the psychoanalytical tradition developed the attachment theory of grief. This was developed from his work in the 1950’s which attempted to explain the impact of separation from the primary caregiver on the developing child. He later related this work to bereavement to describe individual interpretations and experiences of loss, describing grief as a form of separation anxiety (Bowlby, 1998).

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Following Kubler-Ross, a key element of Bowlby's work which has endured in more recent understandings of bereavement is the idea that grief follows a series of stages. Bowlby's stages of grief approach to bereavement sees grief as a process, albeit not a sequential process. The stages described by Bowlby are numbness, protest, despair and yearning, and detachment (Bowlby, 1980) which broadly reflect those proposed by Kubler-Ross. Linked to his work on attachment they reflect the reactions demonstrated by children when left by their primary caregiver. Reactions such as crying, searching and even anger, as seen in the reproach demonstrated towards the returning caregiver, are experienced by bereaved people. Bowlby described anger in grief as reflective of the maintenance of hope held by the bereaved that the deceased will reappear alive; whilst anger continues so too does hope. Bowlby explained this in terms of the notion that irretrievable loss is understood at a deep level, to be rare and so initially is not considered (Bowlby, 1980). Initially Bowlby identified the final outcome of grief to be adaptation, and proposed that an ongoing sense of attachment to the deceased may facilitate this. This was later revised to refer to ultimate detachment from the deceased, echoing earlier psychoanalytical theory (Bowlby, 1980; Bowlby, 1998).

Bowlby's work on attachment formed a basis of work carried out by Parkes, a psychiatrist, who undertook research into the grief reactions of widows; his work used the stages approach to grief identified by Bowlby to explain data (Granek, 2010). For Parkes, as Bowlby, the final outcome of grief was detachment. He could see no worth in symbolic interactions and ongoing connections with the deceased, despite the large proportion of his participants who reported finding comfort in ongoing conversations and interactions with their deceased (Parkes, 2001). He described this as a common but temporary strategy to avoid the pain of grief (Parkes, 1972). Parkes' research reinforced Lindemann's perspective that grief was an illness which could and should be treated (Granek, 2010).

Raphael (1984) drawing on earlier work by Freud, Lindemann, Parkes and Bowlby also described grief as composed of phases. She asserted the first of these to be shock, numbness, disbelief; during which a form of dissociation may be experienced wherein whilst there is intellectual acknowledgement of what has occurred, the full impact of all that the loss involves is denied. Similar to Bowlby's work this initial phase is followed by yearning, pining and longing; during which there may be intense preoccupation with the deceased and hyper arousal alerting the bereaved to any reminder of their existence. During this phase Raphael asserts there may be intense affective responses including anger. With time the reality of the death becomes more real as the absence of the deceased is reinforced; reflecting Freud's use of the concept of decathexis. Subsequently there comes a gradual acceptance with which the relationship bonds are relinquished.

In concluding this section comment should be made regarding bereavement support. Many bereavement interventions were, and continue to be, based on the work of Freud and Parkes which dominated during much of the twentieth century. This is despite the fact that Parkes later revised his view and stated: *"There is no evidence that all bereaved people will benefit from counselling; and research has shown no benefit to arise from the routine referral of people to counselling for no other reason than that they have suffered bereavement"* (Parkes, 1998, page 18).

Stage theory-based interventions focus on the understanding that the outcome of grief is detachment and that adherence to the identified stages or tasks of grief work will lead to this. Critique of this approach has been made by Wortman and Silver (1989) who commented that the stages approach to grief resolution perpetuated unrealistic expectations that initial distress will be completely abated when the intrapersonal loss is worked through. Attig (2004) also argued that the stages approach to grief intervention applies a generalised, linear approach suggesting that the feelings of the bereaved will occur in a prescribed order. Neimeyer (2001) argues there is no research or practice evidence for the stages approach; whilst acknowledging there may be common experiences (Neimeyer, 2000).

The approach also denies the individual opportunity to find meaning in their loss, reinforcing helplessness when they are unable to adhere to the anticipated progression. Hall (2014) highlights the inadequacy of stage theories in addressing the broad range of impacts experienced by the bereaved and their families and networks. A recent paper by Breen et al (2013) provides evidence that the stages approach continues to be the basis for much of the grief education provided to health professionals thus perpetuating this approach. Focus on this approach further serves to perpetuate the risk of literal interpretation because health professionals unaware of more recent, social interpretations of grief have no alternative to offer; adherence to this model may consequently create feelings of stress for the bereaved and cause them to disengage from the help they need. The stages model of grief continues to be widely endorsed as the usual course of bereavement by literature and media; and so the unquestioning acceptance of this as correct persists (Thompson, 2012).

2.2.4 Tasks of grief

In what might be considered a more benign approach to the notion of grief work identified by Freud, Worden (2009) identified four tasks of grieving, all of which he claimed must be completed before grief can be said to be completed and to avoid later difficulties, reflecting the developmental approach previously adopted by Klein (Thompson, 2012). Worden's use of the word "tasks" reflects Freud's idea of "grief work", and recognition of it as an active process in which the bereaved must engage rather than the more passive "phases" which can be

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experienced but do not necessarily demand active engagement as described by Bowlby and Parkes (Worden, 1991; Worden, 2009). Worden claimed that not every bereaved person needed treatment to overcome their grief but identified four tasks of grieving that bereaved individuals needed to address (Worden, 2009):

1. Accept the reality of the loss
2. Deal with the emotional and behavioural pain
3. Identify ways to overcome barriers to readjustment after the loss
4. Find a way to maintain a bond with the deceased while feeling comfortable to reinvest in life.

In the first publication of Worden's seminal work on grief work in 1991, he identified the final task as being detachment. Over subsequent editions this has changed acknowledging a wider move within the discipline from detachment as the outcome of grief to acknowledgment of more recent understandings as being the maintenance of ongoing bonds.

Whilst the tasks of grief approach offers a useful way to understand adaptation to grief; the tasks are broad and lack specific details. The approach has also been criticised for not offering explanation for the more complex aspects of grieving (Thompson, 2012). Neither does it consider the role of context in the experience of grief; more recent models of grieving recognise the impact that social context has on the experience of grief (Thompson, 2012). Field (in Stroebe et al, 2008) suggests that the notion of grief as work reflects a narrow explanation of the concept of adaptation. More contemporary understandings provide a means to understanding grief in a wider context.

2.2.5 Grief as a life event

Counter to the growing body of research claiming grief to be a pathological condition, was further recognition of it as a normal life event. Pincus (1974) reiterated Freud's view that the bereaved do not require specialist medical or psychoanalytical interventions, advocating instead the availability of long-term support to facilitate the bereaved to work through and move on from their grief. Pincus describes how sharing memories, visiting the deceased's grave and contributing to the community have all been found to be of benefit to the bereaved. These activities could all be argued to be forms of continuing bonds, a more recent focus of attention which focuses on the transformation of the relationship between the deceased and the bereaved.

In contrast Raphael (1984) described ongoing links with the deceased as temporary and akin to fantasy, the main purpose of which was to allow the bereaved to deny the reality of their situation, and thus avoid the necessity to move forwards and form new relationships. The view of ongoing interaction with the deceased constituting a form of wish fulfilment was reiterated by

Saunders who also saw it as a sign of unresolved grief, or "*a retreat from reality*" (Saunders, 1989, p 19).

The concept of continuing bonds presents a very different interpretation of grief and reflects a postmodern perspective (Hall, 2014). Stroebe & Schut (2005, page 477) define a continuing bond as "*the presence of an ongoing inner relationship with the deceased person by the bereaved individual*". This definition intimates the purpose of grief as being to facilitate adaptation to changed circumstances rather than signifying finality and detachment. Klass et al (1996) introduced the concept of continuing bonds as an approach to grief resolution focusing to a large extent on links which the bereaved formed as a means to maintain connection to the deceased. Hall (2014) describes how the focus of grief then becomes a question of adapting the former relationship rather than finding a way to detach emotion from memories of it. Continuing bonds are understood as providing a means by which the bereaved may transform their living, embodied relationship with the deceased.

One prominent aspect of the continuing bonds theory is the reinterpretation of the diagnosis of complicated grief that it offers. Whereas earlier theories propose that difficulty in detaching emotional energy from the deceased represented pathology, the continuing bonds approach offers an alternative. Maintaining ongoing links to the deceased may simply indicate a different way of living life as a bereaved person. A report published by the Center (*sic*) for the Advancement of Health (2003) reinforced this view, proposing that the maintenance of continuing bonds is not necessarily an indicator of complicated grieving but that the maintenance of ties is not unusual and can be associated with adaptive behaviour.

Although the concept of ongoing bonds with the deceased is seen as a recent development; elements of the approach can be found in the work of earlier theorists who overtly appeared to emphasise detachment as the ultimate goal of successful grieving. As has been shown Freud did not appear to acknowledge the need for detachment in his own experience of grief (Gay, 1988). He referred to the concept of sublimation of grief; involving the internalisation of aspects of the previous relationship whilst acknowledging the reality of death. Freud's perspective, as in the continuing bonds approach allows for ongoing interaction with the deceased. Bowlby (1980) acknowledged the resolution of grief to involve the establishment of a changed bond with the deceased rather than complete detachment and severance of previous bonds. Bowlby's work on separation assumes the need for bonds to be broken, however perhaps rather confusingly his work also acknowledges the adaptive role that the maintenance of these bonds might play (Bowlby, 1980; Bowlby, 1998).

2.2.6 Form of Continuing Bonds

Whilst early writers on continuing bonds focused on forms which can be described as intrapersonal (Klass et al, 1996); others forms have been explored which reflect behavioural, social and sensory experience (Valentine, 2008). Behaviours such as visiting the grave of the deceased; maintaining the environment as it was when the deceased was still alive; and interacting with their possessions have been recognised (Hall, 2014; Valentine, 2008; Klass et al, 1996). Social representations of ongoing bonds might include sharing memories with others (Valentine, 2008); whilst sensory experiences include sense of presence phenomena (Conant, 1996; Bennett and Bennett, 2000).

It is recognised that the form and meaning of continuing bond is dynamic and may change over time (Hall, 2014). Forhan (2010) describes how her family create the way they maintain ongoing bonds with their child and how these have evolved as her other children have grown older. Social media also provides a means to maintain the presence of the deceased through online memorial websites and maintenance of the deceased's own social media presence. McEwen and Scheaffer (2013) reported 50% of their study participants memorialised their deceased's Facebook page including the maintenance of automated greetings sent on anniversaries and birthdays from the deceased person's page. Moules et al (2004, page 104) propose grief to be an ongoing process that changes over time but reflects an ongoing relationship with the deceased; "moving ahead whilst walking backwards".

Such examples offer methods by which the construction of a durable, ongoing biography of the deceased developed by those who knew them, as proposed by Walters (1996), might be undertaken. This approach represents a departure from other concepts which adopt an individualistic approach by focusing on the sharing of emotional meanings attached to memories of the deceased. Walters' (1996) model proposes a more sociological approach which is in contrast to the psychological emphasis previously placed on experiences of grief. The conversations and sharing which are required to create this enduring biography of the deceased enable a process of moving on with as well as without the person who has died. Walters' further justifies his approach by setting it in the context of a late modern, increasingly secular society lacking in the structures provided by traditional religions.

2.2.7 Continuing Bonds as Positive or Negative Coping Strategies

Rando (1993), echoing psychoanalytic and psychiatric arguments proposed that any form of ongoing relationship or bond with the deceased was maladaptive and a form of unresolved or pathological grief which would inhibit progress. Gassin and Lengel (2014) proposed that prolonged grief was found to be indicative of physical and psychological continuing bonds.

Conversely, Shand, a contemporary of Freud, published work which appeared to support the notion of the adaptive role of continuing bonds (Shand, 1914). Shand described the potential impact of maintaining and relinquishing bonds, whilst also acknowledging that different forms of continuing bonds may provide different outcomes in terms of adaptive and maladaptive coping strategies (Shand, 1914; Stroebe & Schut, 2005).

Bowlby's (1980) work on attachment theory posited that the bereaved may continue to act as they did when the deceased was alive – where the bond to the deceased was problematic in life it is likely to remain so after death. A highly dependent relationship in life may indicate insecure attachment; the personality traits which accompanied the insecure attachment, anxiety, dependence and clinging behaviour, may well manifest in a tenacious maintenance of bonds to the deceased who had previously been a symbol of strength and confidence in life (Bowlby, 1980). Although in such circumstances the bond may be perceived as adaptive in terms of maintaining aspects of life for the widow/er; it is likely to be less helpful in relation to adaptation.

Confirmatory evidence of this was reported by Field et al (2003) who found that widows who demonstrated higher levels of helplessness and less blaming behaviour towards the deceased were more likely to report using continuing bonds as a coping strategy. Use of continuing bonds was also associated with higher levels of grief symptoms at five years following bereavement. Later work by Field et al (2004) identified that continuing bonds were related to negative affect earlier on in widowhood, but became a more positive strategy as time progressed. Neimeyer et al (2006) reported research that suggested the stronger the continuing bond, the greater the level of complex grief symptoms likely to be experienced although this was tempered by the ability of the bereaved to make sense of the death personally, spiritually and practically.

Whilst a large body of literature exists which portrays continuing bonds as adaptive (Field et al, 2005) there continues to be a lack of consensus regarding their efficacy. One of the challenges in establishing the role that ongoing bonds might play over time relates to the lack of reliable means to measure these (Field in Strobe et al, 2008). In a paper which considered how the continuing bonds model of grief might be integrated within Bowlby's attachment theory of loss, Field et al (2005) proposed that extended and unchanging use of specific forms of continuing bonds which reflect a reluctance to relinquish possibility of reunion with the deceased suggest complicated grief. Strada (2013) emphasised the understanding that bonds change over time and hold different meanings and consequences over time. This lies in direct contradiction to Klass et al's (1996) claim that the continuing bonds model refutes the existence of complicated grief. Field et al (2005) claim that the implication that continuing bonds are adaptive is unfounded. This must therefore bring into question the experience of cultures where ongoing bonds in grief are considered core concepts, such as Chinese ancestor worship (Klass and Goss, 2002).

2.2.8 Meaning making in grief

Whilst the debate regarding the value of severing ties or maintaining bonds remains unresolved (Gassin and Lengel, 2014); approaches to grief which emphasise the importance of rebuilding the world and creating meaning from the loss have developed. Adaptation to the new situation prompts an iterative process of meaning-making which requires the development of new meaning for the bereaved (Gillies and Neimeyer, 2006). Difficulty in doing so is claimed to be a contributor to prolonged or complicated grief reactions (Prigerson et al, 2009).

The process of meaning-making following bereavement addresses two issues:

1. Making sense of the loss
2. Finding benefit in the loss, for example personal growth as a result of the experience (Calhoun and Tedeschi, 2013).

Neimeyer et al (2014) describe grief as a social construction and argue it to be an interactive process rather than the intrapsychic process indicated by previous interpretations of the experience. They refer to the importance of being able to communicate with others about the deceased and their loss; in doing so meaning in the loss can be negotiated. This approach reflects Walters' (1996) model and indicates a role for individual and shared continuing bonds in the reconstruction of the deceased's identity.

Hibberd (2013) proposes that the process of finding meaning in the loss should also involve identifying the significance of the life of the bereaved. She argues that through making sense of the loss, the bereaved also reconnect with personally important values and goals and experience aspects of their life as significant. Neither of the models proposed by Neimeyer et al (2014) or Walters (1996) recognise the potential challenges or barriers to meaning reconstruction as might be experienced by those who lack the cognitive skills necessary to engage in the activities and interactions required. They also perhaps pose a challenge to more traditional interpretations of grief which place emphasis on detachment (Stroebe, 1997); although perhaps the focus on grief as work or task-driven may be common to both approaches. Walters' model could be argued to be a social, interpersonal approach; whilst more traditional approaches emphasise intrapersonal experiences. Baddeley and Singer (2009) propose that the benefits and success of interaction with others in the development of meaning from the death, and the transformation of the relationship with the deceased; depend on the relationship between those engaged in the interaction, their personalities and congruency of the individual goals for participation.

2.2.9 Adaptive approaches to grief

Concurrent to the development of the ongoing bonds understanding of grief was the dual process model of grief proposed by Stroebe and Schut (1999). The dual process model proposes two

different styles of coping which work together to produce a dynamic process, leading ultimately to adaptation. The model includes three components: loss and restoration focused processes, and the act of oscillation between the two behaviours (Stroebe and Schut, 2010).

Loss oriented activities are those which involve the individual in accepting and dealing with the loss experience; expression of emotion and rumination on events surrounding the death or the life lost are considered loss oriented behaviours. The restoration oriented focus of the model refers to the demands placed on the bereaved individual to continue to complete everyday life activities; the need to adjust to unfamiliar roles and develop new skills (Stroebe and Schut, 2010). These activities are also recognised as important coping strategies offering respite by means of avoidance of and time-off from grieving; offering valuable distraction from the more emotion focused tasks (Stroebe and Schut, 1999; Shear, 2010). This aspect perhaps reflects Freud's description of grief work occurring in fits and starts due to the emotional energy required. Richardson (2010) and Stroebe and Schut (2010) suggest that loss oriented coping dominates grieving initially and decreases as grieving progresses and restoration coping becomes more relevant or imperative; reminiscent of Freud's view that over time the bereaved sublimates energy into new projects. The dual process model reflects elements of Walters' (1996) work in the way it allows for the adaptation of identity for the bereaved; by developing new skills and ways to live, identity is reviewed and adapted to accommodate loss.

Stroebe et al (1999) propose that there is no recognised pattern of addressing each of the processes in the model, but that individuals will oscillate between the two as necessary. Oscillation between the two forms of coping is a crucial, yet individual component of the model; this aspect acknowledges a confrontation-avoidance pattern of grieving wherein the bereaved deal with their grief in a measured way which allows for individual differences in coping and capacity (Stroebe and Schut, 2010). In a similar way, Parkes (2001) had earlier described a process whereby the bereaved can be observed to move between episodes of overwhelming grief and dealing with the other practical demands of life. However this interpretation of the model is questioned by Fasse and Zech (2016) in a robust Interpretative Phenomenological Analysis of coping after bereavement. Their findings suggest that the two processes do not operate independently of each other and are largely interdependent, often to the point where they appear as one process. Participants spoke of how engagement in restoration focused activities provoked loss oriented activity as participants looked back on how things had been before their partner died. Fasse and Zech (2016) also identified that participants' use of both loss and restoration strategies was non-intentional. They propose a subtle difference from the dual process model in that strategies which provided relief from grief were experienced more as respite from grief than periods of coping with grief. One example of this distinction was seen in how participants described moments of distraction as respite rather than coping. The authors of

this study also proposed that restoration focused activity provided a means to transform ongoing bonds with the deceased; thereby offering a means to link the dual process and continuing bonds models.

Lund et al (2010) investigated restoration focused coping and propose that whilst loss oriented coping largely follows similar patterns, restoration oriented coping is individual. This contrasts with Thompson (2012) who suggests the dual process model overall may offer a more individualistic approach to grief which allows for different patterns of experiencing grief; a proposal which echoes Fasse and Zech's (2016) interpretation. Buglass (2010) and Hall (2014) emphasised the flexibility that the model offers in accommodating both cultural and religious differences; further indicators of its recognition of the individual nature of grief. Although as Rosenblatt (2008) argues the dual process model does make the assumption that grief is universal.

Stroebe et al (2005) have explored how the dual process model may also be understood in relation to Bowlby's attachment theory of loss. Loss oriented grieving may reflect the activation of the attachment system; in turn this reflects Freud's notion of the need to examine and detach from each memory of the deceased (Mikulincer and Shaver, 2008). They propose that people with a more secure attachment style may be able to move more flexibly between loss and restoration oriented coping. Those with an insecure attachment will struggle to move from loss oriented focus; whilst those with an avoidant style will focus on restoration oriented grieving and avoid the loss focused orientation. It would appear that the dual process model may offer a means to link aspects of earlier theories and models of grief which further investigation may elucidate.

2.2.10 Summary of discussion of grief theories and models

This section has outlined the development of bereavement theory, from Freud's work which examined grief as an individual psychological phenomenon to contemporary understandings of bereavement as an adaptive phenomenon as acknowledged by understandings of continuing bonds, the dual-process model and emphasis on meaning-making. Whilst psychological and medical interpretations have tended to promote the necessity for the breaking of ties; more recent sociological and constructionist understandings of bereavement which situate it within a social and interpersonal context, have tended to err towards the maintenance of a relationship with the deceased. Theories of grief have moved from an understanding that grief follows a standardised path to a more individualistic understanding where people are understood to grieve in different ways. This more individualised perspective also accounts for the complexity of grieving; rather than earlier models which offered a prescriptive approach which might imply a more simplistic process of experiences. More recent theories and models of bereavement have been shown to reflect links to earlier theories despite general understanding of them as being

distinct. Nevertheless as Archer (2008) maintains the process by which people move from high levels of distress to states similar to before bereavement remains unclear.

2.3 Occupation

The next section of this chapter will define and discuss how the concept of occupation is understood professionally and within the context of this study. A scoping review of literature on occupation and bereavement will conclude the chapter.

2.3.1 Defining occupation

Occupation is acknowledged to be a complex concept (Golledge, 1998; Chard, 1999; Creek, 2003; Creek et al, 2005); yet despite its presence across the human life span it continues to lack comprehensive definition. Even within the profession of occupational therapy where it arguably constitutes an important focus of attention, the identification of a single accepted definition forms a topic of ongoing, but as yet unresolved, debate (Pierce, 2001).

The term occupation derives from the Latin word "*occupatio*" which means "*to seize or take possession*" (Yerxa et al, 1990). More recently the term is defined by the Concise Oxford English Dictionary (Soanes et al, 2006) as "*the action, state, or period of occupying or being occupied*" and "*a way of spending time.*" In everyday usage, *occupation* is frequently associated with paid or unpaid employment, and productive ways of spending time.

Human beings engage in occupations throughout the lifespan and occupations are described as being central to human experience (Wilcock, 2002). Kielhofner and Burke (1980, page 573) propose that "*all human occupation arises out of an innate, spontaneous tendency of the human system – the urge to explore and master the environment.*" The motivation implied has resonance with Maslow's (1970) work which argued that humans are driven, or motivated, to achieve specific needs ranging from those related to basic survival to those associated with relating to others, creativity and other intellectual achievements. Occupation might be argued to provide a vehicle to facilitate the process of personal development.

The discipline of occupational science views people as active beings who have innate needs to "do"; it is recognised that the fulfilment of these needs contributes to health and wellbeing (Wilcock, 2002; WHO, 1986). Where constraints prevent participation in occupation it might therefore be anticipated that health implications will occur (WFOT (World Federation of Occupational Therapy), 2012). Such constraints might include those commonly experienced as part of aging such as reduced mobility. It must also be recognised that for some people these effects can form less of a barrier to participation in a meaningful life in older age. Clark et al (1997) and McIntyre and Howie (2002) suggest that continued involvement in occupations and connection to social networks in old age act to maintain wellbeing.

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Life transitions such as retirement and bereavement may present further challenges to participation, and whilst received wisdom may suggest that such transitions present opportunity to review and make changes in lifestyle, this is not borne out by evidence. In older age particularly it would appear that maintaining routines and familiar activities are important in the maintenance of wellbeing and satisfaction with life (Rubenstein, 1986; Jackson, 1996; Jonsson et al, 2000; McIntyre and Howie, 2002; Johannesen et al, 2004; Chambers, 2005; Haggbloom-Kronloff et al, 2007). However changes brought about by transitions such as retirement often herald a change in the nature of how routines and occupations are performed. Changes in the marital relationship in older age may see a return to a more “joint” lifestyle (Kalmijn & Bernasco, 2001) similar to early stage relationships where couples are more likely to spend time doing things together and sharing household work; social and leisure interests. Whilst earlier research by Birchler & Webb (1977) indicated that involvement in shared activities within relationships is related to happiness and greater problem-solving skills; the changes provoked by transitions such as retirement may have an impact on health and wellbeing (Blair, 2000; Crider et al, 2015). Spousal bereavement might also be anticipated to pose a significant threat of disruption to life patterns and the occupations which have previously been developed to create meaning and purpose, with subsequent impacts on health and wellbeing.

2.3.2 Occupation and activity

Clarification of the concept of occupation firstly requires consideration of the difference between the terms *occupation* and *activity* which in everyday usage are used interchangeably (Golledge, 1998). Members of the occupational therapy profession accuse the profession of abandoning use of the term *occupation* in all but their title, preferring the term activity with its more commonplace and readily understood definition (Chard, 1999; Polatajko et al, 2004). The development of the discipline of occupational science during the 1990's (Yerxa et al, 1990) initiated recognition and acknowledgement that it was both important and necessary to reclaim the term “occupation” and differentiate it from “activity” (Pierce, 2001; Polatajko et al, 2004). This move served to initiate the search for definitions with which the profession could explain its purpose.

Dictionary definitions describe activity as: “*an action taken in pursuit of an objective – a recreational pursuit*” (Soanes et al, 2006) implying an active process with a focus on leisure pursuits. For Pierce (2001) “activity” refers to a general class or category of action, one which is shared by groups of people within a shared culture. Taking the term “holiday” as an example; a holiday as an activity would refer to broad cultural understandings relating to taking a break from usual routines.

Weinblatt et al (2000) proposed a temporal component of the concept of activity; suggesting that understandings of an activity remain static over time. Understandings of the experience of a “holiday” remain reasonably similar across the age span, history and culture. Activity can thus be understood as a broad category of action, understood at a population level and which is less likely to change over time.

2.3.3 Review of definitions of occupation

In seeking to identify a definition of the concept of “occupation” to underpin the focus of the current study an initial search of the electronic databases was performed. This proved unhelpful due to difficulty identifying valid search terms. The term “occupation” is a generic term used across a broad range of disciplines as well as being a commonly used noun. Instead, hand-searching of the occupational science literature and the internet websites of the occupational therapy professional organisations from English speaking countries were used to identify definitions of the concept of “occupation.” As a profession which assumes occupation as its primary focus and which has grappled to develop a relevant, recognisable interpretation this would appear an appropriate provider of sources. A final search of the World Federation of Occupational Therapists website was made to ensure a broad spectrum of definitions was considered; this produced no further versions.

Recent professional debate regarding the definition of “occupation” arose following the development of occupational science, in the late 1980’s, as a discipline distinct from occupational therapy. Publication of occupational science related papers and research predominantly dates from the 1990’s and so this was taken as the time span from which definitions were considered for this discussion. Earlier definitions appeared largely to focus on defining occupation in relation to the profession of occupational therapy and attended to therapeutic applications; neither did they distinguish between the terms “occupation” and “activity.” Seven definitions were finally selected and are reviewed below.

The earliest definition to be considered here was proposed by Yerxa et al in 1990; considered the initiator of occupational science (WFOT, 2012a). Yerxa et al proposed that “*occupation refers to specific “chunks” of activity within the ongoing stream of human behaviour which are named in the lexicon of the culture*” (Yerxa et al, 1990, page 5). This identifies two components inherent in “occupation”; the relevance of culture and the ongoing nature and role of occupations throughout the lifespan. Differentiation of the concepts “occupation” and “activity” is not offered in this definition.

The development of occupational science as a discipline distinct but contributory to occupational therapy heralded greater emphasis on the role of occupation in the development and maintenance of health and wellbeing. Whilst recalling Yerxa et al’s earlier reference to the role of

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culture in the interpretation of occupation, Wilcock's (1998a) definition of occupation spoke to this wider premise. Her definition acknowledged the idea that in the process of engagement in occupation humans have opportunity to exercise and maintain their skills; and participate and contribute to the social life of the communities in which they live. As described eloquently by Wilcock: *"Occupations demonstrate an individual's culturally sanctioned, intellectual, moral and physical attributes. It is only by what they do that people can demonstrate what they are and what they hope to be"* (Wilcock, 1998a, page 24). This widens the scope of definition although the reference to identity might be accused of neglecting the constraints within which some people must perform their occupations or which might preclude participation in freely chosen occupations. In doing so it ignores the fact that some people may not be able to demonstrate *"what they are"* or *"what they hope to be"* through the things they do; but that need not necessarily mean they do not possess the capacity to demonstrate their *"culturally sanctioned, intellectual, moral and physical attributes."* Thus although the definition proposed by Wilcock (1998a) provided greater recognition of the potential afforded by engagement in occupations it could be argued to provide a narrower scope.

Pierce (2001, page 139) proposed that an occupation was *"a specific individual's personally constructed, non-repeatable experience ... a subjective event in perceived temporal, spatial, and sociocultural conditions that are unique to that one-time occurrence. An occupation has a shape, a pace, a beginning and an ending, a shared or solitary aspect, a cultural meaning to the person, and an infinite number of other perceived contextual qualities."* Whilst lengthy Pierce has incorporated both the individually understood nature of occupation and the complex contextual components – time, location - inherent in the concept, whilst retaining the cultural aspect as proposed earlier. Consideration of occupations as reflecting spatial and temporal contexts clarifies and builds on the proposal forwarded by Yerxa et al (1990) regarding daily life as comprised of a stream of different occupations, *"specific "chunks" of activity within the ongoing stream of human behaviour."* Pierce's definition acknowledges the individual and interpersonal experience and meaning of occupation; and recognises the subjective experience of engagement. Pierce recognised that although an occupation is recognisable by others who are not actively engaged in it, the meaning of the occupation is uniquely interpreted by the person engaged in it.

Following the publication of the MRC guidelines relating to Complex Interventions (MRC, 2000) the British Association of Occupational Therapists commissioned Creek to review occupational therapy against this guidance. Creek's (2003) report included a definition of occupation developed from multiple sources which described occupation as:

"The highest level of complexity of human function which provides longitudinal organisation of time and effort in a person's life. Occupation defines and organises a sphere of action over a

period of time and is perceived by the individual as part of her/his personal and social identity" (Creek, 2003, page 55).

This definition builds on Pierce's work with recognition both of contextual and meaning components whilst also acknowledging the role that occupation plays in the development of identity. Whilst alluded to by Wilcock (1998a) this definition makes clear links between occupation and identity; a notion which has more recently received further attention in work which considers the concept of occupational identity (Christiansen, 1999; Christiansen and Townsend, 2010). The phrase "*highest level of complexity of human function*" lacks sufficient explanation and justification of its relevance to all occupations.

It has been acknowledged that an *activity* is a distinct concept holding a very different interpretation to occupation. As such when the Canadian Association Occupational Therapy (CAOT) published a taxonomy of occupational performance for the profession in an attempt to provide clarity and end confusion within the occupational therapy profession, an agreement was made to clearly distinguish between the terms "occupation" and "activity". The resulting definition, developed by Polatajko et al (2004, page 263) defined occupation as: "*A set of meaningful activities, performed with some consistency or regularity, typically named for the predominant or primary activity.*"

Despite the intention to distinguish between "occupation" and "activity," there is no indication of differentiation between the two concepts. This definition references the meaning and the temporal components of occupation previously identified. It also introduces a new term, "primary activity." In the sense used here a "primary activity" refers to an overarching construct, or grouping of a type of activity such as self-care activity or leisure activity; identified within the occupational therapy profession as "domains of concern" or "practice" (Crepeau et al, 2008). The introduction of this concept in the definition might suggest its use is potentially limited beyond the occupational therapy profession.

The American Occupational Therapy Association (AOTA, 2008) document *Occupational Therapy Practice Framework: Domain and Process* (2nd edition) adopted a definition proposed by Law et al (1997):

"Activities...of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves...enjoying life...and contributing to the social and economic fabric of their communities..." (Law et al, 1997; AOTA, 2008, page 632).

In keeping with definitions already considered here the importance of personal meaning was retained suggesting again that occupations are linked to meaningful experience. However the

inclusion of the phrase “enjoying life” stands out in this definition. Whilst occupations may hold meaning and contribute to overall experience and development of identity, they will not all be universally experienced as enjoyable. These implications could be accused of reflecting a Westernised, developed-world view which is not representative of a broader understanding of human occupation (Hammell 2008; Hammell, 2009). This definition also refers to the notion of occupations playing a contributory role to the wider community. Many of the occupations which humans engage in do make a contribution, albeit indirectly, to the life of a community but this cannot unequivocally be claimed. This statement is therefore insufficiently specific.

The final definition of the term *occupation* to be considered here is taken from the website of the Canadian Association of Occupational Therapy. A layperson’s definition of occupation is provided and states that occupation refers to “*everything that people do during the course of everyday life ... occupations describe who you are and how you feel about yourself*” (Townsend and Polatajko, 2013). This broader definition provides a more accessible description which retains attention to identity; however reference to both the meaning-making aspects and contextual factors of occupation are missing.

This section has introduced in chronological order since 1990, a range of definitions of the term “occupation”; these were drawn from information provided by professional associations and key contributors to the development of occupational science; and identified components inherent in the concept. It is pertinent to acknowledge that the definitions considered derive from a Western, “developed-world” perspective and overall imply that engagement in occupations is positive and personally meaningful. It could be argued therefore that they may lack relevance to non-Westernised populations (Hammell 2008; Hammell, 2009). Despite searching more widely for comparative understandings none could be identified. It is proposed that as this study is an exploration of participants’ experience, and recruitment would be from within the United Kingdom the definitions would provide acceptable parameters for the understanding of occupation for this study.

2.3.4 Components of occupation

A range of components of occupation were identified from the definitions discussed (Table 2.1); these relate to engagement in, and outcome of occupation.

Table 2.1 Components of occupation

Components relevant to engagement in occupation	Components relevant to outcome of occupation
Occupations are complex patterns of behaviour and action (Creek, 2003)	Occupations provide opportunity to develop and exercise skills (Wilcock, 1998a; Law et al, 1997)
Occupations are contextual; they have links and relevance to time, place and culture (Yerxa et al, 1990; Law et al, 1997; Wilcock, 1998a; Pierce, 2001; Creek, 2003; Polatajko et al, 2004)	Occupations provide a sense of meaning and purpose (Law et al, 1997; Pierce, 2001; Polatajko et al, 2004)
Occupations provide a means to organise behaviour and life (Creek, 2003; Townsend and Polatajko, 2013)	Engagement in occupation contributes to the development of personal and social identity (Wilcock, 1998a; Pierce 2001; Creek, 2003; Townsend and Polatajko, 2013)
Occupations provide subjective meanings and are individually interpreted (Law et al, 1997; Pierce, 2001; Townsend and Polatajko, 2013)	

2.3.5 Summary of discussion of the definition of occupation

Occupations are described as complex behaviours whose components contribute both to tangible aspects of living such as the organisation of daily life as well as to less accessible issues of identity development, purpose and support. The definition proposed by Pierce (2001, page 139) reflects the complexity and its reference to contextual aspects provides a perspective from which to understand the external influences on occupation. Therefore this definition has been selected to underpin further discussion and use of the concept of occupation in the current study. From this point the use of the term “occupation” in this thesis will reflect this interpretation; an occupation is deemed to be:

“a specific individual’s personally constructed, non-repeatable experience ... a subjective event in perceived temporal, spatial, and sociocultural conditions that are unique to that one-time occurrence. An occupation has a shape, a pace, a beginning and an ending, a shared or solitary

aspect, a cultural meaning to the person, and an infinite number of other perceived contextual qualities” (Pierce, 2001, page 139).

2.4 Occupation and bereavement: a scoping review of the literature

The final part of this chapter will provide a review of the literature pertaining to occupation and bereavement. This will provide an overview of what is currently known about occupation in bereavement; including key concepts and issues; thereby establish the pre-understanding on which the current study was based. Although occupational therapists work across a broad range of health and social care settings including palliative care and hospice services there is little evidence in the professional literature of work with clients who are referred to their services primarily for help with bereavement related issues. Arksey and O’Malley (2005) describe a scoping review of literature to be a relevant and flexible approach to reviewing evidence where there is thought to be minimal existing literature available; that which there is has been developed through a range of research designs and non-research material (Davis et al, 2009); and to address broad research questions. Levac et al (2010) suggest that a scoping review is a useful tool in the rehabilitation sciences where the evidence base is often limited. Arksey and O’Malley provide a framework for completing a scoping review however this neglects the issue of quality assessment of the literature reviewed; Daudt et al (2013) argue this to be a necessary step in the process. A scoping review allows for the mapping of the range and scope of evidence about a broad topic in order to identify the key concepts and theories. The focus of this literature review was occupation and bereavement; a preliminary brief search of the literature had indicated a small number of research papers whose participants reflected a broad range of ages and types of bereavement. A scoping review was therefore deemed an appropriate approach to adopt.

Arksey and O’Malley (2005, page 22) propose five core stages to a scoping review:

1. identifying the research question
2. identifying relevant studies
3. study selection
4. charting the data
5. collating, summarizing and reporting the results

These were adhered to in the scoping review undertaken for this thesis. In keeping with recommendations by Daudt et al (2013), Levac et al (2010) and Davis et al (2009) to consider quality appraisal of papers included in the review, the final studies selected for the review were reviewed using the Critical Appraisal Skills Programme (CASP) quality assessment tools (CASP, 2014). The outcomes of this stage of the process were synthesised with the outcomes of the scoping review. This additional stage was integrated in order to provide an additional level of confidence in the findings of the review. The process undertaken to complete the scoping review

of literature relevant to this thesis will now be described according to Arksey and O'Malley's (2005) framework.

2.4.1 The research question

In recognition of the minimal existing literature it was important to identify a broad question in order to identify both theoretically driven and practice based research. Arksey and O'Malley (2005) suggest that by commencing with a broad question the search terms can be revised as the search proceeds. This approach is less likely to miss relevant studies but may initially produce large quantities of papers; an iterative approach can therefore be adopted to enable refinement of search terms and inclusion of parameters to limit and refine the breadth of the search (Davis et al, 2009).

Levac et al (2010) and Daudt et al (2013) caution reviewers to link the purpose of their scoping review and the research question in order to ensure relevance and coherence. Thus as this review was aimed at gaining a broad understanding of literature relating to occupation and bereavement the underpinning question was: What is known about occupation following bereavement? The question encompassed three objectives:

1. To identify the role of occupation following bereavement.
2. To identify what needs engagement in occupations meets following bereavement.
3. To identify whether engagement in occupations changes across the age span and with different forms of bereavement.

2.4.2 The search strategy

Core search terms were identified and adapted using Boolean operators AND / OR and truncation "*" (Table 2.2). The term "activity" was included as it is recognised that this is a term commonly used to describe how people spend time and differentiation between the terms "occupation" and "activity" may not have been made by authors. The term "loss" was not included due to the broad nature of the word and the potential for it to attract inappropriate references.

Table 2.2 Search terms used for scoping review on occupation and bereavement

Search terms	Boolean operators
Occupation	“occupation” OR “occup*” OR “occupational therapy” OR “activity” OR “activit*”
Bereavement	“bereavement” OR “grief” OR “mourning”

All searches were completed using the “All Field” option in order to maximise returns, in keeping with the aims of a scoping review. Where searches produced large returns (over 500) additional filters were applied. These limited the returns to papers published in English and in academic journals.

2.4.3 Electronic databases

A search of a range of electronic databases and hand-searching of specific professional journals using the search terms identified in Table 2.2 was undertaken on 26 February 2016. Data bases used were AMED; Cinahl; Delphis; PsychINFO; Scopus; and Web of Science (Table 2.3); together these provide a broad cover of health and social, psychological and sociological literature.

Table 2.3 Databases used to identify literature on occupation and bereavement

Database	Description of coverage
AMED	Covers journals in complementary medicine, palliative care and several professions allied to medicine including physiotherapy, occupational therapy, podiatry and rehabilitation.
CINAHL	Provides extensive coverage of literature from midwifery, nursing, occupational therapy, physiotherapy, podiatry, health education and other related subject areas.
Delphis	Covers a broad range of electronic databases and indexes; and searches the University of Southampton printed resources.
PsychINFO	Offers extensive coverage of psychology and related subject literature; and searches electronic journals, books and dissertations.
Scopus	Offers the largest range of peer-reviewed literature from scientific journals, books and conference proceedings of the world's research output in science, technology, medicine, social sciences, and arts and humanities.
Web of Science	Provides access to a broad range of subjects including health and social science material.

2.4.4 Hand-searching of professional journals

To ensure all relevant literature was identified professional occupational therapy journals were also hand-searched (Table 2.4). Hand-searching is a useful means to compensate for articles not offered by the databases due to mismatches between the keywords selected and those recognised by the databases. Hand-searching involved individual searches of the journals via their online websites; the same search terms were utilised. Journals selected and searched were those which were available electronically or in print locally.

Table 2.4 Occupational therapy journals searched

American Journal of Occupational Therapy	Journal of Occupational Science
Australian Journal of Occupational Therapy	OT Journal of Research: Occupation, Participation and Health
British Journal of Occupational Therapy	OT in Healthcare
Hong Kong Journal of Occupational Therapy	OT International
New Zealand Journal of Occupational Therapy	OT in Mental Health
Scandinavian Journal of Occupational Therapy	Physical and Occupational Therapy in Geriatrics
South African Journal of Occupational Therapy	Physical and Occupational Therapy in Paediatrics
	The Open Journal of Occupational Therapy

2.4.5 Grey literature

Grey literature includes literature which has not been published by mainstream publishers and can include items such as leaflets, government documents and conference proceedings (Hartley Library, 2016). The following grey literature search facilities were searched: Open Grey; Evidence Search Health and Social Care (NICE); The Campbell Collaboration; The King's Fund; SCIE, Social Care Institute for Excellence; Google; and Google Scholar.

2.4.6 Inclusion and exclusion criteria

In order to identify the most relevant papers for review, inclusion and exclusion criteria were identified after the initial literature search of the electronic databases (Colquhoun et al, 2014; Levac et al, 2010; Arksey and O'Malley, 2005) and subsequently applied to the literature search (Table 2.5). Application of these criteria help to enhance and demonstrate transparency and rigour by providing consistency. Both Arksey and O'Malley (2005) and Levac et al (2010) recommend criteria should be developed after literature searching has commenced and an understanding of the literature available has developed. This approach results in the need to take an iterative approach to the review. For the purposes of the current study the criteria were created after the initial electronic database searches. They were refined again during the study selection process when it became apparent that the search had identified papers about engagement in occupation by hospice patients rather than bereaved people. A decision was made at this point to also include papers which explored the experiences of occupation by relatives and informal caregivers of people receiving palliative care; this was felt to potentially reflect anticipatory grief which might offer further insights.

Table 2.5 Inclusion and exclusion criteria applied to the literature search

Inclusion criteria	Exclusion criteria
<p>Studies of populations of all ages – although the current study would focus on older people, themes and findings of different age groups may help to identify relevant issues.</p> <p>Articles which focus on occupations and activities during grief.</p> <p>Studies exploring grief education for occupational therapists – this may offer further insights and may also help to explain other studies.</p> <p>Studies which address occupations of relatives and carers of people who are dying; possibly reflecting the concept of anticipatory grief.</p>	<p>Articles published prior to 1990. This date was selected as it reflects the development of occupational science and renewed focus within the occupational therapy profession on the role of occupation.</p> <p>Papers which focus on aspects of bereavement and grief other than occupation and activity e.g. mental health issues.</p> <p>Studies which focus on losses other than bereavement.</p> <p>Non-English articles – due to time and financial costs which would be required for translation.</p> <p>Papers which focus on occupation at the end-of-life rather than bereavement.</p>

2.4.7 Selection of studies for inclusion

Table 2.6 reports the outcome of the literature search by database and journal. The titles and abstracts of the papers produced by each database and journal search were reviewed; of the 8,996 hits, 37 were duplicates and were removed. A large number of citations returned were irrelevant and it is concluded this was due to the broad nature of the search terms. In defence of these however the terms used were relevant to the research question but are terms used in everyday language and so attracted many hits in the database searches. Hand-searching of the professional journals produced a more focused and relevant selection of literature.

Table 2.6 Outcomes of literature search

Database / Journal	Hits
AMED	121
CINAHL	272
Delphis	379
PsychINFO	347
Scopus	7,149 - further filtered by “relevance” and 500 abstracts reviewed
Web of Science	21
American Journal of Occupational Therapy	196
Australian Journal of Occupational Therapy	30
British Journal of Occupational Therapy	372
Hong Kong Journal of Occupational Therapy	2
New Zealand Journal of Occupational Therapy	1
Scandinavian Journal of Occupational Therapy	4
South African Journal of Occupational Therapy	0
Journal of Occupational Science	37
OT Journal of Research: Occupation, Participation and Health	0
OT in Healthcare	1
OT International	9
OT in Mental Health	9
Physical and Occupational Therapy in Geriatrics	12
Physical and Occupational Therapy in Paediatrics	11
The Open Journal of Occupational Therapy	23

Searching the grey literature was unsuccessful in identifying further papers, and produced only duplicates.

The most frequent reasons for rejection of papers when considered against the inclusion / exclusion criteria were a focus on losses other than bereavement; and the date of publication. The search of the databases and journals resulted in 27 articles selected for review. Review of the reference lists of these papers produced three further citations which met the criteria for inclusion. In total 30 papers were identified for review.

2.4.8 Charting the data

The fourth stage of a scoping review requires documentation of core information from each of the papers identified (Arksey and O'Malley, 2005; Levac et al, 2010; Daudt et al, 2013). Following Arksey and O'Malley (2005) the following information was recorded from each paper where possible: author; year of publication; study location; intervention type (adapted to include data collection method where the paper did not describe an intervention study); duration of the intervention; population; aims of the study; methodology; outcome measures; key results (Arksey and O'Malley, 2005). The charted data is included in Appendix A.

2.4.9 Quality assessment of identified papers

The retrieved papers were assessed using the randomised controlled trial (RCT) or qualitative appraisal checklists produced by the Critical Appraisal Skills Programme (CASP) (CASP, 2014) (Appendix B, C and D). Although not all of the quantitative studies identified were RCTs, this was the most relevant of the CASP checklists to use; where questions were not relevant this has been indicated. Eight quantitative and sixteen qualitative papers were appraised. Six papers were not appraised using the CASP checklists as these were discussion papers (Hurst, 1998; Okoneski, 1991; Stewart, 1997); a descriptive account (Scaletti and Hocking, 2010); and short reports of small scale evaluations (Creed et al, 2001; Ilott, 1996).

2.4.10 Collating, summarising and reporting the results

Arksey and O'Malley (2005) propose that unlike in a systematic review where only a proportion of papers reviewed will be included in the final report, a scoping review seeks to incorporate all of the studies to present a narrative overview of information. The next section of the review will present a thematic review of the literature on occupation and bereavement. The final section will conclude the review with consideration of how the papers address the initial question and objectives.

2.4.11 Occupation in children's bereavement

Six of the retained papers focused on grief in children and aspects of occupation (Creed et al, 2001; McClatchey and Wimmer, 2012; Fluegeman et al, 2013; Brewer and Sparkes, 2011; Scaletti and Hocking, 2010; Miliken et al, 2007). Of these four were studies of bereaved children's experience of specialist camps and considered the role that camp activities played. Whilst the

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participants had all attended camp following different forms of bereavement the focus of these studies was to explore the impact of the activities on the children and their grief experience. Despite these differences the form of activities that campers engaged in were similar in that they were predominantly outdoor and non-solitary in nature; canoeing, camp fires, talent shows and creative activities. McClatchey and Wimmer's study also included counselling sessions; although not specified these appeared to be in a group format.

Key features identified as beneficial by children across all four studies were the opportunity to connect with others in a similar situation which reduced feelings of isolation; encouraged acceptance of support from others; and provided opportunity to engage in fun activities which offered distraction from grief. Interaction and interpersonal support through the medium of occupation were reported to be positive factors identified by participants in each of these studies. Brewer and Sparkes (2011) focused on the role of outdoor activities and identified that the environment and being outdoors were key factors for their participants. They also interviewed older children and young adults who had taken part in the same camp organisation a decade earlier and identified that using outdoor activity and exercise had continued to form a key coping strategy.

The issue of interpersonal support was also indicated by Scaletti and Hocking's (2010) paper. This was written in the form of a fictional case study created by the first author from experience of working with bereaved children in her professional practice. The paper explored the role of story writing and storytelling as therapeutic means to address children's grief. It is the authors' contention that the process of putting experience into story format and sharing this with others provides relief for bereaved children. This paper although not formal research and so lacking the robustness of the previous studies speaks not only to the role of creative occupations but also to similar themes as those in the four studies of children's bereavement camps; namely that benefits can be gained through the interaction and interpersonal occupations.

The final paper which considered children's grief was by Miliken et al (2007); this reported on the outcomes of a postal survey of paediatric school-based occupational therapists; the study had a return rate of 37%. Findings indicated that the majority of responding therapists did not address grief issues experienced by the children they worked with despite recognition that grief may have contributed to the child's difficulties. Qualitative data collected indicated that respondents did not feel it was their role to address these psychosocial issues and that other school staff were more equipped to do so; possibly suggesting a lack of confidence in possessing the skills required.

The first five papers reviewed suggest that occupation has a role in supporting children through grief and that group occupations may offer enhanced benefits. The papers reported that participants who had siblings who took part in the camp and in some instances were also involved

in the research study, identified value in interacting with others outside of the immediate situation rather than relatives who would be dealing with their own grief.

2.4.12 Occupation and adult grief

Five papers which considered grief in adulthood were reviewed (Kang and Yoo, 2007; Vale-Taylor, 2009; Forhan, 2010; Hoppes and Segal, 2010; Ilott, 2006). Kang and Yoo (2007) investigated the impact of a relaxation technique on grief and stress levels; and immune response; Vale-Taylor (2009) a hospice chaplain, investigated the role of remembrance activities by bereaved next-of-kin; an auto-ethnography by Forhan (2010) considered the role of occupation in perinatal grief; and Hoppes and Segal (2010) explored the meaning of occupation to adults experiencing a range of losses.

Kang and Yoo (2007) assessed the impact of Dan-jeon, a Korean breathing and stretching regime, provided in a group format which also offered group support to middle-aged widows bereaved less than six months. Benefits were identified in a reduction of grief and stress symptoms, but not on immune response. Participants in the study were given the choice whether to participate in the intervention group or the control group who completed pre-and post-test measures. The authors did not explore the decision making process of the participants but it would be relevant to do so to identify whether reasoning was pragmatic or emotional. Further study would be valid to determine whether results were due to the Dan-jeon system, or to the supportive group sessions. Findings from the studies of children's grief might suggest the latter were of value.

The three papers by Vale-Taylor (2009); Forhan (2010); and Hoppes and Segal (2010) will be considered together as they link to issues of identity and identity-reconstruction following bereavement. Vale-Taylor's exploration of preferred remembrance activities identified four reasons behind participants' use of these activities: activities undertaken for the deceased; activities to maintain a direct link to the deceased; activities which remembered the deceased within their community; and remembrance acts. Vale-Taylor posits that each of these offered means for the bereaved to maintain a continuing bond with the deceased whilst also maintaining their identity.

Forhan's auto-ethnographic study examined her experience of perinatal death and the impact on herself and her family's engagement in occupation. This paper similarly suggests adaptation of identity; in this case how the family integrated their baby into the family and how they adapted their occupations to incorporate the baby. Forhan describes how the model of *doing, being* and *becoming* (Wilcock, 1998b) used in occupational therapy practice provided a structure with which to understand her experience. Engagement in bereavement-focused and family occupations – *doing* – enabled her to adapt to her situation - *being* - and revise her identity - *becoming* a bereaved mother; from this position she began to pick up the threads of her life.

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Hoppes and Segal's (2010) interview study explored engagement in occupations following the death of a relative. They identified two processes and the role of continuing bonds in occupational adaptation. *Occupational accommodation* in which participants adapted occupations following bereavement in ways which gave meaning to the loss such as changing jobs to a position which felt more meaningful or which had some link to the deceased's experience. *Occupational assimilation* enabled the bereaved to resume previous occupations but in ways which reflected their loss; for example returning to work provided some with the comfort of a predictable, familiar routine. Hoppes and Segal propose that these two processes facilitated participants to adapt to their new situation and reconstruct meaning; whilst the creation of continuing bonds through engagement in occupations formerly relevant to the deceased allowed adaptation of identity.

Ilott (2006) reflected on the occupation of dealing with her mother's belongings after her death and the project she undertook to commission a textile artist to create family *heirlooms* from her mother's craftwork. Although not offered as formal research this critical reflection provides an indication of how the project undertaken by Ilott provided her with an occupation which offered a means to cope with her grief in several ways including distraction and a way to remember the deceased through objects which had held significant meaning for both her mother who created them and herself through her memories of her mother as a creative person. Her interactions with the artist and the artist's appreciation of the pieces of work further enabled her to recognise her mother in new ways. This paper speaks to, and possibly extends Walters' biographical model which refers to the bereaved engaging in conversations about the deceased as means to create a *durable biography* for them (Walters, 1996). Ilott describes the creation of a valued family heirloom as enabling the creation of an ongoing relationship with her mother.

This group of papers suggest potential roles for occupations in relieving the distress of bereavement and grief; and offering a means to adapt to loss. The participant numbers of these studies were small and there may be benefits in completing larger scale studies to identify relevance to wider populations.

2.4.13 Occupation in older age bereavement

Ten papers were identified which focused on aspects of occupation and grieving for older people; this was the largest group of papers identified in this review (Stewart, 1997; Oakley et al, 2002; Caserta et al, 2004; Utz et al, 2004; Fitzpatrick et al, 2001; Utz et al, 2002; McIntyre and Howie, 2002; Utz et al, 2011; Nyman et al, 2014; Mattock and McIntyre, 2016). One of these was a descriptive piece on older people and loss by Stewart (1997) this was designed to offer guidance to occupational therapists and will be discussed in the following section of this review. The

remaining nine papers will be described under four themes: impact of bereavement on functional ability; social interaction; self-competency and agency; and benefits of occupation.

2.4.13.1 Impact of bereavement on functional ability

The first study that focused on the effect that bereavement may have on ability to complete activities of daily living (ADL) was undertaken Oakley et al (2002). This was a small double-blind trial that measured the impact of anti-depressant medication on functional performance. Using the Assessment of Motor and Process Skills assessment (AMPS), a standardised occupational therapy assessment; the functional performance of depressed, older, recently bereaved participants who were not depressed prior to their bereavement was demonstrated to improve with anti-depressant treatment to levels comparable with a well comparison group. This is reported to be the first study to demonstrate significantly lower levels of functional ability due to post-bereavement depression. Levels recorded pre-treatment placed half of the participants in an at risk zone indicating safety risks requiring support to live in the community.

Caserta et al (2004) explored the impact of an 11-week group educational intervention for bereaved older spouses. The intervention covered: managing personal health; stress management; managing finances; understanding grief; medication management; exercise & physical activity; accessing community services; nutrition; home management; social functioning; personal growth. Improvements were identified in active coping, household management and home safety, social interaction & engagement with community resources. Increases in self-perceived ability were noted up to two months post-intervention but not all were maintained at later follow-up. Nevertheless the focus of the group was on providing information for participants to follow-up if they wished and this may have contributed to the reported increased sense of self-efficacy by participants. Improvements in specific skills were differentiated by gender; for example men were more likely to report skills in household maintenance than women who in turn reported more competence and confidence in household management and nutrition. Inclusion of a control group would have enhanced the rigour of the study which was further reduced by use of a self-selection recruitment method.

Utz et al's (2004) study of the time spent completing housework after spousal bereavement identified that widowers were likely to spend more time engaged in housework than before bereavement whilst widows spent less. Utz et al's study was a cross sectional study without any follow-up of participants who may have demonstrated an increase in self-efficacy with familiarity as identified in Caserta et al's study. Utz et al found that where widow/ers had children living close by the time spent doing housework was reduced for both groups.

2.4.13.2 Social interaction

Two papers reported on quantitative studies exploring the role of leisure and social activities: Fitzpatrick et al (2001) and Utz et al (2002). Fitzpatrick et al investigated whether leisure and social activities buffer the effects of stress on health for older men. Results indicated that leisure activities had a positive effect on physical health but not mental health for bereaved and non-bereaved older men; whilst for bereaved men social activities were found to exert a negative effect on physical health. This suggests an element of stress associated with social activities for bereaved older men.

In contrast Utz et al (2002) identified that widowed, older people had higher levels of informal social participation than non-widowed, older people; formal social contacts were comparable between both groups. Social activities were shown to decrease before widowhood as a result of one of the couple being too unwell to socialise; levels were seen to rise after bereavement likely due to increased support during this period. The study followed participants for four years and results were unchanged across this period. Continuity appeared to be a key motivating factor in older widowed people's social interaction with participants making efforts to continue with their previous social activities and levels after bereavement. Social activity was reported to be a means of coping with the psychological impact of widowhood by providing distraction.

A single case study reported by McIntyre and Howie (2002) extended understanding of the role of continuity in occupations as a key factor in wellbeing during widowhood. In this paper the twice-widowed participant reported engagement in occupations as beneficial to health and wellbeing. Maintenance of former occupations and routines served to provide a sense of continuity and facilitated occupational adaptation in widowhood. Engagement in familiar occupations and social relationships was reported to help offset loneliness and boredom whilst maintaining cognitive skills and providing a sense of security, purposeful challenge and wellbeing.

2.4.13.3 Self-competency and agency

A third study by Utz et al (2011) which examined perceived self-competency amongst recently bereaved older people suggested that additional factors associated with occupation included the impact of specific resources. Higher income, education and better health were each identified as providing an enhancing effect in relation to perceived self-competency, coping, health and wellbeing. Widowed people with more resources were more likely to be able to drive and to have the financial resources to be able to participate in more occupations than their non-driving, lower income peers. In turn these two factors facilitated ongoing engagement which offered opportunities to maintain competence in occupations which appeared to contribute to better mental health.

A single case narrative analysis completed by Nyman et al (2014) considered the role of agency in coping with depression following widowhood. This paper considered the contextual aspects of agency in terms of the external factors which mediate engagement in occupation. Agency is described as a transactional process influenced by other people in the individual's environment. In widowhood the impact of her husband's influences on her occupations and the ways they had lived their life together, a state described by Nyman et al as "enacted togetherness," led to an episode of depression for the widow in the study. This was resolved only when she was able to challenge these influences and make changes which allowed her to move forwards.

2.4.13.4 Benefits of occupation

The final theme identified in the papers on occupation and bereavement in older age focuses on the specific benefits of occupation identified in the literature. McIntyre and Howie (2002) allude to the benefits of "doing" and social occupations in relation to enhanced coping and sense of security derived from knowing others were concerned for you. The older widow in Nyman et al's (2014) study identified how encouragement by friends had helped her to overcome depression by engaging in familiar occupations alongside them and gradually tailing off their involvement as she gained confidence and motivation and her belief in her ability returned.

Mattock and McIntyre (2016) identified the benefit of familiar occupations in widowhood as providing a means to maintain self-identity following bereavement. A familiar occupation was found to contribute to identity, coping, and respite by countering the effects of role overload during the pre-widowed period of caring.

2.4.14 Papers with a professional educational focus

Nine papers with a professional or educational focus were identified (Okoneski, 1991; Stewart, 1997; Hurst, 1998; Hasselkus, 1993; Thibeault, 1997; Forhan, 2010; Illott, 1996; Miliken et al, 2007; Breen et al, 2013). Three of these were papers published in the 1990's and were designed to provide information to occupational therapists about grief in specific populations. Okoneski (1991) wrote about gay grief; Stewart (1997) focused on loss and loneliness in older age; Hurst (1998) described grief as experienced by people with learning disabilities. These three papers were all written for occupational therapy professionals and offer broad, descriptive guidance for clinicians working with these client groups; all lack specific detail to make the guidance readily adoptable in practice and appear somewhat dated.

Three of the papers were written about grief experienced by the authors, all occupational therapists. They consider occupation and its role during their period of grieving. Hasselkus (1993) wrote a reflective piece about her experience of being with her mother during her final days and the role of occupation during this time. The paper describes how she was able to connect with her

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mother through care-focused occupations, a concept she described as *presencing*; and the impact of this experience and her grief as she returned to work and resumed her everyday occupations.

Thibeault (1997) wrote a biographical narrative about her experience of grieving for her father. The focus of her piece was to explore whether her professional experience and understanding facilitated her adaptation and grief. Her conclusion was that in ways relating to caring for her father it did not. However her understanding of therapeutic intervention enabled her to appreciate the value of professional intervention to support her own grieving.

The third paper was written by Forhan (2010) and was described in the previous section. Forhan, a practicing occupational therapist and academic, reports in her auto-ethnographic paper, how she felt unable to remain in her previous employment after the death of her son as what were once fulfilling occupations lacked meaning.

These three papers could be considered to focus on informal, experiential understandings held by therapists whilst three further papers identified, which have a professional educational perspective, could be described as focusing on formal, taught knowledge. These were published by Ilott (1996); Miliken et al (2007); and Breen et al (2013). The first of these, Ilott (1996), posited the notion that loss holds a central, yet overlooked, position in occupational therapy practice. She argues that the various causes of loss and its repercussions are pertinent to a significant proportion of occupational therapy clients. Her paper includes an overview of a module on loss delivered as part of an occupational therapy programme; the evaluation included retrospective evaluations completed by graduates a year after graduation which recognised the modules relevance to their everyday practice.

The theme of loss as a neglected area of practice was echoed in findings from Breen et al's (2013) paper. This study investigated the curricula of six health professions educational programmes at a University in Australia. The professions investigated were medicine, nursing, counselling, psychology, social work and occupational therapy. Participants from the academic and student bodies of each of these professions were interviewed and analysed with data gathered from review of programme documentation. Alongside medicine and nursing, the authors report that the occupational therapy programme focused on the stages model of grief and was linked primarily with lectures on palliative care and discussions of the notion of a "good death". Lecturers and students reported that there was insufficient coverage of bereavement and grief in the pre-registration occupational therapy programme. Although this was a small study which only considered one programme; the findings reflect Ilott's claim that loss is a neglected issue in occupational therapy. A claim further reinforced by Miliken et al (2007), the third paper on the theme of professional and educational issues. As previously explained Miliken et al's survey indicated that school-based paediatric occupational therapists felt ill-equipped to deal with grief

issues experienced by children on their caseload. Inclusion of more loss-focused elements to professional training might afford therapists the confidence to incorporate greater attention to these issues in their practice.

2.4.15 The occupations of families and carers of the dying

Five papers were retrieved that focused on the occupations of relatives of people with a terminal diagnosis (Pickens et al, 2010; Hasselkus, 1993; Thibeault, 1997; Hoppes, 2005a; Hoppes, 2005b).

Pickens et al (2010) conducted an ethnographic study over six months in a hospice during which she spent time with staff, patients and their family caregivers. Two themes were identified in relation to occupations; the first described relatives' actions to try to either retain normal occupations, or to develop new occupations in keeping with the patients decline in function as they became more unwell. The focus behind these actions was interpreted to be about engaging with a sense of normalcy, either the past normalcy or a new hospice-based normalcy. This act also resonates with the notion of "*presencing*" described by Hasselkus (1993) and discussed below. The second theme recognised the demands relatives had to cope with in terms of maintaining their usual occupations whilst their relative was in the hospice. Pickens et al (2010) identified the conflict experienced between trying to hold onto everyday occupations whilst making the transition demanded by letting go of their relative as they died.

The other four papers which focused on occupation and caregiving were biographical narrative or auto-ethnographic reports. Hasselkus (1993) described "*presencing*" as being apparent in the shared, meaningful experiences she created with her mother, and proposed that through occupation meaningful ways for the dying and their families to connect can be created. Hasselkus provides examples of occupations such as styling her mother's hair and holding her hand. Pickens et al (2010) describe acts such as families connecting over shared meals with their relative in the hospice as forms of "*presencing*."

In her critical reflection of her professional skills whilst caring for her dying father Thibeault (1997) describes "*connecting*" occupations such as reading with her father. She also explains her feelings of sadness and guilt when she realises that his deteriorating level of function means he can no longer participate in some of these everyday acts.

The focus of two papers by Hoppes (Hoppes, 2005a; Hoppes, 2005b) were the occupations that he engaged in with family members whilst their relative is dying. In the first paper he identifies the family social interaction which occurred whilst caring for his father and in the aftermath of his death. Unlike Thibeault who identified her professional skills as being insufficient for preparing her for this role, Hoppes (2005a) identified situations where his skills had enabled him to care for his father and overcome their previous relationship difficulties in doing so. Further Hoppes

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identified occupation as providing distraction from distressing emotions; but also provided a means to work through some of the more challenging emotions associated with his grief. In the process of adaptation he acknowledged the transformative capacity of occupation to enable him to move from a position of holding a fear of death to one of an awareness of death and the presence of loss throughout life.

The second paper by Hoppes (2005b) used Rando's three phases of grief as a framework against which he identified four phases of occupation to explain the impact of grief on his everyday occupations during and after his nephew's death. He described how initially he had maintained his occupations, *occupational maintenance*, whilst in denial about the seriousness of the situation; he likens this to Rando's Avoidance phase. *Occupational dissolution* allows recognition of how awareness of the reality of the situation began to develop and caused him to drop his usual occupations to engage with his family. He likens this to Rando's Confrontational phase. Rando's final phase is Accommodation and Hoppes describes two aspects to this; *occupational ambivalence* describes how he returned to occupations but the meaning and importance of these had changed as a result of his nephew's death. Finally Hoppes describes *occupational restoration and adaptation*; whilst occupations are restored they may be adapted to accommodate the revised situation. Hasselkus' paper relates a similar progression of engagement including reference to taking work into the hospital to do whilst her mother was ill (*occupational maintenance*); focusing entirely on her mother as her death neared (*occupational dissolution*); and her return to her everyday occupations during which time her focus is interrupted by memories and thoughts of her mother (*occupational restoration and adaptation*).

The notions of *connecting* and *presencing* whilst not explicitly acknowledged in all of these papers is recognisable in each. Papers by Hasselkus (1993), Thibeault (1997) and Hoppes (2005a) acknowledge the potential for conflict between being a health professional and a relative in regard to these two concepts. They highlight the challenge for the health professional in needing to find ways to bridge the gap between themselves and the dying person in order to be present and to connect with them. Hasselkus (1993) and Hoppes (2005a) use their experience of having been both grieving relative and health professional to examine the issue of professional boundaries in palliative care.

2.4.16 Summary of the main findings of the review

Thirty papers have been reviewed and organised into groups reflecting research on occupations and bereavement at different stages of the life span and in two distinct contexts; occupations of family members whilst their relative is dying, and bereavement in relation to professional practice and education. The final stage of the scoping review requires a return to the initial research question: What is known about occupation and bereavement?

Three objectives were identified which underpinned the question; these will be addressed in turn:

1. To identify the role of occupation following bereavement.
2. To identify what needs engagement in occupations meets following bereavement.
3. To identify whether engagement in occupations changes across the age span and after different forms of bereavement.

2.4.17 Objective 1: To identify the role of occupation following bereavement

Occupation offers a means to reconstruct identity following bereavement (Forhan, 2010; Hoppes, 2005a; Hoppes, 2005b; Hoppes and Segal, 2010; Mattock and McIntyre, 2016; Vale-Taylor, 2009). By engaging in familiar occupations or those linked with the deceased the bereaved begin to reassemble their lives and how they will live after bereavement. Engaging in occupations with others also allows for the reconstruction of the relationship with the deceased (Hoppes and Segal, 2010; Vale-Taylor, 2009) in line with Walters' concept of a living biography which proposes that the bereaved create an ongoing, durable biography of the deceased which situates them within their lives, facilitating integration into their ongoing lives (Walters, 1996). Remembrance activities and creative occupations were also seen to provide a means to memorialise the deceased in a way which facilitated the ongoing lives of the survivors (Ilott, 2006; Vale-Taylor, 2009).

Linked with this was the finding that occupation can afford the bereaved a means to identify meaning in their loss (Hoppes and Segal, 2010). Through re-engagement in occupations following loss, Hoppes and Segal proposed that the bereaved make changes in either how or why they performed the occupation. For some people new occupations demonstrate revised life courses subsequent to bereavement as the events they had experienced caused them to question the meaning in how they organised their life.

Occupation has been demonstrated in the studies reviewed to provide distraction from grief (Brewer and Sparkes, 2011; Creed et al, 2001; Fluegeman et al, 2013; Ilott, 2006; McClatchey and Wimmer, 2012; McIntyre and Howie, 2002; Mattock and McIntyre, 2016; Hoppes, 2005a; Hoppes 2005b). In studies which addressed the grief experience of children, occupation offered fun experiences which provided diversion from grief. In papers about adults' grief experience, distraction was identified and used as a coping strategy. Both interpretations reflect explanations of restoration focused aspects of the dual-process model of grief (Stroebe and Schut, 1999).

2.4.18 Objective 2: To identify what needs engagement in occupations meets following bereavement

In the studies reviewed engagement in occupations following bereavement met needs for support; continuity of experience; maintenance of roles; and connection. Studies indicated that

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engagement in social occupations provided children with opportunity to meet others who had had similar experiences which provided reassurance that they were not alone in experiencing grief (Brewer and Sparkes, 2011; Creed et al, 2001; Fluegeman et al, 2013; McClatchey and Wimmer, 2012; Scaletti and Hocking, 2010). For adults similar findings were demonstrated, as well as recognition of the value of support gained from others during social occupations (Fitzpatrick et al, 2001; McIntyre and Howie, 2002; Utz et al, 2002). Kang and Yoo (2007) reported on the benefits of a group relaxation programme; the paper acknowledged the benefits of the exercise for participants but did not acknowledge the role that interpersonal support within the group may have played. Considering results from other studies indicating the benefit of support from others this may have been an important aspect to consider.

Occupations hold an important role in continuity of experience for bereaved people. Familiar occupations and routines were found to provide reassurance and a stability which provided comfort and confidence during difficult times. Continuity in occupations also provided a means to maintain a sense of control in life; skills were maintained which in turn maintained self-confidence (Hoppes and Segal, 2010; McIntyre and Howie, 2002; Mattock and McIntyre, 2016; Nyman et al, 2014; Utz et al, 2002).

Social and leisure occupations offer a means to maintain health and wellbeing (Fitzpatrick et al, 2001; McIntyre and Howie, 2002). Good health was seen by Utz et al (2011) to be a contributory factor in perceived self-efficacy for bereaved people; in turn this was linked with more positive mental health. It can be concluded that maintaining involvement in everyday activities and preferred occupations promotes better health outcomes for bereaved people; further emphasising the role of continuity of occupations during this period (Mattock and McIntyre, 2016; Utz et al, 2011).

The fourth need which appears to be met by engagement in occupation following bereavement was connection. This refers to the importance of connecting with others and to the wider world and was noted in studies of grief in children and adults (Brewer and Sparkes, 2011; Creed et al, 2001; Fluegeman et al, 2013; McClatchey and Wimmer, 2012; McIntyre and Howie, 2016). Another interpretation of connecting was identified in relation to anticipatory grief where people use occupations to connect with their dying relative as a means to maintain their relationship (Hasselkus, 1993; Pickens et al, 2010; Thibeault, 1997). Pickens et al (2010) also describe this as a way of normalising the experience of losing someone close; in this way it can be seen to link with the need to maintain continuity.

2.4.19 Objective 3: To identify whether engagement in occupations changes across the age span and with different forms of bereavement

No papers were identified which considered the form of occupations across the lifespan or in different forms of bereavement. The majority of papers retrieved which related to children's grief focused on outdoor and camp activities, but this does not indicate such occupations are commonplace or available to all bereaved children. The majority of papers addressing grief issues for adults and older people referred to everyday activities or activities of daily living but specific occupations were not clarified. Participant groups in these studies reflected a broad range of bereavements. Nine papers explored spousal bereavement; sixteen did not specify a particular form of bereavement and participants studied had different experiences; the remaining five papers were papers which explored bereavement in relation to occupational therapy practice and education.

2.4.20 Gaps in the literature

The literature reviewed provided evidence regarding the role of and needs potentially met by occupation following bereavement. No evidence was found to explain the form of occupation at this time, or the significance of specific kinds of occupations at different times across the lifespan. This remains an area to be investigated and would provide understanding to inform occupational therapy practice. The paper by Oakley et al (2002) was the only paper to investigate the impact of bereavement on occupational function within the profession. Considering the impact that this paper found and the emphasis within the profession on occupation this should serve as a call to occupational therapists to consider this effect.

The papers reviewed which focused on the occupational therapy profession and professional education indicate a paucity of evidence of occupational therapists who address bereavement and loss in their practice with clients despite claims of the centrality of loss to their work (Breen et al, 2013; Ilott, 1996; Miliken et al, 2007). Given the significant impact that a wide range of losses might have on the organisation of routines and occupations, the lack of papers relating to bereavement should be a cause of concern and is argued to be a significant gap in the current professional literature.

A final note should be made on the strength of the evidence reviewed. Sixteen of the thirty papers used qualitative methods; eight were quantitative of which only one was a randomised controlled trial. The fact that the majority of papers reviewed would sit in the lower levels of the research quality hierarchy (Polit and Beck, 2014) should be of concern. Occupational therapists work across health and social care and as claimed by Ilott (1996) bereavement and loss are likely to be experienced in some form by a broad range of clients; a more robust understanding of these topics is therefore required by the therapists who work with them.

2.4.21 Summary of scoping review

This review has presented the small body of published literature on occupation and bereavement. Thirty papers were identified of which the majority were by occupational therapists. The papers dated back to 1991 and represent the sum of the professions understanding of the topic published in the last 25 years. Analysis of these papers indicated what is known about the role of occupation following bereavement and what needs it might address. Gaps in the literature have been identified and attention drawn to the quality of evidence available.

2.5 Conclusion

This chapter has presented an overview of bereavement theory, primarily since the publication of Freud's text *Mourning and Melancholia* to the more recent dual-process model; this period reflects a move in understanding of this phenomena from the view that the breaking of bonds with the deceased is necessary to current understandings of the potential role of maintaining bonds and meaning-making in grief. The second part of the chapter explored definitions of the concept of occupation. The final part of the chapter reviewed literature on occupation and bereavement. This is a small body of work and as has been shown no previous work has been completed which focuses on the same issues as those proposed for the current study. One paper had used a phenomenological methodology to explore bereaved children's experience of a bereavement camp experience; a further study used an interpretative phenomenological approach to investigate the occupations of spousal carers of people with dementia. The majority of the other qualitative papers used an ethnographic or auto-ethnographic approach. The lived experience of occupation for older widowed people therefore represents an area so far not researched.

The next chapter will explain the epistemology, ontology, methodology, and study design adopted to undertake the current study.

Chapter 3 Methodology

3.1 Introduction

This study aimed to investigate the lived experience of older people's engagement in occupations during their first year of widowhood. Although bereavement is a common life experience (Stroebe et al, 2012), literature pertaining to engagement in occupation during grief remains limited and it was therefore appropriate to adopt a qualitative methodology which would facilitate an exploratory approach (Patton, 2002). This focus guided subsequent decisions regarding the underpinning philosophical perspective and the subsequent method with which data would be collected. The decisions at the outset of a research study are taken in order to ensure the adoption of an appropriate lens through which to understand the data and provide a means by which to address the research question. The decisions which were made in relation to how this study would be approached and undertaken and justification for them will be the focus of this chapter. Crotty (2003) identified four elements to the research process – epistemology, ontology, methodology and method. This chapter will consider these in relation to this study. This chapter will also discuss issues of quality assurance in qualitative work relevant to the current study.

3.2 Epistemology

Research, or the production of knowledge, has been understood in terms of two paradigms; the quantitative and qualitative paradigms (Denzin and Lincoln, 2011). Lincoln and Guba (1985) explain paradigms as belief systems founded on ontological, epistemological, and methodological understandings (Lincoln and Guba, 1985). These differ significantly in terms of their underpinning beliefs and the kind of knowledge they aspire to produce. The outcomes of research undertaken within each paradigm therefore differ both in the kind of knowledge produced and the research questions they can address. This arises from the differing epistemologies or the philosophical perspectives upon which they are based.

Epistemology refers to the theory of knowledge and relates to how we understand, or know, what we know and is described by Schwandt (2001, page 71) as “the study of the nature of knowledge and justification.” Carter and Little (2007, page 1317) summarise epistemology as the “justification of knowledge”; whilst Flick (2014) defines epistemology as relating to how scientific knowledge is understood. Although these three definitions encompass three subtly different definitions together they describe the philosophical understanding of knowledge; namely what it is, why it is what it is and how it is understood. They also serve to help differentiate epistemology from the more specific applications of philosophy related to research praxis.

The evolution of qualitative research, which has roots in both ethnography (Denzin and Lincoln, 2011) and phenomenology (Smith et al, 2009), has seen the development of multiple paradigms.

These include constructivist-interpretivist, critical, and feminist-post structural (Denzin and Lincoln, 2011); constructivist, interpretive and critical theory (Bryman, 1984; Duncan and Nicol, 2004). All lay claim to a shared epistemology which understands reality to be multiple and knowledge to be created through the construction of interpretations of experience (Patton, 2002; Ravenek and Laliberte Rudman, 2013). Qualitative research aims to explore and understand the experiences of human beings; acknowledging these to be dynamic and individual (Brinkmann and Kvale, 2015; Ravenek and Laliberte Rudman, 2013).

Whilst epistemology remains essentially a philosophical and theoretical debate, in relating epistemology to research, specific applications, or methodologies, have developed and these can act as a guide for the researcher in the identification of appropriate principles and procedures (Carter and Little, 2007). However Van Manen (1997) and Flick (2014) propose that the research question should be the starting point for the decision making process regarding appropriate methodology and method. Others differ in this view, instead arguing that decisions regarding methodology and method should be congruent with the researcher's beliefs and values regarding the theory of knowledge and nature of being; or their epistemological and ontological stance (Schwandt, 2001; Crotty, 2003). Alvesson and Sköldberg (2009) propose epistemology and ontology provide an overarching guide to the *whole* research undertaking from identification of the issue to be investigated through to the method in which the study is undertaken and outcomes presented. It is perhaps inevitable that the researcher's ontological beliefs will inform the methodology and method of the study to some extent as these provide a guide to how the world is understood (Hammersley and Atkinson, 1983; Patton, 2002; Corbin and Strauss, 2008). It is at this preliminary stage however that research preparation must move from philosophical debate to a more technical, methodological one (Bryman, 1984).

In relation to the current study, as understanding of the experience of engaging in occupations following bereavement remains limited; the research was most appropriately constructed to consider how this is experienced by the participants. A qualitative approach was thus deemed appropriate for the completion of the current study; this would reflect the individual experiences and understandings of the participants.

3.3 Ontological considerations

Ontology refers to how the nature of reality is understood (Glaser and Strauss, 1967; Hammersley and Atkinson, 1983; Patton, 2002; Corbin and Strauss, 2008). Whilst a positivist, realist perspective holds there to be a single, true view of a phenomenon, a qualitative, relativist perspective views reality as being interpreted or constructed by the researcher or between the researcher and the researched (Patton, 2002; Denzin and Lincoln, 2005). A post-positivist, relativist ontology proposes that the world and knowledge can only be understood imperfectly

(Ravenek and Laliberte Rudman, 2013) and as comprised of “multiple, constructed realities” (Denzin and Lincoln, 2011, page 13). The researcher’s and the research participants’ personal understanding and interpretation of the world, and specifically the situation under investigation will have been informed by their life experiences. These understandings will in turn come to bear on the interpretations the researcher constructs from the experiences of the research participants (Van Manen, 1997; Smith et al, 2009).

The aim of research in the qualitative tradition is to represent the experiences of participants. Denzin and Lincoln (2011) propose that an interpretive ontology views individuals as constantly constructing understanding and meaning through their interactions. The researcher aims to engage with their participants to create a situation wherein they attempt to construct a shared interpretation of their understanding of the world and the meanings that phenomena hold for them (Denzin and Lincoln, 2005; Hammersley and Atkinson, 1983). The experiences and perceptions of both the researched and the researcher are seen as intrinsically part of the outcome; with the researcher understood as an integral component of the world under investigation whose “perceptions ... are intricately interwoven” with those being studied (Grbich, 1999, p. 5). In being so positioned interpretations of the situations under investigation are made through the individual lens of the researcher in collaboration with the participants (Hammersley and Atkinson, 1983); one, single interpretation cannot therefore exist. Instead the qualitative research process involves both participant and researcher in constructing a shared understanding of the experiences and realities which comprise the focus of the research (Denzin and Lincoln, 2005). This shared understanding is also argued to be an evolving interpretation which is flexible to future examination and reinterpretation by others (Carter and Little, 2007).

The interpretivist perspective reflects my own view; one which mirrored the client-centred approach (Rogers, 1995) I used in my professional practice which placed emphasis on supporting and collaborating with clients to create an understanding of their experience and hopes for their future. Underpinning this was the perception that each client, regardless of sharing a diagnosis with another would have their own interpretation of their situation. Perhaps as a result of this experience, an interpretive approach, whilst appropriate for the current study, also felt an appropriate fit with my own ontological stance. In the current study the two primary experiences to be examined, bereavement and occupation, are both understood to be social constructions in that experience of both is influenced by contextual influences such as temporal, cultural and historical. Experience of both is therefore likely to be individual and unique. To this end a relativist, interpretivist ontological lens was deemed an appropriate approach. This reflected the researcher’s understandings of reality and the purpose of the current study which was to explore the experience of engagement in occupation by older widowed people.

3.4 Methodology

Crotty (2003) proposes that alongside consideration of ontological and epistemological stances the researcher must decide upon the specific methodology and methods to be utilised.

Methodology refers to the strategy or overarching design of a research project and should provide a link between the methods used and the outcomes anticipated; the method adopted refers to the tools and techniques used to collect and analyse the data. Schwandt (2001) describes methodology as providing the middle ground between the philosophical debate related to ontological understandings of the nature of reality and the methods, or “how”, the research will be executed.

The identified aim of this research was to explore how participation in occupations by widowed older people was experienced and understood. It has been acknowledged and demonstrated how this fits within an interpretive, qualitative approach. Carter and Little (2007) identify methodology as the second level of deliberations required of the researcher. The first level, epistemology informs methodology which in turn provides justification for the methods used to complete a research study. Whilst various synonyms are used, for example Cresswell (2007) uses the term *traditions of inquiry*, the focus of methodology is to provide an overarching means to formulate, analyse and evaluate research (Carter and Little, 2007). As the current study was an exploratory study which would investigate the experiences of the participants; it was appropriate to adopt a phenomenological approach (Merleau-Ponty, 1962; Van Manen, 1997). This would provide an appropriate structure and lens through which to explore the lived experiences of the participants.

3.5 Phenomenology

Phenomenology is described as the study of lived experience or the lifeworld as it is experienced by individuals (Van Manen, 1997; Smith et al, 2009). This refers to how individuals experience the world in a pre-reflective way. Phenomenology attends to subjective experience and interpretation with the understanding that we can only know how things appear to us. Merleau-Ponty’s explanation provides a succinct summary: “The world is not what I think but what I live through” (Merleau-Ponty, 2002, page xviii). Phenomenology aims to develop understanding of the experience of a phenomena before it is subjected to the classification and categorisation that forms part of human experience and which allows us to situate an experience (Van Manen, 1997; Ashworth, 2003). Whilst it has a philosophical base it has also developed as a research methodology (Moran and Mooney, 2002). With its focus on lived experience it was an appropriate methodology to guide the completion of the current study.

The aspiration to explore the phenomenon of engagement in occupation by older widow/ers underpinned the current study. The inclusion of information about the researcher’s professional

background in chapter one whilst not provided in line with Husserl's bracketing, is provided in the spirit of transparency and to provide contextual background to the study. Concern regarding whether it is possible to sustain suspension of pre-understandings and adopt a neutral stance prompted a decision to explore the work of Heidegger. Heidegger was a student of Husserl who took his work in a different direction and focused on the interpretation of experience rather than description.

3.6 Interpretive phenomenology

Developed by Husserl as the study of conscious experience of the world; phenomenology was a descriptive approach aiming to describe lived experience (Harré, 2006). Heidegger subsequently took a new direction' with the aim of developing an understanding of existence and the concept of "being." The work for which Heidegger is perhaps best known is "Being and Time"; published in 1927 the text explains his understanding of human beings and their state of "being" as the phenomena to be analysed (Heidegger 1927/1962; Smith et al, 2009). In contrast to Husserl's emphasis on the essence of existence; for Heidegger key questions related to what he called an "analysis of existence" (Finlay and Gough, 2003). Heidegger believed phenomenology should develop an understanding of what it was to live as a human being.

His work focused on humans' engagement with objects and social interactions in their world and over time; and their understanding and experience of these (Finlay and Gough, 2003). Heidegger used the term "thrown" which can be defined in terms of humans being "thrown" into the world (Heidegger, 1927/1962). This explains the intentions behind the current study; occupations provide clear evidence of people's engagement with their environment and with other people within it; and thereby their occupations. If widowhood is understood as potentially forcing a significant transition to a new way of living, it can be seen how the concept of "being thrown" into the new world might be applied to the current study.

Heidegger described humans as "dasein" or "da-sein" which can be translated as "being there" (Heidegger, 1927/1962). For Heidegger "being there" relates to "being in the world", being present in the world of objects (Smith et al, 2009). Humans were not seen as separate entities but are a part of the complex structure which contributes to existence.

Heidegger differentiates between two important concepts - theory and practice and recognises that through practice, and by this he means engagement with, real life and the world occurs. This takes place before theorising can occur. His work therefore proposes that rather than the interpretive account of the world previously espoused by philosophy it is more important to develop a phenomenological account of the lived experience of being-in the world (Smith et al, 2009).

Heidegger's work addresses how things - objects and experiences - appear to us; in this he understood these things to have meanings for the individual and these can be both visible and invisible. Heidegger spoke of things showing themselves; this is how they appear to humans. For Heidegger being-in-the-world involves engagement with objects which he describes as "present-at-hand" and "ready-to-hand". "Present-at-hand" refers to a theoretical understanding of the world as made up of objects; "ready-to-hand" are those objects with which we interact. The latter are seen to hold significance and meaning for humans (Mulhall, 1996). Within this explanation of the situating of humans in relation to their world; Heidegger also acknowledges that humans are not alone and that the world is full of other people. Daily life involves complex social processes all of which are experienced by others; Heidegger refers to this as "being-with", or "mitsein" (Heidegger, 1927/1962; Mulhall, 1996).

A key aspect of Heidegger's work relates to the concept of time, or temporality. For Heidegger time refers to the notion that humans are constantly moving towards their end; or their death. He uses the term "being-towards-death" (Heidegger, 1927/1962). The idea of time as a linear concept involving the past, present and future is not one with which he engages specifically but rather relates it to humans' nature to always project towards the future. However in so doing humans gather experiences and complexity from their experiences in the world which they take to their future; Heidegger refers to this as "having-beenness", or "gewesenheit" (Heidegger 1927/1962). Through a process termed *resoluteness* through which Heidegger understood humans as being able to make a decision to overcome their past; the point at which this decision might be made is termed the *moment of vision* and it is at this moment that Heidegger believes *authentic* dasein is revealed (Heidegger, 1927/1962).

Time for Heidegger is finite and comprises all three temporal dimensions - past, present and future - which come to an end with death. Death to Heidegger was an experience which was certain and important, so much so that he saw the totality of lived experience as a journey towards it, or "being-towards-death" (Heidegger 1927/1962). However in the face of this certainty, regardless of attempts to ignore the fact, lies the uncertainty of when death will occur. Heidegger recognised that humans live with this mystery, or the possibility of impossibility, until death occurs and renders possibility impotent (Heidegger, 1927/1962). Rather than seeing life as a pessimistic experience however Heidegger instead interprets this as bringing a sense of anticipation and opportunity; in knowing death will occur humans can turn their attention instead to creating an authentic life (Sheehan, 2015).

A further component of Heidegger's understanding of death was that it is non-relational. By this he meant that only one's own death was relevant in terms of the creation of an authentic life; the experience of and motivation for which cannot be gained through the deaths of others (Heidegger 1927/1962). Arguments against Heidegger's view forward the understanding that experience of

grief in relation to the deaths of others opens up individual understanding and contributes to the need to create an authentic life experience; this might be understood as a form of personal growth consequent to experience of grief (Calhoun and Tedeschi, 2013).

In using the terms “authentic” and “inauthentic” Heidegger was referring to the characteristic of humans which allows them to make choices and determine their possibilities. Heidegger saw this characteristic as intrinsic to *dasein* and not the result of experience in the world. Varga and Guignon’s (2015) interpretation of Heidegger’s understanding of these concepts proposes that humans are always in one of three states; authentic, average or inauthentic. Average refers to those periods in which we live much of the time. Heidegger proposed that time spent in the authentic mode is “owned” time; in the inauthentic mode it is “disowned” and the average mode is “unowned”. The unowned time therefore holds possibility for authenticity or inauthenticity. Heidegger saw humans as beings who are constantly making choices that demonstrate who they are despite the fact that when they are in the “average” state they are in a sense adrift, a state Heidegger called “falling.” Falling is a condition that allows for the shared-ness of social existence that enables us to be fully human; those periods when humans enact roles and tasks as required by their community and which enable life to continue, but which may not express the unique possibilities of the human being. However in this condition we cannot be the authors of our own lives that we might otherwise aspire to be and which might otherwise be identified as authentic (Varga and Guignon, 2015).

These understandings are central to “Being and Time”; however what was also made explicit in this work was Heidegger’s mode of phenomenology as an interpretive activity informed by the phenomenologist’s prior understanding. In contrast to Husserl and his perspective of phenomenology as one in which the phenomenologist should engage in a process of self-reflection in order to “bracket” their former understandings, Heidegger’s interpretive phenomenology acknowledges that all interpretations of phenomena are built from the prior understandings of the researcher (Finlay, 2008).

“Whenever something is interpreted as something, the interpretation will be founded essentially upon fore-having, fore-sight, and fore-conception. An interpretation is never a presuppositionless apprehending of something presented to us” (Heidegger, 1962/1927, page 191-192).

Heidegger adds a caution to this though by stating that interpretations should privilege the object or experience, and not the phenomenologist’s prior understanding (Heidegger, 1927/1962).

Whilst pre-understanding may inform the interpretation of the phenomena, the process of examining and interpreting the phenomena might also result in new aspects being illuminated for the phenomenologist. Thus the process might be seen as a cyclical one implying a process of interpretation of interpretation, providing opportunity for a self-reflexive approach (Smith et al, 2009).

In summary Heidegger's work forwarded the notion that being is time and time is finite; one of the key purposes of human life for Heidegger was the notion of "being-towards-death". In accordance with this, humans direct, or opt not to direct, their life towards this end. Heideggerian phenomenology works towards a contextual understanding of being, interpreted through individual pre-understanding of life and what it is to be human.

Van Manen (1997) argues that the classification of what constitutes interpretation is a difficult concept. A description aims to explain lived experience; however the focus of such description can be argued in itself to be an interpretation. As identified earlier, the lived experience as it is experienced pre-reflection can be seen as an impossible experience to obtain because as soon as someone is asked to talk about their experience of a phenomenon they create an interpretation. Thus in an interview situation it is argued that in relating an experience, an interpretation of it has already been created. For the researcher too, their pre-understandings when listening to a participant relating their experience will direct them to attend to certain aspects whilst paying less attention to others.

With its emphasis on integrating direct quotations from the participant interviews; phenomenology offered opportunity to possibly more completely reflect and honour the voice of the participant. The sensitive context of the current study, bereavement, could place significant demand on the participants; recognition of their contribution to its completion was therefore of importance. However in adopting this approach it was deemed necessary to consider means to make explicit the underlying meanings behind the participants' interpretations; for these reasons a hermeneutic interpretive phenomenological methodology was deemed most appropriate.

3.7 Hermeneutic phenomenology

Heidegger's interpretive approach led him to explain phenomenology as hermeneutic, the theory of interpretation (Smith et al, 2009). Originally focused on the understanding and interpretation of biblical texts developed by Schleiermacher, hermeneutics evolved to provide a philosophical foundation for the interpretation of historical texts. In this endeavour hermeneutics sought to interpret the intentions and underlying meanings of the author, and the relationships between contexts of a texts production and its interpretation. In relation to phenomenological research this might equate to the researcher analysing a transcription of an interview to build an interpretation of their experience of a life event (Smith et al, 2009).

The integration of hermeneutics and phenomenology offered an approach to interpret the meanings behind lived experience. These interpretations must always be acknowledged as a construction created in the instance in which they were completed; interpretation remains the work of the analyst and will reflect their pre-understandings. Hermeneutic phenomenology

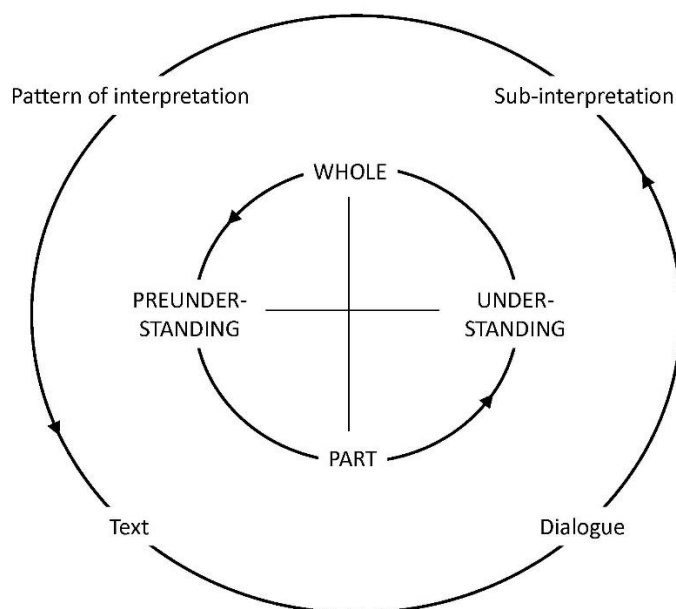
acknowledges the influence of preconceptions and stresses the importance of awareness of these (Smith et al, 2009).

For Schleiermacher the role of contextual factors was also crucial to any interpretation; time and historical contexts influence interpretation and understanding and must also therefore be incorporated into the analysis (Smith et al, 2009). Gadamer concurred, stating that hermeneutic phenomenologists must maintain an awareness of their own pre-understandings whilst seeking to understand the meanings of an experience to another (Gadamer, 2004). However as Smith et al (2009) suggest at times our preconceptions may only become apparent after we have explored an interpretation. The role and attention of the researcher must however remain focused on uncovering the experience of the researched and not on the researchers experience and fore-knowledge and so a balance must be established. Adoption of a reflexive approach allows the researcher to explicitly recognise their former experiences and understandings. In the current study a credible appreciation of the experience of engaging in occupations during the early period of widowhood might be achieved through iterative exploration of both the participants experience and my own understanding of the experience of bereavement based on theory and professional experience. Schutz (1932/1972), although Husserlian in his initial engagement with phenomenology, recognised this process of interpretation of experience in his discussion of temporality and experience: *“something new grows out of what was something old and then gives place to something still newer. I cannot distinguish between the Now and the Earlier, between the later Now and the Now that has just been, except that I know that what has just been is different from what now is”* (Schutz, 1932/1967, page 47).

The concept of the hermeneutic circle provides a reflexive means to develop interpretations of lived experience. The hermeneutic circle describes the iterative process of hermeneutics where attention is dynamic, moving between part and whole. The process involves attention to both the whole of the experience, or transcription, and part of it (Smith et al, 2009). This iterative process may also incorporate a temporal aspect whereby earlier experience is understood in relation to later experiences. Movement is made between the pre-understanding and the understanding of the researcher; as sub-interpretations are made following analysis of parts of the text these are compared or related to the whole; in turn these are considered in light of the pre-understandings held by the researcher (Finlay, 2008). Subsequent adjustment of the interpretation is made and the process begins again. Alvesson and Sköldbberg (2009) identify four further key components involved in the hermeneutic process – patterns of interpretation, text, dialogue and sub-interpretation (Figure 3.1). “Patterns of interpretation” refer to the need for the interpretations to either reflect and develop previous explanations or offer a rationale why they may not. A “text” is the material for the analysis and may be a written document or social act or event. “Dialogue” refers to the interrogative approach adopted by the researcher who must approach the task of

analysing the text with a questioning approach prepared to ask questions of the text, their pre-understandings and their interpretations. The final component, “sub-interpretation” reflects the process of identifying possible interpretations which are gradually adapted with each new perspective taken, deepening the focus as new insights develop.

Figure 3.1 The hermeneutic circle (taken from Alvesson and Sköldberg, 2009)



The concept of the hermeneutic circle was critiqued by Shklar (2004) who struggled with the concept of a circle which she felt implied a centre and stated that proponents had not clarified whether this was the position taken by the analyst – possibly implying an authority which could be questioned (Alvesson and Sköldberg, 2009) - or by some as yet undiscovered truth. She also queried the central role of interpretation, arguing instead that explanation should come first; and also that in some cases interpretation was little more than “unstated evaluation poses as interpretation and it is unfair to the subject no less than to the reader” (Shklar, 2004, page 674). A key thrust of Shklar’s (2004) paper was a call for researchers to focus on developing clear explanations of social acts rather than attempting to interpret their meaning; possibly reflecting a Husserlian approach with emphasis on description. It could be argued though that the act of description involves elements of interpretation; the selection of experience to examine and describe, the language used in description, and temporal and contextual influences within which the act of description takes place will all have an impact on the description constructed.

Analysis of data collected in the course of the current study would therefore involve an iterative process between examination of the data collected, previous experience of working as an

occupational therapist and with people who have been bereaved, and theoretical understandings of occupation and bereavement. Together these factors and the analytic process will facilitate the development of an interpretation of the experience of occupation for older people who have been widowed.

3.8 Research procedure

The proposed study aimed to develop understanding of the experience of engagement in occupation during the first year of widowhood. As has been argued interpretive phenomenology offered an appropriate methodology with which to undertake this (Brinkmann and Kvale, 2015). In keeping with both Crotty's (2003) and Carter and Little's (2007) guidelines on the research planning process the final stage is the method. The method provides the practical structure under which data will be collected, managed and analysed (Carter and Little, 2007); the following section of the chapter will provide explanation and discussion of the data collection procedures for the current study.

To achieve the level of engagement with participants necessary to develop an appreciation of their experiences of engaging in occupation during the transition period following bereavement, an interview study was deemed appropriate. It was anticipated that the participants may find talking about their situation difficult (Stroebe et al, 2012). Van Manen (1997) proposes that individual interviews offer a sensitive method to explore experiences; whilst Brinkmann and Kvale (2015) propose that individual interviews offer a means by which engagement and rapport can be individually established and thereby distress managed.

3.9 Longitudinal approach

Theorists including Bowlby (1989) and Raphael (1984) propose grief to be a process with distinct stages which are claimed to be clearly delineated with each stage reflected in different behaviours and emotions which impact on how daily life is experienced. In acknowledging this it was anticipated that participants' experience of occupation may also change during the process of adapting to their new situation. According to Miles et al (2014) longitudinal research serves to provide a longer term understanding of how change might proceed. The use of a longitudinal approach thereby offered the opportunity to return to participants to identify change. A repeated interview method was deemed a realistic means to gather data rather than a cross-sectional approach involving just one interview which might necessitate reliance on recall.

Interviewing each participant twice at different points during the first year of widowhood would form a complete story of the experience of engaging in occupations during the first year of widowhood. The first interviews would tell the first part of this story, but ultimately may be incomplete on their own. The second interviews would allow the participants to conclude their

story and provide a more complete understanding of the evolution of changes. This decision was reflective of both the transitional nature of bereavement and the hermeneutic tradition; the two interviews offered a further means to understand both the part and the whole of the experience for the participants.

3.10 Interviews in phenomenology

Interviews offer a means to explore individual perceptions of experience and therefore reflect the focus of phenomenological research (Van Manen, 1997; Smith et al, 2009). In the current study the focus of data collection was to develop an interpretation of the subjective experiences of occupation for the participants during the first year after bereavement. Thomson and Brinkmann (2009) propose strategies to try to assure that participant descriptions reflect what the interviewer perceives them to be about and remain close to the lived experience of the participant. To this end efforts were made in the current study to structure questions in a way to maintain the focus on the participants' experiences. In order to emphasise this the researcher also included contextual prompts such as time cues; such as "before" or "after the funeral". By allowing participants time and freedom within these prompts it was anticipated that they would feel able to relate memories and stories in their own way with minimal interference by a more strictly imposed structure.

Brinkmann and Kvale (2015) argue interviews are a social practice involving a situated interaction from which an interpretation of reality is created. Interviews within phenomenology can also reflect the hermeneutic approach in that they can offer a means to reflect with participants and develop an iterative approach; in doing so a collaborative atmosphere can develop (Van Manen, 1997). The researcher's approach to interviewing for the current study could be argued to follow a Heideggerian approach in that previous understandings of occupation and bereavement were not concealed. Two aims underpinned the organisation of the interviews used in the current study. Firstly to gather data to support the development of an understanding of engaging in occupation after bereavement; secondly to gain an appreciation of the meaning of the experience for participants (Wimpenny and Gass, 2000).

Unlike a therapeutic interview in which the interviewer may commence with little idea of what to expect; a research interview has a specific and distinct purpose (Brinkmann and Kvale, 2015). Van Manen (1997) cautions against the unstructured interview which can risk losing focus; to avoid this a semi-structured approach was deemed appropriate. An interview schedule was developed which would act as a prompt during the completion of the interviews to ensure that data relevant to addressing the research question was collected.

Understandings gained from professional practice and the study of literature on bereavement research, occupational science and engagement in occupation by older people informed the early drafts of the schedule with attention paid to both the topics covered and the order in which they were presented. This was then revised following discussion with one of the researcher's supervisors who had extensive experience of interviewing bereaved people (Appendix E). The schedule was designed to be used as an aide-memoire or checklist to support the direction of conversation rather than be strictly adhered to. Four key areas were identified under which prompts were organised; the four areas were routines, activities, shared activities and coping. The schedule was conceived as an evolving tool and was reviewed prior to each interview in order to incorporate issues of interest which arose in previous interviews (Schreiber and Stern, 2001). This reflective and iterative approach provided assurance that topics of importance to individual participants would be investigated for relevance to others.

Professional practice has afforded experience and confidence to encourage exploration of topics in an open way; each interview therefore began with the same question to participants. This was designed to establish the focus of the interview and to provide a starting point from which to begin conversation. The question asked was "Can you tell me about a typical day for you?" Interpretation of this opening question was open but it provided a flexible, common point from which to begin to explore both which occupations were engaged in and individual experience of these.

With the informed consent of each participant, confirmed before starting each interview in both phases of interviewing; the interviews were audio recorded. Subsequently the first stage of organising the interview data for analysis involved transcription of the recorded interview material. Whilst there is an argument for not recording or transcribing interview material, with both Glaser and Strauss claiming it to be unnecessary (Flick, 2014; Schreiber and Stern, 2001; Stern and Covan, 2001) here both processes were deemed valuable as due to the constraints of time and work commitments it was unlikely that analysis could begin immediately after each interview.

3.11 Field notes

The experience of interviewing a participant is argued to be where analysis of the data begins (Patton, 2002; Corbin and Strauss, 2008). As well as engaging in the interview conversation the interviewer will have gathered other, non-verbal information which provides contextual information (Corbin and Strauss, 2008; Janesick, 2011). In order to capture these insights; immediately after each interview notes were made in a fieldwork diary. These were often made

rapidly and included notes on aspects of the interaction, the environment, or ideas that came to mind during the interview.

As well as the immediate notes made; a reflexive diary was maintained throughout the research experience in which issues which appeared significant were reflected upon and explored (Finlay and Gough, 2003). This provided a means to reflect on my own role in the interview and how I may have impacted on the participant's response. This was an important process because, in qualitative research, the researcher is part of the research process.

3.12 Consideration of quality

The quality of research is inarguably an important issue for researchers undertaking research within both quantitative and qualitative paradigms. The approach to how quality is considered and enacted differs fundamentally between the two paradigms (Morrow, 2005; Ravenek and Laliberte Rudman, 2013). Within a qualitative paradigm it has been seen as particularly challenging and has attracted considerable discussion regarding how quality issues should be addressed (Mays and Pope, 2000; Smith et al, 2009; Denzin and Lincoln, 2011). Quantitative research traditionally addresses issues such as objectivity, reliability and rigor (Bowling, 2009); reliance on techniques and measurements which purport to eliminate bias is essential and the research process and resulting data must aim to accurately and transparently demonstrate this. It is conceded that these approaches are incompatible with qualitative research which recognises there is no value or bias free research design and that different strategies to both maximise and assess quality are required (Leininger, 1994; Whittemore, 2001; Morrow, 2005; Underwood et al, 2010).

Methods used in the qualitative paradigm necessarily vary between different methods (Yardley, 2000; Sparkes, 2001; Flick, 2014). Seale et al (2007) argued that a pragmatic approach to quality criteria based on methodology and method rather than on the overarching paradigm should be adopted. Morse (2012, page 32) claims that this is necessary due to the "value-laden, subjective and usually beyond the reach of quantification" nature of qualitative research. However Ballinger (2006) argued that both paradigmatic and methodological influences are of importance in the identification of quality criteria in qualitative research. Reflecting Patton (2002) and Morrow (2005) Ballinger (2006) also proposes that reflexivity and clear, honest articulation of the research process enhance transparency and credibility and thereby serve to reflect attention to quality. Whilst acknowledging the complex range of qualitative methodologies in use Yardley (2000) warns of the risk of different approaches for different methodologies; suggesting that this could lead to researchers only being familiar with a narrow range of quality strategies.

Reicher et al (2000) highlight the risk that in struggling to meet, or be seen to meet quality demands, particularly those imposed by positivist science, the qualitative researcher runs the risk

of neglecting the real focus of study i.e. human experience. They argue therefore for approaches to value and quality assurance that are relevant to the broad range of methodologies necessary to gain understanding of their human subject. In general three key concepts are commonly accepted as alternative indicators of the quality and value of research - these aspire to ensure the research is trustworthy, in the sense that it demonstrates both rigour and relevance, relating to the process and end product of the study (Finlay, 2006).

Concepts proposed by Lincoln and Guba (1985) are considered appropriate to qualitative work and widely adopted within the research community; these are referred to as domains of trustworthiness and comprise four criteria: credibility, dependability, transferability and confirmability. Credibility relates to the ability of readers to have confidence in the findings of the research. The output of credible research should provide a depth of meaning and a richness of understanding of the field under investigation. Dependability refers to the consistency of findings and is demonstrated by a clear audit trail. Transferability indicates the ability to generalise findings to other contexts. Emphasis here is on the researcher to provide sufficient information about their participants and the context of the study to enable the reader to make sense of the findings. Confirmability is demonstrated in the degree to which findings reflect the responses of the participants and not the interests of the researcher.

These are defined in Table 3.1 with indications of how these criteria were adopted in the completion of the current study.

3.13 Yardley's criteria for quality

Lincoln and Guba's (1985) criteria provide clear and accessible concepts for working with qualitative research. Other criteria are also relevant and no claims are made that these are the most relevant to the current study. Those proposed by Yardley (2000) which perhaps have clear resonance with a phenomenological approach were also considered in the completion of this study. In the sense that qualitative research reflects co-construction of truth and reality Yardley questions whether fixed criteria can be possible; nevertheless she identified four criteria against which the quality, value and integrity of qualitative research might be assessed:

- Sensitivity to context
- Commitment and rigour
- Transparency and coherence
- Impact and importance

In the completion of the current study these as well as those proposed by Lincoln and Guba (1985) were adopted. The latter were viewed as fundamental underpinning concepts to the completion of the project; whilst those forwarded by Yardley offered a means to clearly reflect

the specific methodological approach used, namely phenomenology. Table 3.1 provides examples of how these eight principles were addressed; it is acknowledged that there are some actions which demonstrate more than one concept but for means of clarity repetition has been avoided.

Table 3.1 Quality criteria as applied during the completion of the study

Credibility	<p>Considered selection of quotations from participant interviews in order to best represent the interpretations demonstrate credibility. However this might also be deemed a risk <i>in relation to</i> the implied emphasis on those sections of the analysis which are illustrated with quotations selected by the researcher (Corden and Sainsbury, 2006; Flick, 2014). Credible qualitative research demands interaction with, and involvement in, the area under study (Corbin and Strauss, 2008; Seale, 1999). A fieldwork diary was used to record events and feelings engendered by involvement in the study. This permitted interaction with participants on a personal level; whilst providing means for reflective and reflexive monitoring (Charmaz, 2006).</p> <p>Consideration of “negative cases” (Charmaz, 2006) provided opportunity to expand the analysis whilst memo writing provided evidence of the development of the analysis. (Corbin and Straus, 2008). Flick (2014) proposes that a narrative approach to interviewing in which the participant is given opportunity to tell their story with minimal interruption serves to enhance the validity of data, and avoid a “checklist” approach.</p>
Dependability	<p>Seale (1999) proposes that audit strategies provide further opportunities to enhance dependability of qualitative research. To this end evidence of the development and completion of the study provide opportunities to explicate the processes undertaken. Evidence of these will be made available in the various outputs of the study. Audio recordings and interview transcripts have been stored providing a means to audit the quality of the study. Use of a fieldwork diary also contributed to the creation of an audit trail (Finlay, 2006). Discussion with research supervisors offered opportunity to review interpretations made during the process of data analysis.</p>
Transferability	<p>Whilst the study does not claim to provide findings which can be widely generalised, it is anticipated that they will inform understanding of engagement in occupations when people experience bereavement and loss.</p>
Confirmability	<p>Use of a fieldwork diary to record reactions and acknowledge differing perspectives served to ensure the outcomes of the study remained grounded</p>

	<p>in the data. The field work diary facilitated a reflexive approach to the work, allowing acknowledgement of my role and presence in the research and the perceptions I brought to it and how these inform the research process (Finlay, 2002; Underwood et al, 2010). It is hoped that this thesis provides clear description of a coherent and transparent flow of decision making and actions which will contribute to the conviction the reader attributes to the work.</p>
Sensitivity to context	<p>Professional experience and understanding provided familiarity with the phenomenon under investigation. Adoption of an “interested but naïve” position was taken during data collection. My professional background was not shared with participants unless they asked in order to create an atmosphere in which they felt comfortable; this was not done in an attempt to mislead or trick participants rather to avoid creating concern. Attention to the impact of the research on the participants.</p> <p>Repeated listening to the audio recordings as well as reading of the interview transcripts with the aim to retain sensitivity to the linguistic cues which may not have translated adequately onto paper. This also provided opportunity to recall unique environmental information which may not have been noted in the midst of interviewing.</p>
Commitment and rigour	<p>Lengthy involvement in bereavement related work and considerable time spent in the completion of the study are indicators of commitment to the phenomenon, project and to the participants. Rigour is claimed in the collection and analysis of data for the project. Use of purposive sampling to ensure the adequacy of the participant group to reflect the focus of the study (Cresswell, 2007; Flick, 2014). Completion of second interviews offered a means for participants to validate or clarify information shared in the first interview. Data analysis aimed to identify and form an understanding of variations between participants’ experience, contributing to the conviction of the findings. Use of the hermeneutic circle and a longitudinal approach are further indication of rigour. A data analysis exercise was completed with one supervisor and indicated consistency in interpretation of findings.</p>
Transparency and coherence	<p>Detailed and considered explanation of the study and presentation of the findings; and efforts made to present these in an accessible and meaningful way reflect the transparency of the work. The findings chapters of the thesis provide evidence of transparency with the inclusion of excerpts from interview transcripts and researcher commentary which further reflect a reflexive stance.</p>

	The adoption of a phenomenological perspective with which to address the aim of the investigation, structure the study and organise the analysis aims to create a coherent impression.
Impact and importance	Findings reflect the relevance of the study in relation to contemporary socio-political and professional influences; these are identified in the final chapters of the thesis.

In sum it is intended that together the strategies identified provide an indication of the efforts made to assure the quality of the work undertaken and a transparent means against which the study may be judged. The combination of criteria proposed by Lincoln and Guba (1985); and by Yardley (2000) may appear cumbersome but the strategies required to meet them involved a careful and respectful approach towards the participants and their experience; an approach which it is hoped is apparent to the reader of this work.

3.14 Summary

This chapter has explained and justified the decisions taken in the planning and completion of the current study in relation to the guiding epistemology, ontology, methodology and method. The aim of the study was to gain an understanding of the lived experience of engagement in occupation following spousal bereavement. An interpretive phenomenological methodology was adopted as a relevant and appropriate approach to completion of the study. A longitudinal study using individual interviews to collect data provided opportunity to gain an understanding of the experience of engagement in occupations over the course of the first year of widowhood. Criteria adopted to demonstrate the trustworthiness of the study followed those proposed by Lincoln and Guba (1985) and Yardley (2000); these have been explicated with examples of how they were addressed and integrated throughout the study.

The following chapter will explain the study design. The procedures followed to collect, manage and analyse the data will be discussed.

Chapter 4 Study design and Method

4.1 Introduction

The previous chapter focused on the selection and justification of a qualitative, interpretivist epistemology and an interpretive phenomenological methodology in order to reflect the exploratory nature of the research question which formed the focus of this research project. The preceding chapter also explained the decision to use a longitudinal, interview method. These decisions were deemed most appropriate to achieve the aim of the study which was to develop an understanding of the lived experiences of older participants in relation to engagement in occupation during the first year after spousal bereavement.

This chapter is presented in three sections. Firstly the process of data collection will be discussed; this will include explanation of preparations made for data collection, data collection and actions taken following data collection. This section will also explain the ethical issues considered relevant to the study and how these were addressed. The second section will explain how the data collected was managed including discussion of the recording and transcription of the interviews from both phases of data collection. The final section will consider data analysis; the process for doing this will be explained and extracts from the data provided to illustrate aspects of the analysis, decision making and reasoning involved. Explanation of the analysis will focus primarily on the development of one of the final themes identified.

4.2 Research question, aims and outcomes

The research question underpinning this study was:

- How is engagement in occupation perceived by older, bereaved spouses?

The aim of the research was:

- To explore the lived experience of participation and engagement in occupations during the first year following spousal bereavement.

The anticipated outcomes of the study were:

- Development of an understanding of the lived experience of engaging in occupations during the first year of widowhood in older age.
- Identification of how older people who are bereaved perceive their daily routines and activities.

4.3 Preparation for Data Collection

4.3.1 Ethical Approval

This study underwent peer review within the School of Health Sciences (now Faculty of Health Sciences) before ethical approval was sought and received from Southampton and South West Hampshire Research Ethics Committee (A) (Appendix F). The study reference number was: 08/H0502/137. The study was sponsored by the University of Southampton (Appendix G) and Southampton University Hospitals Trust (Appendix H); and was insured by the University of Southampton (Appendix I).

Prior to the commencement of data collection with participants recruited via Hospice B an honorary contract with Southampton University Hospitals Trust (now University Hospital Southampton NHS Foundation Trust) was required (Appendix J). This was not a requirement of Hospice A where the hospice management group gave approval.

4.3.2 Timing of data collection

The timing of when to interview participants during their first year of widowhood was given careful consideration. It was deemed important to avoid recall of early experiences of engagement in occupation as far as possible; whilst also wishing to prevent undue distress being caused to participants. The decision of when first to approach participants was guided by the bereavement literature. This suggested that much bereavement research is carried out six months or more after the death has occurred however work by Bennett (2004) was identified in which older widowed participants were recruited at three months post-bereavement for a study on cause of death attributions. Longitudinal studies by Bonanno et al (2005) explored grief at 4 and 18 months post-bereavement; Field and Friedrichs' (2004) examined the course of continuing bonds at 4 and 24 months post-bereavement. Ong et al (2004) recruited widowed participants even earlier at 18-42 days after bereavement having made initial contact at 7 days post-loss to investigate the role of positive emotions following bereavement.

It was therefore decided that it would be appropriate to undertake the first phase of data collection with participants at approximately 3-6 months post-bereavement. A second phase of interviewing would take place at 10-13 months after bereavement.

4.3.3 Recruitment sites

Participants in this study were recruited from two hospices in the south of England; these will be referred to as Hospice A and Hospice B. Both provide specialist palliative care services to people with cancer; Hospice A extend their services to other health conditions requiring palliative care.

Hospice A is a charity funded hospice. As part of routine practice the bereavement team at this hospice make contact with the next-of-kin of people who die whilst under the care of the hospice three months after their relative has died. At this time the next-of-kin is invited to a non-denominational remembrance afternoon. Bereavement support offered from this hospice is primarily on an individual basis with most support provided by a team of trained volunteers coordinated by a team leader with formal counselling experience and training, under the auspices of a Family Support Team. Information about the support available is sent to the next-of-kin of the bereaved three months after a death has occurred.

Hospice B receives a combination of NHS and charity funding. Support for people bereaved following the death of someone cared for by the hospice is provided by a small team of social workers who also provide family support prior to the patient's death. The bereavement care provided at this hospice is a combination of group and individual support. Two groups are offered on a monthly basis; one for people under 65 years of age which takes place in the evening and a second group for people aged over 65 years which takes place once per month during the afternoon. Information about these is sent to the next of kin three months after the death of their relative or friend.

4.3.4 Inclusion criteria

This study adopted a purposive sampling approach ensuring participants most likely to be able to provide the information required were recruited (Cresswell, 2007; Flick, 2014). Purposive sampling offers the opportunity to learn about a particular issue from a group of people who have experience of that specific situation (Patton, 2002). In order to ensure the participants had some common experiences; and to provide boundaries to the reach of the project, a range of inclusion criteria were developed to aid recruitment. Table 4.1 explains the inclusion criteria adopted.

Table 4.1 Inclusion criteria

Recruitment criteria	Justification for criteria
Participants will be older adults aged over 65 years who had been in a heterosexual marriage prior to bereavement	The focus on older adults aimed to provide data about the experience of participation in occupations following bereavement at a time of life where other external demands are less likely to have influence. It was considered that the inclusion of younger participants may give rise to issues of compulsion to engage in some activities due to external demands such as child care and financial need. It was anticipated that older adults are perhaps less likely to be subject to such pressures

	<p>although it was acknowledged that financial constraints may be of concern to participants.</p> <p>It is acknowledged that only selecting married people excluded people who co-habited and same-sex couples. These patterns of habitation are less common in those of the generation under investigation (Office for National Statistics, 2014) and would possibly present a distinct group of their own.</p>
Participants will have been retired for a minimum of 5 years to allow for adaptation following retirement and establishment of a daily routine in which full-time paid work does not form a part. If they did not work, their spouse will have been retired for a minimum of five years	Luborsky (1994) proposes that it can take several years to settle into a routine of meaningful activities and occupations after the cessation of paid employment. It was felt appropriate to include participants who had been retired for five years in order to accommodate this transition.
Participants will live independently, or with family, but not in residential care.	<p>The inclusion of criteria regarding independent living and health status was intended to maximise the likelihood that participants are in a position to exercise choice in how they structure their daily routine, whilst recognising that health issues do not necessarily preclude participation in activity.</p>
Participants will be mobile, either independently or with the use of mobility aids	
Participants' general health will be good, and will not impose limitations on their ability to participate in chosen activities	
Participants will not have been cared for by the deceased prior to bereavement	
Participants will not have evident cognitive impairment	
Participants will be English speaking	<p>Time and financial constraints of the study suggested it would be appropriate to exclude people who did not speak English to avoid the necessity to employ translators. Whilst the use of translators may be appropriate in some</p>

	research, in this qualitative study it was important that the participant and researcher shared a common language so that the subtleties of individual interpretations of experience were recognised.
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4.3.5 Recruitment procedures

4.3.5.1 Hospice A

Next of kin whose relative had died in the previous three months were sent a participant information pack informing them about the proposed study. This was sent out by members of the hospice bereavement team as an inclusion to the usual invitation to attend a memorial afternoon at the hospice. The participant information pack included an information sheet about the study with inclusion criteria, an expression of interest form and a stamped addressed envelope (Appendix K). In order to ensure over recruitment did not occur a rolling programme was initiated and facilitated by the bereavement staff at the hospice. Information packs were posted on three consecutive months (Table 4.2) and included a letter of introduction from the bereavement team coordinator (Appendix L).

Table 4.2 Hospice A recruitment information

Date of posting participant packs	12 th Jan 2009	18 th Feb 2009	18 th Mar 2009
Number of information packs posted	44	50	60

4.3.5.2 Hospice B

As for Hospice A the information pack sent out included a participant information sheet with information about the inclusion criteria for the study, an expression of interest form and an envelope. A letter of introduction from the bereavement team coordinator at the hospice was also included.

Due to the number of potential participants that had responded to recruitment at Hospice A only one posting was made to potential participants via Hospice B. Therefore 36 information packs were posted on 24th March 2009. The response received from both hospices at this point was deemed to be potentially sufficient to provide the necessary range and richness of data to address the aims of the study. It was agreed with the bereavement teams at both hospices that further recruitment would be made at a later date if it was felt additional participants were required. This

avoided overburdening the bereavement team staff at hospice B; retrospectively this reflects best practice in relation to ethical research practice (Sque et al, 2014).

4.3.6 Recruitment process

People who received the information about the study and were interested in participating were asked to complete and return an expression of interest form. Telephone contact was made on the same day of receipt of this during which the inclusion criteria were checked and further information provided as required. The focus of the study was explained to the participants and in recognition of the potential for this to cause distress it was suggested that if they decided to participate it might be helpful to identify a friend or relative who would be available after their interview should they feel upset.

A date and time for a first interview was agreed with those who met the inclusion criteria and wished to participate. A confirmation letter was then sent to the participant. With their prior agreement a telephone call was made to each participant the day before their planned interview to confirm ongoing consent.

4.3.7 Response to recruitment

In total nineteen interviews formed the first phase of interviewing. Twelve were recruited with the help of Hospice A; seven with the help of Hospice B. Interviews in this phase of the study took place between 2nd February and 1st June 2009.

4.3.8 Preparation for phase 1 interviews

The interview schedule was reviewed prior to each interview to ensure familiarity. A copy was taken to each interview with a copy of the participant information sheet and four copies of the consent form. Four copies were taken because each participant was required to initial and sign two copies; one of which they kept and one which was retained; this was later stored with the expression of interest form for each participant. The spare copies were taken in case an error was made in completion of the form.

As each interview was to be audio recorded the digital recorder was checked and a new folder opened for the participant. Where interviews were interrupted and the recorder switched off a new file was opened each time the interview recommenced; containing them all within a specific folder aided transcription. Spare batteries were kept with the recorder and taken to each interview.

In order to make sure the researcher was able to find the location for each interview it was necessary to take the initial expression of interest form to each interview but this was returned to a locked filing cabinet on completion of the interview.

The University of Southampton Lone Working policy (2010) was followed and a risk assessment completed before the interviews commenced. A colleague at the University was identified before each interview and an envelope was provided to that person containing the name and address of the participant to be opened if the researcher had not made telephone contact by the time specified on the outside of the envelope. A code word was agreed to be used should the researcher be concerned about how the interview was progressing; this was also included in the envelope with the contact details of the researcher's PhD supervisor.

4.3.9 Pilot interviews

In order to ensure the areas covered in the interview provided data which would address the aims of the study, the first two interviews were considered to be pilot interviews. This was explained to the first two participants and their verbal consent gained. The researcher had previously completed a research interview training course which had involved opportunity to practice interviewing and had experience of completing research interviews as well as experience of interviewing and working with bereaved and distressed people in her previous employment.

Review of the pilot interviews did not indicate further changes were necessary. Data collected from these two interviews was incorporated with and analysed in the same way as data collected from subsequent interviews.

4.4 Data Collection

4.4.1 Completion of first interviews

Each interview began with an explanation of the study and the aims. The structure of the interview was explained to each participant including reassurance that they could take a break or terminate the interview at any point if they wished to do so. Participants were also reassured that expressions of sadness were acceptable and that they could choose to take a break or stop the interview if this occurred.

Prior to commencing each interview the participants were offered the opportunity to ask any questions they wished in order to clarify their involvement in the study, the reason for the research and what was expected of them. Participants were then asked to sign the consent form (Appendix M). The consent form included requests for consent to participate in the study, audio recording of the interview and use of participant quotations in later reports.

A final check of the digital recorder was made and it was positioned within reach so checks that it was recording could be made. In recognition that people may speak quietly or hesitantly when they are upset and that some older people may speak more quietly (Iliades, 2013), a microphone

was used to ensure that the participants' voices were recorded clearly; this was placed near to them.

One interview did not record due to an interruption in the interview. This was noticed immediately after the interview and so extensive notes were made whilst recall of the interview was clear.

During several interviews participants shared photographs and other artefacts of their spouse's life with the researcher. These items provided opportunity for the participant to expand on their responses to questions and reference to them and the nature of the artefact was recorded in the field notes for later review.

Each of the participants demonstrated some distress during the first phase of interviews; none chose to end the interview. Most people preferred to carry on when given the opportunity to pause, stop or change topic. It became apparent that for many this was the first opportunity they had had to talk about the last period of their spouse's life and although the interview schedule did not ask about this time all of the participants at some stage of their interview referred back to it in their responses to the questions asked.

At the end of each interview participants were asked if there was anything else they wished to say. Generally the response to this was negative but some participants took the opportunity to consider what they would like to tell other people who found themselves in a similar situation almost as a form of summary or conclusion to their story.

Finally each participant was asked if they would be prepared to undertake a second interview in 9 – 10 months' time. All consented to being contacted and confirmed they would be happy to take part in a further interview. Participants were offered a summary of the study findings although advised that as the study was longitudinal this would not be until after the completion of both sets of interviews and the analysis; all readily confirmed they would like to learn about the findings of the study. The digital recorder was kept on until these final two questions had been asked so that the information was recorded and would be included in the interview transcript.

Participants were thanked for their participation and a copy of an information sheet about where to access local bereavement support was offered (Appendix N). Where participants had been particularly distressed during the interview the researcher stayed with them for a short while afterwards to make sure they had recovered and had plans for the rest of their day to provide distraction or some company. None had caused significant concern about their mental state such that it was necessary to organise more formal contact with their General Practitioner or mental health services.

4.4.2 Post interview procedure

Immediately after each interview the researcher drove a short distance so as not to be sitting immediately outside the participant's home. Telephone contact was made with the colleague who acted as the "lone worker buddy" to confirm that the interview had concluded and there were no concerns. Notes were made in the fieldwork diary (Finlay and Gough, 2003); these included immediate impressions and observations of the interview; specific behaviours and incidents and the participant's reactions and non-verbal communication and responses (Covan, 2007). As the interviews took place in the participants' homes the interview environment varied each time and so notes on this were also made. Brinkmann and Kvale (2015) argue that these details provide valuable context to the interview transcriptions and supplement analysis. On a few occasions brief, rough diagrams of the environment were also made where this was felt significant. Later the same day the interview recording was listened to in its entirety, at this time additional notes were added to the field notes made earlier.

The following day a thank you letter was sent to each participant to thank them for their time and the information they had shared. In this an approximate date for the second interview was identified. This was done to try to avoid any worry for the participant about when this contact might be. Telephone contact was made with one participant who had been particularly distressed to check she had recovered and to offer further support if necessary.

4.4.3 Preparation for phase 2 interviews

Approximately two weeks before the proposed time for each second interview telephone contact was made with each of the participants to confirm consent to participate and agree a convenient time. It was not possible to make contact with one participant; all of the other participants agreed to participate and as before preferred to be interviewed in their own home. Eighteen interviews were completed during this phase of the study.

Second interviews took place between 25th November 2009 and 13th April 2010 except for one with a participant who was staying in a nursing home following a period of ill health; after gaining the consent of the manager of the home this took place on 7th June 2010. Although this was not in keeping with the original inclusion criteria for the study which required that participants lived in their own home, as the first interview had taken place in his home and at the time of the interview he was planning to return to his own home it felt appropriate to agree to carry out the interview.

At the time of the second interviews all of the first interviews had been transcribed; this provided familiarity with the content and facilitated preparation for the second interviews. Rereading of the first interview transcriptions facilitated identification of issues to be followed up. These were

added to the interview schedule used in the first phase of interviews and resulted in individual schedules being created for each participant. Immediately prior to each second interview the first interview transcript and notes in the fieldwork diary pertaining to this were reviewed. The digital recorder was checked and spare batteries stored with the equipment.

4.4.4 Completion of second interviews

After agreeing a convenient date, time and location to carry out the second interview written confirmation was sent. With each participant's prior agreement, a confirmatory telephone call was made the day before their interview to ensure it was still convenient to visit. As for the first interviews the University of Southampton policy on Lone Working (2008) guided the procedure to be followed.

Upon arrival at the participant's home rapport was re-established by engaging in social conversation to help the participant to feel relaxed. Without exception all of the participants appeared keen to provide an update about the preceding year and any changes which had occurred. In order to avoid too much of this information being lost to the interview itself the researcher attempted to keep these conversations on more superficial topics; as most of the interviews took place in the winter months around a period of unsettled, snowy weather this provided a suitable topic on which to converse.

Each interview was audio recorded as before. Participants were again required to complete two copies of the consent form; one copy was retained by the participant. The format of the interview remained as for the first interviews and was explained to each participant including opportunity to take breaks or stop.

It was noted that participants were less visibly distressed and tearful this time; this is not to say they were not upset, some were but appeared to recover themselves more quickly. At the end of each interview participants were reminded that this would be the last interview they would be asked to take part in for this study. Confirmation that a summary of the findings **would** be made available was provided.

Many of the participants offered a cup of tea after their interview had been completed. It felt appropriate to agree to this, less this time to ensure they had recovered if they had been upset and more to provide a satisfactory conclusion to the interaction. All appeared comfortable to engage in social conversation and several were keen to show recent photographs of their family or to talk about changes they had made to their home. Each participant was thanked for their participation.

4.4.5 Post second interview procedure

After driving a short distance the “lone worker buddy” was contacted and notes recorded in the fieldwork diary. A check was also made that the recorder had recorded the interview.

The following day a thank you note was sent to each participant to thank them for their participation.

4.5 Ethical issues

Respect for ethical practice underpinned the development, organisation and execution of this study. The four principles of biomedical ethics as defined by Beauchamp and Childress (2013) provide a structure for consideration of the key issues in this study.

Respect for autonomy refers to the capacity and opportunity for people to make informed choices. The use of a consent form at both data collection points in the study and a flexible approach to the structure and completion of the interviews allowed participants to remain in control of the information they shared.

Beneficence relates to the necessity to balance potential benefits with possible risks. All of the participants had very recently been bereaved and it was acknowledged that as a result they were likely to be coping with a range of new experiences as well as coping with grief. It could therefore be argued that a degree of distress would be anticipated. Nevertheless careful consideration was given to when and how data would be collected. The timing of both data collection phases was based in part on evidence from the literature; this was balanced with the wish to capture participants’ experiences without the risk of inaccurate recall of distant events.

Whilst there was a real risk of causing distress to participants, the benefits were primarily likely to be experienced in relation to the research and so not directly by participants; this realisation further emphasised the complexity of the ethical issues inherent in the project. The researcher must manage a balance between the need to seek information and the importance of respecting privacy in order to maintain the safety of the participant and avoid them disclosing information they may later regret sharing. This issue was acknowledged by Wolgemuth et al (2015) in their exploratory study of participant experiences of qualitative interviews; anxiety about being identified and experiencing emotional pain were identified, particularly in longitudinal studies where a fear of emotional pain was found to be particularly evident. They argued though that this was justified by participants’ belief that emotional pain can bring healing and so in this way can be tolerated. Indeed several participants in the current study identified wanting to take part in order to help others who may go through the same experience.

Non-maleficence highlights the importance of avoiding or minimising harm; in this study harm was considered in relation to distress and was of paramount importance. The researcher has experience of working with people in distress however it was acknowledged that distress provoked by participation may not just have occurred during the interviews. Participants were encouraged to identify a friend or relative who they could make contact with after their interview if necessary. Each participant was also provided with an information sheet agreed with the bereavement team at each of the hospices who supported recruitment to the study; these explained avenues for local, more formal bereavement support and how to access these. This was offered to each participant at the end of their interview.

A further issue considered in relation to maleficence related to the second phase of data collection. Acknowledging the potential for an increase in sadness and distress around anniversaries and periods such as Christmas and New Year (Worden, 2009; Sque et al, 2014), at least one month around this time was avoided when organising the second interviews with the participants.

Justice promotes the belief that people should be treated in an equitable manner. Adherence to a protocol for each stage of the data collection for the study provided a means that data collection followed a routine which ensured each participant was treated in the same way and provided with support at each stage and as necessary. I completed all of the interviews; this provided first-hand experience of the data but also allowed for the development of rapport and trust between myself and each of the participants. I felt this to be an important aspect of researching such a potentially sensitive topic with people who may be considered vulnerable (Liamputtong, 2006). It was hoped that engaging with participants in this way would allow them to feel more comfortable to share difficult information.

Principles of biomedical ethics as presented by Beauchamp and Childress' (2013) provided a useful structure to explore ethical issues pertaining to the current study. Ultimately it was important to respect the participants' capacity to be able to make their own decisions regarding their participation and what they chose to share during the interviews. Retrospectively the structure followed and the strategies employed in the completion of this study reflect recommendations for ethical practice proposed by Sque et al (2014).

4.6 Data management

4.6.1 Preparation for first phase of interviews

Prior to the first phase of interviews participants were allocated a participant number commencing P01, P02 and so on; participant numbers were allocated in the order in which they agreed to participate. These numbers were recorded on a list which included just the participants

surname and initial; this was stored on a password protected computer accessible only by the researcher. The participants' contact details as listed on the expression of interest form were stored in a locked filing cabinet.

4.6.2 Participant pseudonyms

Following completion of each first phase interview the initial number allocated to each participant was changed to a pseudonym to protect their anonymity. Pseudonyms were chosen in alphabetical order so the first participant interviewed was given a pseudonym starting with the letter "A"; the second with a pseudonym beginning with the letter "B".

4.6.3 Preparation for data analysis

This section of the chapter will explain the preparations made prior to data analysis. It will consider the process for converting the recorded material into transcripts for analysis and the purpose of the fieldwork diary in analysis.

4.6.4 Transcription of interview data

Recorded interview data was downloaded onto a computer as soon as possible after each interview; this version was used for transcription. In order to develop familiarity with the data the researcher transcribed all of the interviews completed in the first phase of the study. Time constraints necessitated professional transcription of 9 second interviews. Interview data transcribed by the professional transcriber was converted into MP3 files; due to breaks during the interviews each part of the interview formed a separate file; these were named and organised in consecutive order to facilitate ease of use and accuracy by the transcriber who was unfamiliar with the participants' voices and the interviews. Those transcriptions completed by the transcriber were returned on a data stick rather than by email to maintain confidentiality.

To compensate for individual decisions the transcriber would have made when transcribing the data the researcher listened to each recording whilst reading the completed transcriptions. The original computer file was used for this process rather than the MP3 version to ensure accuracy and to make sure relevant material had not been omitted.

In considering the transcribers reproduction of the data it is necessary also to consider the impact of the data on the transcriber. It is acknowledged that some of the material was very moving; the researcher's previous work experience may have facilitated ways to cope with this but this could not be assumed for the transcriber and as Liamputtong (2007) suggests the transcriber is placed in a potentially emotionally overwhelming position. The nature of the interviews was discussed with the transcriber during the first contact. She was confident this would not cause her any difficulties; nevertheless in keeping with Gregory et al's (1997) proposals for working with transcribers, this was checked during each contact with her.

Interview transcriptions were organised to protect the anonymity of the participant as well as facilitate analysis. This meant that data which might compromise anonymity was not included in the transcription. For analysis purposes type was double-spaced with each page numbered; line numbers were included with line numbers beginning on each page rather than running through the whole transcript. Each interview was headed with the participants' pseudonym, the number of the interview i.e. first or second; and the date on which the interview took place and was transcribed.

In transcribing the interviews as many non-lexical sounds as it was possible to identify and find a means to type or convey were included (Flick, 2014). Whilst there is an argument for "cleaning up" the data to facilitate analysis of the content of the speech; in these interviews the additional non-verbal utterances and non-lexical sounds such as sighing, crying and laughter as well as changes in tone and volume of voice were deemed to provide context and further material to consider and were noted in the transcription (Halcomb and Davidson, 2006). Punctuation was included in the transcriptions where speech indicated the end of sentences or phrases.

Where a participant's speech was accompanied by an expression of emotion this was recorded in parentheses at the start or end of their statement; for example (laughing) or (sighs). Pauses were recorded at the point in speech where they occurred as "(Pause)" or "(lengthy pause)" where the break in speech was more than a few seconds. Information which might compromise the participants' anonymity was removed; this included locations, information about their family, and past experiences where these were unusual or likely to be linked uniquely to the individual.

Concern with reflecting the participant as closely as possible in the transcriptions involved replicating individual speech patterns which may not have kept to principles of correct grammar and which may have contained local colloquialisms, or other indicators of age, gender or regional accent (Wellard and McKenna, 2001). They reflected the participants' ways of expressing themselves and were deemed integral to their story (Table 4.3).

Table 4.3 Excerpts from participant transcripts to illustrate approach to transcription

"Erm and then I've got me own car not um I can't walk far ..." (Frank, interview 01, page 1, line 18-19).

"Nine I've got no reason to get up before that it's erm well sometimes I have to get up before that but invariably that's me time I get up" (Frank, interview 02, page 1, lines 33-34).

Transcribing is an active process requiring a high level of engagement; involving frequent decisions about what to transcribe, what to remove, and how to include more complex aspects of

speech. The transcription process itself requires listening and re-listening to small chunks of material; on completion each transcription was checked requiring at least one further hearing of the spoken version of the interview (Thomas, 2006). This facilitated recollection of the participant and their interview; a practice Churchill et al (1998) describe as “empathic dwelling” which facilitates the researcher in becoming more open to the experience of the participant and the experiences they have shared. Churchill et al (1998) propose that this allows the researcher to begin to set aside their pre-understandings and more fully engage with the participants’ experience.

Paper copies of the interview transcriptions used for data analysis were stored in a locked filing cabinet when not in use.

4.6.5 Using the fieldwork diary

Notes recorded in the fieldwork diary immediately after each interview were further supplemented by thoughts identified whilst listening to the interview recordings and reading the interview transcriptions; providing further material for analysis. Charmaz (2006) suggested field notes serve to capture aspects and subtleties of the interaction which occur to the researcher and in this way provided additional data; whilst Flick (2014) argues that interpretation begins at the level of field notes and thus an interpretation has already been created before the transcription process is undertaken.

4.7 Data analysis

Analysis of the data was undertaken using the hermeneutic circle as a guide; and followed an iterative approach moving between the interview data, pre-understandings and sub-interpretations; refining the interpretations developed at each stage. This was conducted inductively meaning that themes were developed from the data rather than adopting a more deductive approach whereby themes developed from the researcher’s pre-understandings were applied to the analysis. Despite this approach to the data it is acknowledged that the iterative nature of the analysis – moving across and between interview transcripts and additional notes and commentary in the fieldwork diary - involved an element of deduction (Pope et al, 2000). Use of deduction arose in the act of looking for evidence of emergent themes in the data; it is accepted that the researcher’s pre-understandings would have informed the development of these (Heidegger, 1927/1962).

Table 4.4 Recovering Occupation – sub-themes, themes and super-ordinate theme

Sub-themes	Themes	Superordinate theme
Continuing Bonds: Being supported	<i>Retreating to the familiar</i>	Recovering occupation <i>The lived experience of engaging in occupations following spousal bereavement in older age</i>
Learning to be alone Adapting to a different pace Learning new ways	<i>Taking stock</i>	
Companionship and talking Taking ownership (Re)filling the day Revising occupation	<i>Taking yourself forwards</i>	

Through the iterative process involving repeated circles of analysis using the hermeneutic circle; an overarching superordinate theme underpinned by three themes and a range of sub-themes were developed (Table 4.4). The remaining sections of this chapter will integrate excerpts from the data and explanation of the reasoning and decision making involved to explain the analytic process. These explanations provide an audit trail to further validate the findings developed. The process of the analysis will be presented in accordance with the hermeneutic circle as discussed in the Methodology chapter and will follow the development of the first sub-theme (*continuing bonds*) of the first theme, *retreating to the familiar*. Excerpts from the interviews will be integrated. Each of the components of the diagram (Figure 4.1) will be considered with discussion and illustration using material from the data and analysis. Figure 4.2 provides an overview of the whole analytic process.

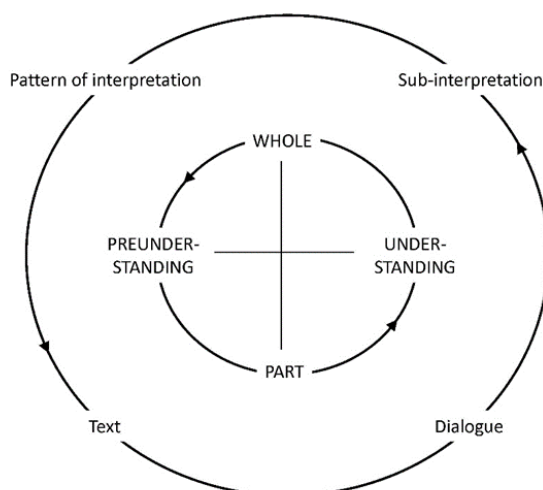
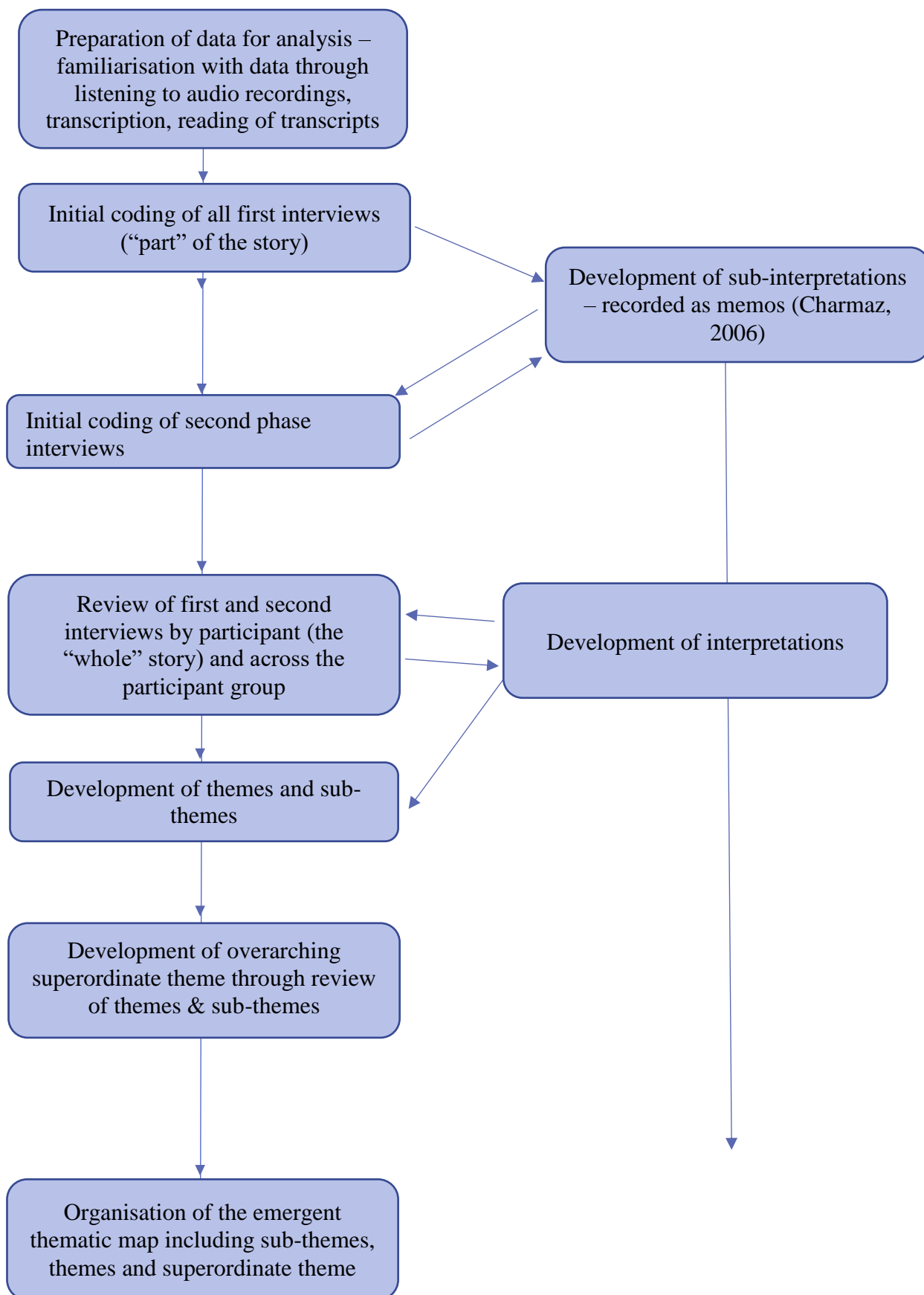
Figure 4.1 The hermeneutic circle (taken from Alvesson and Sköldberg, 2009)

Figure 4.2 Overview of the analytic process



4.7.1 Initial Coding of first phase interviews

The first stage of analysis using the hermeneutic circle involved initial coding. Identification of actions, events, viewpoints, contexts, and feelings expressed by the participants were defined or described using a short phrase or code which reflected the participants' words and thereby their experience and meaning (Thomas, 2006; Star, 2007). Flick (2014, page 373) describes initial coding as the process of "labelling" segments of the data. Where appropriate the participants' actual language and terminology was incorporated into the codes identified, these are referred to as in-vivo codes (Thomas, 2006; Charmaz, 2006) (Table 4.5). During initial coding focus was on identifying data which appeared to link to, or reflect the aim of the research in some way – material which related to occupations and activity; participation and engagement in these (Charmaz, 2006). These were examined for what they revealed about the experience for the participants (Van Manen, 1997). This first stage of analysis of the first phase of interviews reflects the "Part" stage of the hermeneutic circle and facilitated the development of early sub-interpretations (Alvesson and Sköldbberg, 2009).

Initial coding was completed by hand using a printed copy of each interview transcript. Type was organised on the left hand side of the page to allow space for codes to be recorded on the right hand side of the page (Thomas, 2006). All of the interview transcripts from the first phase of interviews was completed on a line-by-line basis even though as coding progressed certain codes became more prevalent. On completion of coding of the first 6 interview transcripts sections of data were then reviewed against the identified codes allowing for earlier codes to be developed and refined further. This revision process was undertaken on a regular basis throughout the remainder of the initial coding phase.

The process of initial coding involved the application of several different forms of codes. Table 4.5 provides an example of these; initial codes were primarily descriptive; in-vivo codes use the actual words used by the participant; conceptual codes reflect sections of data which reflect theoretical or conceptual understandings (Smith et al, 2009).

Table 4.5 Excerpt from interview with example of initial coding in red; in-vivo codes shown in purple; conceptual codes in green

Transcript - Spencer, interview 1, page 1, lines 19-36	Code
<p>P ... it might be oh quarter past, half past seven before I'll finally emerge, I say good morning to my wife every morning, her photograph is beside the bed and I kiss her photograph, I can't ever see a time not doing that</p> <p>I Do you talk to her during the day as well?</p> <p>P Oh yes, yes long spiels sometimes and out loud almost like the other day when my son came, he phoned me on Friday and said "I'm gonna come down tomorrow" which was absolutely lovely, and I have such nice times with them but he came and I said to my wife "****'s coming today" and then later on I said "We're having a great time, hope you're enjoying ...</p> <p>P ... it's a piece called "Death is nothing at all" er and this was read for my wife because it's so beautiful because it says "Laugh like we used to laugh, say the things we used to talk" and that's how I feel about her so er at odd times of the day there's a picture in beside of the bed if I ever go in there, if I'm going off shopping I say "Going out, won't be all that long" and it's as though she was here and well she is here</p>	<p>Morning routine; Greeting spouse</p> <p>Morning routine</p> <p>Continuing bond</p> <p>Talking to spouse; Talking aloud</p> <p>Spending time with family</p> <p>Enjoying time with family; Talking to spouse</p> <p>Updating spouse; Involving spouse as continuing bond</p> <p>Recalling past events with spouse</p> <p>"Seeing" spouse; image of spouse</p> <p>Informing spouse of activities / Continuing communication; She is here</p>

4.7.2 Development of sub-interpretations

Between coding of the two interviews sub-interpretations were formed. By asking questions of the data which reflects the “dialogue” stage of the hermeneutic circle, the researcher’s pre-understandings of occupation and bereavement facilitated the formation of sub-interpretations (Alvesson and Sköldbberg, 2009). In relation to *retreating to the familiar* Table 4.6 and Table 4.7 provide examples of these processes following initial analysis of the first interview with Lorraine.

Table 4.6 Questioning the data during initial analysis (Dialogue)

Lorraine, interview 1, page 18, lines 2-4	Commentary illustrating the process of asking questions of the data
there are times when <i>you need to retreat</i> I find still ...	<i>“you need to retreat”</i> - retreat from what and why are there some times when this is necessary indicating that at other times she doesn’t have to?
<i>you can’t always go out to other people and</i>	<i>“you can’t always go out to other people”</i> – does going out to other people imply an active decision to seek support from others? Or more of a lack of decision / ability to do so sometimes i.e. she can’t physically / emotionally go out to others? Is she referring to a form of emotional retreat?
sometimes I think <i>you need just to be on your own</i>	<i>“you need just to be on your own”</i> – is this about being alone with emotions or memories, or both? Or about being quiet / resting? She had spoken about the house being full of people whilst her husband was alive and perhaps this is a reaction to that.

Table 4.7 Sub-interpretation developed from initial analysis of “part” of Lorraine’s story

<p>There appears to be a sense of movement in the early period of grief. Lorraine described wanting/needing to retreat from the world whilst at other times values (or needs?) the contact from her step-daughters and neighbours. Their support seems to be valued in relation to helping her to complete chores, particularly those which her husband previously would have undertaken. At the same time there was a sense that she valued the quiet times when they had all left and she could sit quietly. Aside from this contact she appears not to be able to return to the hobbies she used to enjoy; her quiet time appears to be when she can just sit and reflect. She appeared to be pulled back to her familiar environment; and at other times pushed to let others in to help her with the many demands she experiences. Her wish to be quiet and retreat perhaps reflects a wish to return to the quieter life with her husband; a means to hold onto that time. Perhaps a form of continuing bond? She identified other forms of bond (keeping his possessions nearby etc).</p>
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4.7.3 Initial coding of second phase interviews

Prior to coding each second interview, the participant's first interview was reread; this provided a reminder of the first interview and the codes identified in the data. The first and second interviews were thereby understood as each participant's complete story of their experience of engagement in occupation across the first year of widowhood; reflecting a "Whole" in relation to the hermeneutic circle (Alvesson and Sköldberg, 2009). Further "Whole" views of the data were considered as the whole body of data was brought together.

When both interviews with Lorraine were considered together the various ideas about the nature of "retreating" were explored again across both transcripts. At the later time point she did not appear to allude to the need to retreat to solely familiar occupations; she spoke at length about the ways she filled her time with the majority of occupations appearing to be self-initiated. Table 4.8 and Table 4.9 provide illustration of the researcher's commentary on the interview data and an extract from a memo written to record the subsequent interpretation.

Table 4.8 Dialogue with the data in second interviews

Lorraine – interview 2, page 4, lines 19-27	Questions and commentary illustrating interaction with the data
<p>Lorraine described taking 6 walks per week, visiting her brother, having lunch with friends, belonging to weekly walking and craft groups as well as <i>"phone calls, fielding those; letters to write or something; housework, cleaning, washing – sticking the washing out – that sort of thing. Well, gardening ..."</i> (page 1, lines 38-39)</p> <p><i>"So, yes, that - what's a typical day? – so I may not do much in the evening time, certainly in the wintertime I'll do my craft work in the evening; I'll have music on or something like that. I might have somebody round for tea or something because I mean, you know, the neighbours pop in and I go to them sometimes, but not very much in the evening, certainly not. And actually I don't mind that because sometimes I get quite tired [chuckles], and I find if I'm trying to watch something – not that there's very often anything on – I'll sit and I'll just go zump! And within a minute I'm asleep and I wake up sort of about half an hour later, which I think is dreadful. I never used to do that"</i></p>	<p>Data indicates more social occupation which appears to be self-initiated. Is this how she was before her husband became ill? Or is this an indication of denial? The initial reluctance or lack of motivation for routine tasks was not apparent.</p> <p>Does this indicate a sense of recovery?</p> <p>No sense of retreating or sitting quietly without activity. All of her time now appears to be filled with occupations she has chosen and / or wants to do.</p> <p>Previously was tired all of the time and wanted quiet time to recover.</p> <p>Now she appears tired as a result of "doing" and being busy.</p> <p>Acknowledging change.</p>

Table 4.9 Extract from interpretation developed from analysis of the “whole” of Lorraine’s story

Retreating appears to have been a temporary state for Lorraine. There seemed to be no indication of Lorraine needing to retreat at this time. Her engagement with occupations appears active and personally meaningful. By *retreating* she was able to both disappear to recuperate after the challenges of the previous year; and withdraw from the outside world to the one she had shared with her husband. The fact that she retreated to her armchair in the lounge which had become her husband’s bedroom in the final stage of his illness perhaps gives credence to this; she was able to physically take herself back to that experience. Her armchair had become the centre from which she managed his care during the later stages of his illness. Although these had been a distressing times, they were also the last times she was with her husband. During the first interview she would look around the room and indicate where various things had been and events had taken place as if reliving them. By *retreating* she was able to re-immers herself in her life when her husband was alive. With time the need to do this had reduced and she was able to re-engage with the outside world more easily. Retreating might therefore reflect a form of ongoing bond with past times as well as with her husband.

4.7.4 Refinement of initial codes

On completion of initial coding of all of the interviews in both phases of interviews a large number of initial codes had been created. Some of these appeared to be similar in meaning and so an iterative process of reviewing the codes and the sections of the data to which they had been applied was undertaken. In contrast to the sequential approach of line-by-line coding this activity took more of a sampling approach. This exercise served to create a more consistent and refined list of codes. Table 4.10 provides an example of this process and the reasoning applied for the decisions taken.

Table 4.10 Refinement of initial codes

Participant	Extract from interview transcript	Initial codes allocated during line-by-line coding and commentary on later refinement	Extract from interview transcript	Participant
Charlie Interview 1; page 9- 10; lines 47-49/ 1-10	<p>P You know damn well that you can't get her back, but I still speak to her because I know very well that she's around here.</p> <p>I It helps...</p> <p>P Oh yeah. If I've got a problem, erm, a stain on something, I think "what stuff do I use to get this out" and I go and put my hand on the very thing I want. And I don't know before ... I say "Come and help me" and the answer is in my hand. So I'm sure she's there.</p>	<p>Speaking to spouse/Talking to spouse</p> <p><i>Codes which described communicating with the deceased spouse after their death were refined into one code "Talking to spouse". The exception to this was where the participant spoke to the spouse to ask their advice – see below.</i></p> <p>Seeking advice from spouse</p> <p>Asking for help</p> <p><i>Codes which referred to asking for advice / help were refined to "Seeking advice from spouse". Consideration was given to whether a separate code should be allocated dependent on whether the help sought was practical or opinion focused. As all cases where this phenomenon was noted related to issues where the participant was asking a question to which they reportedly did not know the answer it was decided the action represented a similar issue – one of seeking advice.</i></p>	<p>P I try to but I'm afraid if it's weather like this I talk to my dear lady and she says "well I shouldn't go if I were you, the weather's not good enough."</p> <p>I Right</p> <p>P So as soon as she says no, after we've both got an idea this is what we want to do, then um I'll go to the Cathedral.</p>	Quentin Interview 1; page 9; lines 18-31

4.7.5 Text

This component of the hermeneutic circle requires integration of the findings with pre-understandings of the identified phenomena. Alvesson and Sköldberg (2009) propose that this stage of hermeneutic analysis considers the issue of contextual perspectives and understandings of the phenomenon. These were considered in a memo constructed to begin to justify the proposal of occupation providing a form of continuing bond (Table 4.11). This reflects further development of the early sub-interpretation initiated by Lorraine's "retreat" to past times when her husband was alive. By this stage understanding and interpretation of these behaviours indicated that participants were seen to undertake routines and occupations reminiscent of times when their spouse was alive; these were considered a form of continuing bond.

Table 4.11 Memo considering occupation as a form of continuing bond

Occupation as a continuing bond

The idea of returning to previous routines as presenting a form of continuing bond (CB) would appear to be a novel presentation. Although many forms of CB imply a form of action they tend to be regarded as a psychological or emotional concept to provide a link to the deceased; the enactment or appearance of these involves action on the part of the bereaved. Talking to, talking about, using the deceased's belongings or looking at photographs or other memorabilia all involve activity. Referring to Pierce's (2001, page 139) definition of an occupation as "*a specific individual's personally constructed, non-repeatable experience ... a subjective event in perceived temporal, spatial, and sociocultural conditions that are unique to that one-time occurrence. An occupation has a shape, a pace, a beginning and an ending, a shared or solitary aspect, a cultural meaning to the person, and an infinite number of other perceived contextual qualities.*"

This definition clearly allows for the notion of engagement in previous occupations and routines as a form of CB. For each participant their engagement in the occupation or routine was unique to them (*personally constructed*); and *non-repeatable* in the sense that each instance represented a unique encounter with their spouse. The unique temporal context of early bereavement reflects the commonly understood period in which CB are established. For many of the participants the fact that these CB were repeated patterns of behaviour (routines) adds a further temporal component reminiscent of Yerxa's (1990) definition of occupations as "specific "chunks" of activity within the ongoing stream of human behaviour".

The spatial context is clear in that these occupations were performed within a defined space – the home. The relationship which is being recreated is the marital relationship which can be considered in terms of the sociocultural context; the majority of the participants had long term marriages of several decades.

Pierce's other criteria - *a shape, a pace, a beginning and an ending, a shared or solitary aspect, a cultural meaning to the person* – are also clearly relevant to the notion of the repetition of the occupations and routines which had previously been part of the participants' relationship and life with their spouse. The bereavement experiences of the two participants who had been long term carers throw up further data to qualify this proposal. Their sense of being lost in terms of how to fill their time reflects the lack of shared occupations and routines with their spouses who had been dependent on them for completion of those routines and occupations which others had shared between them. Therefore when they died their widowers had no shared occupations to recreate as their daily life had revolved around caring.

4.7.6 Development of themes

This part of the analysis reflected the Patterns of Interpretation stage of the hermeneutic circle which relates to the ability of the interpretations to convince the reader. The process of developing the themes required the researcher to undertake a conscious stepping away from pre-understandings of occupation formed through professional practice and test the provisional interpretations by reviewing these against the data.

Whilst Thomas (2006) described the development of themes as a process of ongoing revision of the initial codes; the process of developing, or "fixing" themes (Van Manen, 1997), was more complex than this might suggest. A theme is a means to capture and explain the participants' experience and to explain the essence of the phenomenon. However it can never claim to fully explain every aspect, meaning and experience of the notion; as such it offers a reduction of it (Van Manen, 1997; Moran and Mooney, 2002). A theme allows for sense to be made of experience (Van Manen, 1997); as such it is both a descriptive and an interpretive act (Van Manen, 1997).

The process of reviewing and organising the initial codes developed required both cognitive and intuitive praxis. Cognitive work involved organising and arranging lists of the identified codes; whilst intuitive activity was evident as a result of the familiarity with the whole transcripts, notes in the fieldwork diary and pre-understanding of both occupation and bereavement. Iterative movement between these elements enabled the process of sorting codes into groups which reflected the participants' experience. This process again illustrates the iterative notion inherent in the hermeneutic circle.

Whilst initially it was not clear which codes were sub-themes, consideration and movement between all aspects of the analysis allowed for patterns and links to be made between different codes. It was in this way that *continuing bonds* and *being supported* became linked in the developing interpretation of the data. Both related to the early period of widowhood and to the interpretation of participants' behaviour at this time in relation to engagement in occupations. Engagement at this time reflected temporal and interactive elements of occupation; support was frequently valued or sought even when the occupation was ordinarily a solitary one. Participants engaged in occupations which were familiar to them and linked to their life with their spouse. They relied significantly at this time on the support of others in their family and social circle to do so. Consequently these two concepts became linked under one theme – *retreating to the familiar*. This title was selected because it reflects participants' preference for support; achievement of a quieter period after the challenging time preceding it whilst their spouse was ill; and preference for familiar occupations, people and environments. Development of other themes indicated that participants did engage in new occupations but in the early period after their spouse's death these were by necessity and not choice. During this first period preferred occupations were mostly familiar ones; either those which previously formed part of their life with their spouse, or which could be undertaken with familiar people. As Van Manen (1997) proposes a theme explains a notion; the theme of *retreating to the familiar* was developed to explain the participants' experience.

The complete analysis saw the development of three themes – *retreating to the familiar*; *taking stock*; and *taking yourself forward*. The two further themes were developed using the same analytic techniques and interactive approach to the data. The organisation of the themes and development of the superordinate theme which linked them was completed by further analysis which indicated temporal elements which were reflected in when each of the themes appeared to occur most commonly for the participants. *Retreating to the familiar* was exclusively linked to the first period after bereavement; whilst *taking stock* with its focus on adaptation preceded *revising occupation* which was identified as a later stage behaviour as participants reported feeling more confident to re-engage in occupations. Together these suggested movement; first back, then neutral and finally forwards. Organised in this way the themes implied a sequence of actions with the aim of recouping what had been temporarily been lost or missing. Although this should not be assumed to reflect a process such as suggested by some bereavement theory; in relation to occupation following bereavement, it does imply the intrapersonal movement likely to be necessary in the rebuilding of occupational identity.

4.7.7 Development of superordinate theme

The final stage of the analysis occurred after the establishment of the themes. This was the development of a superordinate theme which provided an overarching, explanatory concept which linked and organised the themes together. As intimated in the previous section the identified themes were interpreted by the researcher as an indicator of the journey undertaken by participants in the rebuilding of their occupational identity and occupational repertoire. To capture this the superordinate theme *recovering occupation* was developed.

The term *recovering occupation* was selected after deliberation and consideration of possible alternatives. Although the notion of “*recovery*” fits with the data and the interpretations developed, the researcher was aware that this is a concept which is challenged in relation to bereavement.

In relation to the current study the term “*recovery*” refers to the act of *regaining possession of something that was lost* i.e. occupation. The term “*recovery*” is used here as a metaphor for reclaiming and resuming participation in occupation. Lakoff and Johnson (2003) describe metaphor as playing a central role in how we understand and experience the world. Our understanding of the world and how we communicate this is derived from concepts which in themselves are frequently metaphorical. The bereavement experience could be said to be rife with metaphor and associated imagery; examples include describing the deceased as “lost”, “passed” or “left.” These describe the impact the deceased has had on the bereaved person’s life – “we lost him”; “she left us” and may make the definiteness of death more bearable.

Alternative terms were considered instead of recovering. “*Restoring*” was felt to place excessive emphasis on the idea of returning life and occupational engagement to how it had been previously but the notion of returning aspects of life, such as occupational repertoire, to the same state they had been in prior to bereavement is likely to be unrealistic and was not borne out in the data. The term “*rebuilding*” suggested a complete renewal of participants’ engagement in occupations which did not appear to be their experience; re-engagement was for the most part related to the resumption of those occupations which had formerly been a part of their life.

Recovery offers another metaphor but one which Balk (2004) claims is widely disputed in relation to bereavement. The notion that people can recover from bereavement has been debated and is generally considered an inappropriate concept to apply for several reasons. Common usage of the word “*recover*” relates to returning something to a previous state; in relation to bereavement this is not possible, the deceased cannot be returned to life and to use the term may feel insensitive to those who have experienced a significant loss such as spousal bereavement. Life will not be exactly the same again for people in this situation and so recovery in this sense cannot be claimed.

A further concern considered in relation to the use of the term “recovery” after bereavement is the implication that grief is an illness. “Recovery” is often used in relation to someone getting better from an illness - such as in “he made a full recovery.” Although grief may be associated with signs often seen as linked to health – fatigue, anxiety, loss of appetite and other somatic symptoms - it is not generally considered an illness. To consider it such goes against more recent interpretations of bereavement theory and potentially serves to pathologise normal reactions to loss.

Rosenblatt (2008) asserted that whilst the bereaved may return to a level of functioning which if after an illness might be described as a recovery; a bereaved person can never recover their previous status because their life has been permanently changed by their loss. Balk (2004) however argues that recovery does occur following bereavement and is the outcome of re-engagement with life. As an occupational therapist the notion of occupation and engagement as contributing to recovery, following most challenging situations is a familiar notion and one which underpins the occupational therapy profession. The symbol of the British Association of Occupational Therapists is the phoenix rising from the fire; the profession aspires to support clients to reclaim their lives. Furthermore the recovery approach (Mental Health Foundation, 2016), used widely in mental health services and increasingly in other areas of healthcare practice, is based on the idea that recovery refers to re-establishment of a meaningful life within the limitations of a health condition or challenging situation rather than absence of symptoms.

On balance, the points considered above were reasoned to offer justification of the relevance of the concept of recovery in relation to bereavement. Additionally over time participants were seen to re-engage with both occupations which had been meaningful before their spouse’s death, and with new occupations. “Recovering” was proposed to most closely reflect the experience of the widows and widowers who participated in the current study in explaining their journey back to occupation and thus was deemed an appropriate term to name the superordinate theme – *recovering occupation*. The explanation of the deliberation over the most appropriate title for the superordinate theme as described above again reflects the hermeneutic approach adopted for the analysis of data collected during the current study. Movement between the data and pre-understandings facilitated development of the overarching theme which brought together the three themes identified.

4.8 Summary

This chapter has described the study design with explanations and justifications offered for some of the key decisions made in the process of planning and completing the data collection analysis. Careful consideration was given to the collection of data to ensure a sensitive balance between aiming to cause the least distress possible to the participants whilst attempting to design and

undertake a study which would be judged to be methodologically robust and clearly reflective of the phenomenological perspective adopted. The time constraints inherent in undertaking such a project whilst working full time also introduced a necessary element of pragmatism to this balance. It is hoped that this account will have provided clear justification for the method in which this study set out to explore how older people experience occupations during the first year of widowhood. The analysis of data was guided by the principles of hermeneutic interpretation (Van Manen, 1997; Alvesson and Sköldberg, 2009). Extracts from the data have been integrated to illustrate the stages of the analysis and the cognitive engagement involved.

The next chapter will explain the findings developed from the data. Extracts from the interview data will be used to provide evidence for the interpretations made. The subsequent chapter will provide discussion of relevant research and theory from three key bodies of knowledge, occupational science, occupational therapy and bereavement. These will be integrated to demonstrate how the findings from the current study relate to established understandings.

Chapter 5 Findings

5.1 Introduction

The aim of this longitudinal, qualitative study was to develop an understanding of the lived experience of engagement in occupations by older people during the first year of widowhood. Data collection focused on the first year of widowhood for older people and involved participants in two interviews which explored their experiences of participation in occupations.

This chapter of the thesis will explain the findings. Data was analysed in accordance with the hermeneutic circle; as Smith et al (2009) describe, the interview transcripts from the first interviews were viewed both as complete documents – the story at that time – and later as part of the complete story when viewed together with the second interviews. The single stories of individual participants were examined individually and in turn these were also considered as part of the whole body of data collected; attention moved iteratively between part and whole. Pre-understandings of bereavement and occupation, both professional and from theory and literature were integrated in order to develop the findings

A superordinate theme of Recovering Occupation was identified and comprised three themes: Retreating; Taking stock; and Taking yourself forwards. Each of these will be discussed using quotations taken from the interview transcripts in order to maintain the participants' voice; to illustrate the scope of the theme and to enhance the credibility of the study by providing evidence that the findings arose directly from the data collected from those who had experienced spousal bereavement. The superordinate theme will be discussed after the three themes and will explain how the themes link together. Efforts have been made to include quotes from each participant to indicate the relevance of the findings to the participants. Quotations are presented in parentheses in italics followed by the participant's pseudonym, interview number, page and line numbers; these are presented as:

(Participant's name, interview number / page number / line numbers)

For example *(Aileen, 1/1/1-3)* would relate to a quotation from page one of the first interview with Aileen, lines 1-3.

Quotations have been reproduced here as they appear in the interview transcripts except for the removal of repeated "ums" and "ers" to aid fluency of reading. Inclusion of "..." in a quotation indicates omission of material which was recorded in the original transcription but which was deemed unrelated to the theme and which might possibly complicate or confuse understanding of the point being made. An example might be where the participant was relating an experience

and mid-sentence noted it had started to rain or commented on a sound heard nearby, for example “Oh that’s the postman.”

5.2 The participants

Table 5.1 provides demographic information about the 19 participants and dates when they were interviewed for this study. This is followed by short vignettes of each participant;

Table 5.1 Participant information (* cancer not specified)

Participant	Age at 1 st interview	Gender	Role / work (before retirement)	Cause of spouse’s death	Date of spouse’s death	Date of 1 st interview	Date of 2 nd interview
Aileen	80 years	F	Administration	Non-cancer / not specified	10/08	02/02/09	30/11/09
Brenda	78 years	F	Housewife	Mesothelioma	10/08	06/02/09	25/11/09
Charlie	76 years	M	Gardener	Breast cancer	10/08	09/02/09	02/12/09
Davina	75 years	F	Nurse	Oesophageal cancer	11/08	11/03/09	10/12/09
Ernest	82 years	M	Civil servant	Cancer – ns*	11/08	12/03/09	21/02/10
Frank	67 years	M	Publican	Oesophageal cancer	11/08	24/03/09	14/01/10
Geraldine	69 years	F	Teacher	Cancer – ns*	11/08	30/03/09	09/02/10
Harry	84 years	M	Surveyor / carer	Myeloma	11/08	03/04/09	18/02/10
Iris	69 years	F	Nurse	Oesophageal cancer	11/08	06/04/09	01/03/10
Jackie	66 years	F	Teacher	Brain cancer	12/08	29/04/09	22/03/10
Ken	65 years	M	Driver / long term carer	Pancreatic cancer	12/08	01/05/09	Not traceable
Lorraine	69 years	F	Administration	Oesophageal cancer	12/08	07/05/09	02/03/10
Martin	81 years	M	Legal	Brain cancer	11/08	08/05/09	07/06/10
Norma	80 years	F	Nurse	Cancer – ns*	12/08	11/05/09	13/04/10
Oliver	79 years	M	Military	Cancer – ns*	12/08	12/05/09	26/03/10
Pamela	79 years	F	Personal assistant	Oesophageal cancer	12/08	14/05/09	09/03/10
Quentin	84 years	M	Post Office employee	Cancer – ns*	01/09	19/05/09	08/03/10
Rose	76 years	F	Teacher	Prostate cancer	01/09	21/05/09	08/03/10
Spencer	83 years	M	Banking	Cancer – ns*	01/09	01/06/09	04/03/10

5.3 Participant vignettes

Nineteen participants were recruited to the study; ten were female, nine male. Participants were aged 65 years to 84 years representing a good spread of ages within the older age category. The following brief vignettes introduce the participants and provide contextual information regarding their home environment, support networks and their previous occupations.

Aileen, 80 years

Aileen lived in a ground floor flat with her dog. Her husband, who had worked abroad for long periods until his retirement, had died in a local hospice following a long illness. Aileen had cared for him with minimal help from carers. She had two children and five grandchildren and maintained regular contact with them all. She had been an athlete in her youth and maintaining her fitness was important to her.

Brenda, 78 years

Brenda had worked after leaving school but had stopped when she married preferring to be at home to care for her family. She had two children and one grandson. She had regular contact several times per week with her daughter and grandson who lived close by. Brenda's husband had died in a local hospice after several months of ill health due to a condition he had contracted as a result of his work prior to retirement. Brenda did not drive and had no regular interests outside of the home.

Charlie, 76 years

Charlie had worked as a gardener for the local Council until accepting early retirement in order to care for his wife and her mother both of whom had experienced periods of ill health. He had cared for his wife at home until she was admitted to a hospice during the weeks before her death. Charlie had a lifelong interest in aviation and maintained a keen interest in aviation issues; his circle of friends were all fellow enthusiasts.

Davina, 75 years

Davina had been married before her marriage to her husband who she had cared for at home until his death. Between them they had nine children. She had regular contact with them all although none of them were local. Davina had been a nurse during her first marriage and had continued to work occasionally during her second marriage. She had a strong Catholic faith and most of her social and leisure occupations were linked with the church which she visited daily.

Ernest, 82 years

Ernest was born in Austria but had been on a school trip to Australia when the 2nd World War began. He remained in Australia until after the war by which time he was in his late teens when he returned briefly to Austria. On returning to Australia he worked, studied part time and met his wife. After stints working abroad they moved to England and he joined the Civil Service where he remained until his retirement. His wife had died in a hospice after a short period of illness.

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Frank, 67 years

Frank had been a publican and moved to the South of England after his first marriage ended. There he met his second wife who was also a publican and together they had run several pubs. They had enjoyed taking regular holidays and Frank continued to with this after her death. They had five children between them but contact with them reduced after his wife died. She had been ill for an extended period and he had cared for her until she was admitted to a hospice.

Geraldine, 69 years

Geraldine had worked as a teacher until retiring early following a depressive illness. Her husband had been a writer and they had maintained a flexible routine in retirement to accommodate his writing. They had two children and two grandchildren. Geraldine avoided a strict routine but enjoyed craftwork and socialising with friends in the small community where she lived.

Harry, 84 years

Harry had worked as a surveyor until taking early retirement to care for his wife for twenty years following her stroke which resulted in her developing dysphasia. Harry's primary source of communication during this time was with other carers at a weekly dysphasia group they had attended. She had developed cancer and died in a hospice; Harry claimed he had been unaware how ill she was until just before her death. He had a deteriorating visual impairment which reduced his engagement in many occupations. He had stopped driving prior to his wife's death.

Iris, 69 years

Iris had been a nurse prior to her retirement and so had felt confident to care for her husband at home until just before his death when he was admitted to a hospice. He had been ill for several years. She had two children and had regular contact with them both although neither were nearby. She also had two grandchildren who she regularly cared for whilst her daughter worked. Iris had several friends who she saw regularly and she also cared for her elderly neighbour. She was planning to move house to be nearer to her daughter.

Jackie, 66 years

Jackie had worked as a teacher before retiring. In retirement she had become an active member of an art society and regularly competed in competitions. She also belonged to two choirs and performed regularly with them. She had one daughter and saw her regularly although she was not local. Jackie was a confident driver. She had a large group of friends and enjoyed spending time with them.

Ken, 65 years

Ken had cared for his second wife for 13 years after she experienced a stroke. Until this time he had been a driver but he had stopped working as she required full time care. Between them they had four daughters but he only had regular contact with one after his wife's death. He had enjoyed gardening and creating a nice garden where his wife spent a lot of time in her wheelchair. She had attended a day centre each week and Ken had accompanied her.

Lorraine, 69 years

Lorraine had married her husband after the death of his first wife. He had four young daughters who she had brought up and remained very close to. She had worked prior to retirement in an administration role. She enjoyed walking and craft work and engaged in both regularly. She had taken up sailing as this was a passion of her husband although they had reduced their engagement in this following his stroke after his retirement. Lorraine had a large group of friends within the community in which she lived.

Martin, 81 years

Martin had worked in the legal department of his local council until his retirement. Following the death of his first wife he had married again. He did not have any children but was close to his step-daughter and her children. Martin enjoyed art, particularly drawing and went to a day centre once per week where he participated in an art session.

Norma, 80 years

Norma lived in a large house with an extensive garden which she maintained by herself. She spent as much time as possible in her garden and resented anything which interrupted this. Her husband had worked away for long periods during their marriage and she was used to a solitary existence and valued the opportunity to focus on her garden. She had one daughter who lived nearby; they maintained regular contact. Norma had been a nurse before her daughter was born and had travelled extensively with her job.

Oliver, 79 years

Oliver was a military man who maintained strong links with his regiment and an interest in military issues; he missed the military life. He had three children and several grandchildren. His daughters did not live nearby but he had regular contact with them. His son lived in the same road and had persuaded his father to move near to him after Oliver experienced a stroke which reduced his mobility. Oliver saw his son and daughter-in-law each day; he would look after their dog whilst they worked. He had a group of longstanding friends who although not nearby maintained close contact.

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Pamela, 79 years

Pamela lived with her son and his wife; they had returned to the UK when her husband had become ill and had decided to stay after his death. Pamela had cared for her husband at home until his death; she had received help in this from MacMillan nurses. Before his illness Pamela had maintained an active social life belonging to several groups including a book club, a gardening group and a local affairs group. She had taken active roles in all of these. Before retirement she had worked as a Personal Assistant.

Quentin, 84 years

Quentin had two children; a son who lived nearby and a daughter who he saw less often. Quentin had worked for the Post Office prior to retirement. After retirement he had spent most of his time with his wife and reported resenting activities which prevented this. He enjoyed spending time working in his garden and photography. He had a strong faith and was very involved with his church.

Rose, 76 years

Rose was a former teacher who had cared for her third husband at home until his final days when he was admitted to a hospice. She had a daughter with whom she had regular contact and a sister who lived in another part of the country. Rose had health difficulties which had made engagement in the active occupations, such as gardening which she enjoyed, difficult for her; she spent much of her time reading and doing word puzzles. She enjoyed working in her garden but was finding this increasingly difficult.

Spencer, 83 years

Spencer had three children with whom he had regular contact. He had worked in banking prior to retirement. His wife had had health issues for much of their marriage and as a result they had gradually curtailed many of the occupations they initially enjoyed together. After her death he began visiting friends and family for short trips which he had not done before. He enjoyed cooking; jigsaw puzzles; and chatting with his friends on the telephone.

5.4 Overview of findings from the study

Analysis of all of the data from both sets of interviews was undertaken in line with the hermeneutic circle and was documented in chapter four; this resulted in the development of a superordinate theme and three themes each with a range of sub-themes (Table 5.2). Evidence of the sub-themes was strong across the participant group providing support to the strength of the findings (Table 5.3).

Table 5.2 Recovering Occupation – sub-themes, themes and super-ordinate theme

Sub-themes	Themes	Superordinate theme
Continuing Bonds: Being supported	<i>Retreating to the familiar</i>	Recovering occupation <i>The lived experience of engaging in occupations following spousal bereavement in older age</i>
Learning to be alone Adapting to a different pace Learning new ways	<i>Taking stock</i>	
Companionship and talking Taking ownership (Re)filling the day Revising occupation	<i>Taking yourself forwards</i>	

Table 5.3 Frequency of sub-theme expression by participants

Participant/ sub-theme	Continuing Bonds	Being supported	Learning to be alone	Adapting to a different pace	Learning new ways	Staying in touch	Taking ownership	(Re)filling the day	Revising occupation
Aileen	✓	✓	✓	-	-	✓	✓	-	✓
Brenda	-	✓	✓	✓	✓	✓	✓	✓	✓
Charlie	✓	✓	✓	✓	✓	✓	✓	✓	✓
Davina	✓	✓	✓	✓	✓	✓	✓	✓	✓
Ernest	✓	-	✓	✓	✓	✓	✓	✓	✓
Frank	✓	✓	✓	✓	-	✓	-	-	✓
Geraldine	✓	✓	✓	-	✓	✓	✓	✓	✓
Harry	✓	✓	-	✓	✓	✓	-	-	✓
Iris	-	✓	✓	✓	✓	✓	✓	✓	✓
Jackie	-	✓	✓	✓	✓	✓	✓	✓	✓
Ken	✓	-	✓	✓	-	✓	-	-	-
Lorraine	✓	✓	✓	✓	✓	✓	✓	✓	✓
Martin	-	✓	✓	-	✓	-	✓	-	✓
Norma	-	-	✓	-	✓	✓	✓	✓	✓
Oliver	✓	✓	✓	-	-	✓	-	-	✓
Pamela	✓	✓	✓	✓	✓	✓	✓	✓	✓
Quentin	✓	✓	✓	-	✓	✓	✓	✓	✓
Rose	✓	✓	✓	✓	✓	✓	-	✓	✓
Spencer	✓	✓	✓	-	-	✓	✓	✓	✓

N.B Except for Continuing Bonds where ticks indicate the presence of an ongoing bond with their spouse; ticks in the other columns indicate expressions of the sub-theme across the spectrum of the sub-theme; for example for Aileen, Norma and Pamela being alone was not a new experience as their husbands had all worked away from home but each spoke about aspects of widowhood which differed from their previous experience of temporary periods of being alone and which required adaptation; hence ticks in the column relating to Learning to be alone.

5.5 Theme 1: Retreating to the familiar

Retreating to the familiar explains how participants began to re-engage in occupations and routines after their spouses' death; two sub-themes were identified which contribute to this theme. These are: *continuing bonds* and *being supported*. These two sub-themes refer to the intrapersonal (*continuing bonds*) and interpersonal (*being supported*) means of support which facilitated the participants to *retreat to the familiar*. Although the concept of *continuing bonds* may not traditionally be considered in relation to occupation, participants spoke of the bonds they developed with their spouse after their death. Here these referred to recreating the interactions and occupations they had shared whilst they were alive, such as greeting each other in the morning. The two sub-themes describe how participants were able to retreat from new and perhaps challenging occupations to more familiar occupations with the support afforded by either the continuing bond with their spouse or the support offered by family and friends. These will now be explained using quotations from the participant interview transcripts.

5.5.1 Continuing bonds

In this study 14 of the 19 participants acknowledged continuing bonds to their deceased spouse. The forms of continuing bonds experienced by participants (Table 5.4) were frequently described in terms suggesting active occupational engagement with the spouse such as engaging in conversation with the deceased.

Table 5.4 Forms of continuing bonds described by participants

Participant	Experience of Continuing Bonds	Form of Continuing Bond
Aileen	Yes	Reminiscing; considering husband's opinions; maintaining his place within the family
Brenda	No	N/A
Charlie	Yes	Conversation; looking at and talking to photographs of life together; seeking wife's advice
Davina	Yes	Conversation; spouse as a guide
Ernest	Yes	Reminiscing with photographs; keeping wife's favoured belongings visible in the home
Frank	Yes	Conversation; detailing actions throughout the day to wife; looking at photographs
Geraldine	Yes	Interacts with photograph of husband; talking and reminiscing about husband to family and friends
Harry	Yes	Conversation; reminiscing with photographs with relatives

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Iris	No	N/A
Jackie	No	Experienced 2 x sense of presence episodes which were distressing
Ken	Yes	Conversation; watching television programmes wife had enjoyed; taking wife's ashes to places she enjoyed
Lorraine	Yes	Maintaining and interacting with husband's possessions
Martin	No	N/A
Norma	No	N/A
Oliver	Yes	Reminiscing with friends and family
Pamela	Yes	Conversation; seeking advice
Quentin	Yes	Conversation, seeking advice and reassurance
Rose	Yes	Interaction with image on mobile telephone; use of husband's possessions
Spencer	Yes	Conversation; adopting wife's behaviours (e.g. buying flowers); interaction with photographs;

The integration of the bond into the routines and occupations of the participants was notable; rather than just describing the bond expression participants gave descriptions of how these behaviours had become an integral part of their routines. Spencer's continuing bond with his wife appeared to constitute specific components of his routines much like attending to self-care activities might also form part of his morning routine.

"... it might be oh quarter past, half past seven before I'll finally emerge I say good morning to my wife every morning, her photograph is beside the bed and I kiss her photograph, I can't ever see a time not doing that" (Spencer, 1/1/19-22).

"... if I'm going off shopping I say "Going out, won't be all that long" and it's as though she was here and well she is here" (Spencer, 1/1/34-36).

And Quentin described "hearing" his wife at specific times and places during his daily routines.

"... so now we're no longer together I always talk to her when I'm upstairs in bed and sometimes I talk to her when I'm down here and I'm quiet you know and yes and I think she talks back to me ... Well she usually says "I'm here."

I How do you hear that?

P In my head" (Quentin, 1/5-6/48-50 and 1-8).

Several participants identified ongoing links with their spouses in which they sought their advice in completing unfamiliar household chores; Charlie described asking his wife for help.

"If I've got a problem, a stain on something, I think "what stuff do I use to get this out" and I go and put my hand on the very thing I want. And I don't know before ... I say "Come and help me" and the answer is in my hand. So I'm sure she's there" (Charlie, 1/10/3-6).

Rose described how she saw her husband's photograph appear on her mobile telephone each evening and how this now formed part of her evening routine.

"... I text rather than use it as a phone and ... one night I was feeling particularly low and I'd been texting and the phone rang, it was my sister on the phone and the, from the usual picture that comes up ... it went black and then it came up with the picture of my husband and I don't know why it did it, I have no idea, I'm sure there is something built in that will cause it to do that but at the time it wasn't anything I'd done ... and I went on talking to my sister, I was crying my eyes out and she said "Does it frighten you?" and I said "No, I don't know why I'm crying because I don't feel sad any longer" it was comforting and every night I get a text from my daughter and I'll hold the mobile and then after a while it will go dark and up it comes again and then after a short while it will go and the usual picture will come up and now before I go to bed I always say to him "Come and see me" and he does"... I don't really want to know why it happens because I'm sure there's a reason for it but it suits me to believe the first time anyway it was of his own volition" (Rose, 1/14-15/44-50 and 1-12).

Rose also described how she continues to involve her husband in the occupations she engages in.

"... when I go shopping I put his disabled card, I know that's illegal, but I've got mine in the car and it feels as if he's come shopping with me" (Rose, 1/14/21-22).

Like Rose other participants continued to do things which served to maintain their former relationship; some of these had become integrated into their everyday occupations and involved new occupations such as for Lorraine who kept her husband's dressing gown hanging on the bedroom door so that she could hug it. Ernest and Harry created time to review and reminisce over times past using photographs. Ken described how he would talk to his wife and recreate their previous occupations.

"I will say good morning to her and I'll tell her what the weather is, whether it's shining, whether it's raining. ... I don't care what people think of me. I took her to the garden when the camellia came out so that she could feast her eyes at the camellia because that was one of her favourite shrubs in our garden. ... yeh I do talk to her a lot" (Ken, 1/2/26-31).

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*I've taken her ashes with me because she used to like a ride in the car up over *** you know we used to go round for a ride and I've taken her a couple of times" (Ken, 1/4/45-47).*

All of the participants who spoke of ongoing bonds with their spouses during the first interviews acknowledged their continued existence in the second interviews indicating the durability and longevity of these connections. None of the participants appeared uncomfortable about their ongoing bonds with their spouses and none experienced the notion of a continuing bond as distressing. Quentin felt the continuing bonds formed with his wife provided support for the changes he had made to how he was organising his life. He gave an example of offering a lift to a neighbour:

"I talked to my wife upstairs, I said, "I hope I've done the right thing." And she said, "Yes, you have" (Quentin, 2/11/22-23).

"But I do, I ask her advice sometimes. And I know it may be silly, but I get the answers" (Quentin, 2/11/32-33).

Those participants who did not recognise a continuing bond at the time of the first interview did not develop one later on before the second interview.

Two of the participants who did not identify any such bonds expressed some distress about this and appeared almost to see it as a failing. Brenda experienced distress that she was unable to consciously experience this phenomena.

"I don't talk to him, or anything like that. I wished I could be like that, but I'm not ... No, well I, I'd like to think that, but there's no proof or anything ... And I feel if there was my husband would have made some sort of ... Oh, I've talked to him to try and bring it, you talk to try and feel if he's there, if there is something, but I can't see, I'm more practical, I can't, you know I can't see ..." (Brenda, 1/14/4-14).

This was a clear statement by Brenda indicating she did not feel she had a continuing bond with her husband. She later referred to the distress that reminders of her husband caused her such as when she looked at the photographs of him around her home but this appeared to be an automatic reaction and not a conscious act of seeking his image such as might be expected with a continuing bond. This is reflected in the following quotation where she begins by speaking about her husband's photographic image being present in the rooms of her home.

"oh yes he's around, and unfortunately every time I look at them I have a bit of a weep. I think when we first, I think at the beginning you want to turn round and talk to him, and he's not there to talk to. And somebody tells you something and you think "Oh never knew that, I'll tell my husband" and you think "No, I can't, he's not there."" (Brenda, 1/18/12-16).

Some participants in this study identified what may be a novel expression of a continuing bond in their attempts to maintain some of the daily routines that had structured their lives prior to bereavement. In what may have been part of the process of *retreating to the familiar* participants attempted to return to familiar routines and occupations ostensibly as a means to create a sense of security and calm after the upheaval and chaos of the recent past. Although linked to retreating to the familiar, this action differed in that participants spoke about deliberately working to recreate the same routines and occupations they had maintained with their spouse. Martin described his current daily routine as:

“well, what I try to do is to replicate as far as I can the sort of day I would have if my wife was still here” (Martin, 1/1/13-14).

Ernest described how he had maintained similar routines to those he had shared with his wife although these had become slower since her death.

“I’m very reluctant to wake up in the morning, but the routine thereafter is very much like it used to be except perhaps a bit slower. I don’t feel the need to hurry because I’m not going out anywhere and no one to talk to ...” (Ernest, 1/1/20-23).

For Quentin the act of keeping things the same involved replicating routines originally inspired by his wife.

“Well what I’ve done is I’ve tried to keep the routine that my wife had. Because [when] I was at work, I didn’t sit down to a meal - you probably had a few sandwiches and that’s it – but when I retired she got me into this method. So for something like, Oh, I don’t know, 15 years, 16, 17 years while she was alive, we got into this way of doing things. So I just continued, I just continued on with it. I, I don’t see any reason to change. There’s no ... it works... I mean if it’s not broke don’t mend it” (Quentin, 2/ 35/ 7-15).

Routines and occupations from the past life with the spouse were re-enacted even when not necessarily those engaged in with the deceased spouse, but perhaps like Quentin due to habit or the compulsion of a routine. Although not specifically identified as an ongoing bond; these did appear to offer a means to recreate the familiarity of the past and reflected links to long held occupations they had engaged in before bereavement. These acts could therefore indicate a retreat to a more familiar life before bereavement. Aileen, who as a young woman had been an athlete, described how she had maintained her long held routines even during her husband’s illness. She explained how these were linked with a lifelong habit of regular exercise and her commitment to her dog, but she also recognised them as a coping strategy. She maintained these during her husband’s illness and continued them after his death.

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"I have a commitment to a dog ... I'm absolutely paranoid in walking her fairly early in the mornings so I'm up at 6.30 ... and I go on a different walk everyday ... but that really sets me on the right road and I did that even when I was nursing my husband at home" (Aileen, 1/1/13-22).

"... that's how I coped because walking the dog recharged my batteries, and maybe enabled me to go through the day" (Aileen, 1/2/45-46).

These experiences suggest the use of routines and occupations as an alternative form of a continuing bond with the spouse and their life together. The experiences recounted by participants indicate that *retreating to the familiar* is not necessarily about making things easier.

Despite use of continuing bonds and claims to be working to keep things the same, changes were noted. These were evident to the researcher but the participants did not appear to be aware of them. A code was identified during analysis to explain this phenomenon which was interesting when considered in relation to other behaviours in the early period after bereavement which focused on maintaining links to the past – *making blind changes*. Examples of this include Martin's description of how he had started to use a Meals-on-Wheels service whilst stating that he was working to replicate previous routines and the meals his wife had provided; Quentin started to buy ready meals from the supermarket rather than try to cook the same meals his wife had cooked and which he initially attempted to recreate.

"... I mean if you start working out making a pie, first of all you've got to get the ingredients, and having spent time doing the pastry and putting everything in ... then you put it in the oven and then cook it, if you work out how much that costs you with the raw materials 'til the time it comes out, it's gonna cost you more, but on the other hand it's probably gonna be nicer, but ... I want to do something else, I don't really wanna spend my time cooking" (Quentin, 1/4/35-41).

This section has considered the implications of varying forms of continuing bonds as experienced and understood by the participants. Continuing bonds involving occupation were identified as a novel form of ongoing bond which involved replicating the past routines. At the same time some of the participants began to make changes to their routines although did not appear to recognise these as such.

5.5.2 Being supported

The second sub-theme of *retreating to the familiar - being supported* - provides an interpretation of frequent references made by participants to the support they received from others which enabled them to either engage in necessary day-to-day occupations, or to complete occupations which had previously been managed by their spouse. Support offered was both practical and

emotional and in the early period of grief allowed participants to retreat from having to take on new challenges alone or which might feel difficult alone due either to inexperience, lack of confidence, fatigue and health issues, or practical constraints. Support was largely provided by familiar people; family, friends, neighbours and people from Church if the participant was a churchgoer. *Being supported* referred to the opportunity that the support permitted participants to retreat from new challenges and demands.

However accepting support provoked a sense of conflict for many participants. Motivation to be independent was strong. Asking for help after spousal bereavement may be the first time the widow/er has needed to do so as previously the couple had functioned as an independent unit; their individual strengths working together. Brenda acknowledged her dependence on her children to complete the practical household and financial responsibilities that her husband had previously carried out, but experienced anxiety and conflict over this and felt she had no option but to accept support from her daughter.

"Because I want her to have her independence from me, I don't want her always thinking "Oh I must go in and see how mum is" and things like that. Mum's got to get on with it now, and I can't, she has been so good in helping me and now I've got to stand on my own two feet" (Brenda, 1/2/6-9).

"I don't think anyone's got the right to say "Well I can't do that." Well you have a try and you've got to have a go and see if you can do it. If you can't do it then you find somebody else who can do it with you, or you look around for somebody who'll help you. You've got to do it. ... I've got to try. Unfortunately there are things I cannot do and I know I can't do. I'm not good on paperwork. We had a letter from the income tax people yesterday, and I read it down, and I read it down again, and my daughter came last night ... and she said "It's a formality mum." I said "I'm not getting enough money for income tax, and she said "no you're not". So she said "We'll just file it away"" (Brenda, 1/9/3-15).

Where relatives live further away the provision of support was more complex for the participants who felt that asking for help to do things was more complicated as their requests demanded more time and effort from their relatives. Davina found not being able to do financial, household or car maintenance tasks after her husband died very difficult, more so because their children were not local. She described feeling envious of neighbours whose children lived nearby and would call in regularly as needed.

"... in an emergency one of the children would come down you know if it was a real emergency. I try, I try for that not to happen" (Davina, 1/7/1-3).

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"... if my daughter lived round the corner I wouldn't worry would I? Or [my] son lived round the corner I wouldn't worry, because one or two of these widows at the church you know they've either got a daughter or a son that lives very close and they just say if a light bulb bursts they just phone up ... but you see I've got none of that, and so ... This is one of the things that I never sort of realised before to be away from your family ... that in itself is scary" (Davina, 1/12/42-47).

She described having to post documents to her children for them to deal with for her; or they would come to stay for a weekend to deal with several tasks which were causing her anxiety. Like Brenda, Davina spoke for other participants when she described her reluctance to impose on others in order to do the things she needed to do.

"I think the hardest thing is you don't really want to start being a burden to people" (Davina, 1/6/48-49).

For those participants with no immediate family, support with practical occupations was often provided by neighbours or members of local organisations such as the Church. Harry described how in the absence of family except for his wife's elderly relatives who lived a long distance away, other people had offered help. Some he was reluctant to accept; but support offered by organisations such as the Church felt easier to accept.

"... the neighbour she said well you can ring up and we'll give you a lift somewhere, well I don't, I'd only do it in an emergency. I'd either call a taxi or go to the bus, I don't like to keep imposing on them because it would inevitably become a bit of a bore I think for them" (Harry, 1/5/45-49).

"well I didn't have a bad opinion of the Catholic church before but I mean there are people there who are extremely helpful, and the priest, the number of times he's been along to see me and offered help, he used to come and bring me home from [the hospice]" (Harry, 1/21/31-35).

Although Martin had some relatives who provided help and support, he had also received unsolicited help from others and like Harry appeared accepting of this. The contact he received from the Church and his neighbours provided him a route to begin to engage in alternative, social occupations.

"I've found the local WRVS do Meals-on-Wheels which is a great help. Meals-on-Wheels people turn up about half past eleven in the morning, that sort of time and then I have a home help who comes in twice a week, she keeps me pretty well, pretty well dragooned into doing things" (Martin, 1/1/42-45).

*"the local church that I go to ... In fact they've been extremely good and they've really helped me over this period ... I think probably just because they're there, I feel that I have people I can rely on if I need somebody about almost anything, the local vicar Father *** is a real friend and he was*

most well I think it's an unusual word to use but loving really when my wife passed away (Martin, 1/5-6/43-50 and 1-2).

"My next door neighbour for example has cut my lawn, now they're a member of the Roman Catholic church which I'm not I'm just ordinary Church of England, but without any sort of prompting or anything they came over and cut the front grass so the place looks a bit tidier they're very nice indeed, the wife comes in, will come in on a weekly basis just to see how I am, if everything's alright, so it's very nice and we sort of joke, I say "Oh you're one of the rival mob"" (Martin, 1/6/9-15).

During the early period of grief seeking help to engage in occupations felt difficult and perhaps posed an additional worry for participants, but as life began to feel more settled they began to contemplate the resumption of occupations beyond those necessary day-to-day demands and those outside of the home which perhaps they had recently avoided during a period of retreating from the world. Again the support of others assisted in this. Lorraine described how driving to her local supermarket had become something she avoided because of the memories of her difficult trips there to try to find food her husband might be able to eat when he was very ill. In order to boost her confidence she asked her neighbour to accompany her.

"It does get better and the confidence I think does come back but it's, I'll never forget that, going in the car the first time I said to [my neighbour] "Would you come with me?" "Of course I will" ... and then you sort of, it gradually gets better (Lorraine, 1/17/14-17).

Over time though the support of others begins to tail off; as Lorraine described in her situation this was done in an overt and supportive way by her caring neighbours.

*"They've been marvellous since, they've all checked and *** next door although she's got four children, she used to come in, ***'s [neighbour] always cut the grass in the front, and she used to come in everyday and check that I was alright and that sort of thing and then gradually it was every other day and so on until I was able to say "no honestly I'm absolutely fine" but everybody is just, it's just a very supportive neighbourhood round here which is marvellous" (Lorraine, 1/6/34-42).*

Others, like Ken, found themselves suddenly increasingly alone and with no real support. After having cared for his wife for twenty years after a stroke, her daughters' lack of contact was a cause of distress for Ken. He had few options to venture out of the home as his wife's children had been their primary source of activity beyond her care and domestic occupations.

"I haven't seen [wife's grand-daughter]) since the funeral, that was in December ... I haven't seen them for I don't know how long. I see them once a month, they bring a dinner down ...but that's it,

so that's how much it has altered, they can say "oh you come down home" but they're never there" (Ken, 1/19/11-22).

Following bereavement the support offered and provided by others was described by the participants as valuable; it was seen however to also provoke feelings of conflict as participants struggled with a sense that they should, or would prefer to, be independent. There was a strong sense of not wanting to appear to be a burden but also recognition that support was necessary at this time. Where participants sought support themselves it appeared to be primarily focused on enabling them to engage in necessary occupations and to facilitate a return to previous levels of engagement. Some participants had few friends and family nearby and relied more often on organisations such as the church. Those without a religious faith and no close family appeared particularly isolated unless they had good relationships with neighbours.

5.5.3 Retreating to the familiar

The theme *retreating to the familiar* was developed primarily from data in the first interview transcripts and refers to the period early on in widowhood. Participants spoke of the intensely busy period leading up to and immediately after their spouse's death during which their time was frequently filled with practical occupations relating to the care of their spouse. This resulted in little time and inclination to engage in the personal, domestic, social and leisure occupations they had previously engaged in, and which represented "*the familiar*" for them. After their spouse's death participants spoke of taking opportunities to engage in occupations which were familiar and nurturing; providing opportunity to rest and begin to recover physically and emotionally.

All of the participants had experienced the need to put their own occupations on hold during the time their spouse was ill and for many there was a need to recover from this before re-engaging in them again. Retreating to the familiar describes the experience of withdrawing from recent demanding occupations in order to recover sufficiently to return to those with which they had previously chosen to engage.

After caring for his wife through several illnesses Charlie described how his health had been affected but since her death he felt a sense of freedom to be able to choose how he spent his time.

"Well in one way it was a relief because I [can] do as I like, the time's my own ... At the height of my wife's troubles I had a blood pressure of a hundred and ninety over sixty I think it was, so he [GP] shoved me on these tablets. But since my wife's gone, in fact this was about three weeks ago I had to go up for a flu jab which I hadn't bothered because of all my wife's troubles, I hadn't bothered with mine but they stamped it on my prescription you know so I went up there. While I was up there I said to the nurse will you take my blood pressure, supposed to take it regularly,

never have done, and she said "That's a text book one." It was a hundred and twenty over sixty-two she said. Well it still meant nothing to me but I came home and looked it up on the computer, and it was normal. So I was under tremendous stress with my wife you see" (Charlie, 1/8/13-23).

By the time of the second interview Charlie had begun to re-engage in occupations outside of his home; he spoke about Christmas and compared how he had spent his first Christmas without his wife and how he planned to spend the second.

"and the offers I've had for Christmas dinner ... Oh yeah I'm taking the first one, but, last year it was terrible on my own, you know but ... I wanted to just be on my own. I didn't feel like much, you know" (Charlie, 2/8/24-41).

And how he could now choose how he spent his time.

"I'm having a rest still. I'm doing a lot of things, like going out with my brothers. I lead my own life to a degree. I think, well I'd do so-and-so today, and I do it." (Charlie, 2/14/8-9).

The first statement perhaps reflects Charlie's sense of responsibility and duty; he had neglected his own needs whilst his wife was ill and only once relieved of his caring responsibilities began to consider his own needs; over time recognising the freedom he now had to pursue other occupations.

Similarly Lorraine talked about ignoring her own health whilst caring for her husband. Her prioritisation of his needs took precedence over her own discomfort which she only attended to when after his death she had attempted to re-join her walking group. During her husband's illness she had ceased engaging in her long-term leisure occupations in order to spend as much time as possible with him.

"our doctor said to us it will take over your lives and it did because you couldn't think of anything else, you couldn't do anything else so everything went by the board you know? (Lorraine, 1/5/31-33).

"I think we were all so desperately tired at the end, all you wanted to do was sleep but you had, you didn't sleep because of course you had flashbacks, everything goes through your mind over and over again and could it have been different, because you can't think straight, and of course it couldn't have been different, it wouldn't have made any difference whatever you did and it becomes logical in the end but not to begin with, but you're just so desperately tired and sometimes you just want to shut yourself away from everything and let the world flow over your head, you know pretend it hasn't happened, so I think that's the main thing, you're just so, so exhausted, it's, it's the sleeping, but of course the other thing was, with the lifting. I had, I think I

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had strained my shoulder terribly and I still have trouble with that but it's getting better now so I don't take any notice of it, but when I, my husband changed his internet provider and I was doing the cabling all around the floor because he couldn't bend down then, I banged down very hard on this knee and it pained and it swelled up. I didn't take any notice because I, he was so ill, couldn't do anything about that, so you just shove a bandage on, but it's plagued me ever since, it's blown up and I've had pain periodically ..." (Lorraine, 1/12/3-25).

Lorraine described how in the weeks after her husband's death she had retreated from the world and outside occupation in order to come to terms with all that had happened.

"I think I probably have slowed down cos there are times when you need to retreat ... sometimes I think you need just to be on your own, at least I do, you just need to be on your own to reflect a bit and have a quiet time, and I think that's important" (Lorraine 1/18/2-5).

In her second interview Lorraine recounted how she had gradually returned to going shopping having avoided doing so in the first months after her husband's death. She described how she had come to dread shopping for her husband as he continued to lose weight during his illness, but with time she regained some confidence and decided she had to return to this occupation.

"when I went into Marks & Spencer's because I was having to buy things that were smaller and smaller, and you know, I don't necessarily like going into Marks very much because that reminds me very much ... But I do. We just, you just have to get on with it." (Lorraine, 2/16/3-6).

She also identified having engaged with a range of new or familiar meaningful occupations.

"I also go to other groups; I belong to a sewing group ... And I joined about last September, I'd heard of this group, and I love making things. I love making things, I always have all my life I've adored sort of craft work of any sort" (Lorraine, 2/2/29-38).

5.6 Theme 2: Taking stock

"then comes the time I suppose when you've got all that organised and done when you think about what are you gonna do in the future" (Ernest, 1/11/31-33).

This theme reflects the experiences and actions taken by participants to create a basis upon which to start to re-engage in occupations and routines in widowhood. They began to identify things that needed to change in order to facilitate a new organisation to daily life. For several participants this included the effort involved to sort out their spouses possessions and in some cases their own as their recent bereavement had brought an increased awareness of their own mortality. For participants preparing to re-engage in occupation necessitated learning new ways to undertake occupations and interact with the world beyond their home. The notion of *taking stock* reflects traditional definitions of the term including "making an overall assessment of a

particular situation" (Soanes and Stevenson, 2006); and "to think carefully about a situation before making a decision" (Makins, 1994). All of these definitions can be related to the experience of participants who after a period spent *retreating to the familiar* begin to take steps to review their life and decide how to proceed. This experience was reflected in three sub-themes: *learning to be alone*; *adapting to a different pace*; and *learning new ways*.

5.6.1 Learning to be alone

Whilst *retreating to the familiar* participants became aware that they were alone. For several of the participants being alone for an extended period was a very new experience having been married for several decades and not having lived alone before marriage. This experience was particularly significant in relation to acknowledgement of their new situation as a widow. For the majority of participants it also brought a realisation of the occupations which had previously been undertaken by their spouse and to which they must now attend.

At this point participants appeared to be able to take a step back from their grief and look at things from a somewhat more removed perspective. Aileen spoke of how she knew realistically that she and her husband would not die together and that one of them would die first leaving the other alone.

"I'm lucky and life's what you throw at it, I mean you get to my age, if you are sensible in life and a lot of people aren't, one of you is going first, fact of life, why do you try to pretend you're going together? Unless you go to the Digidy-whatnot thing clinic in Switzerland together. It's not going to happen. One of you is going first and it does concern me that people have not got their head round that and a lot haven't have they? And they really have not and it's like shutting their eyes, this is society shutting their eyes to death, it's not going to happen to me, well I've got news for you it jolly well is and wasn't I lucky to have nearly sixty years with my husband?" (Aileen, 2/25/35-43).

Aileen presented during both interviews as a generally confident and assertive person giving only brief insights into the fundamentally unsettling impact of bereavement and how this had affected her; being alone did not appear to be a challenge for her although she had an appreciation that for others it might be. She spoke about other people's experience of relationships and loss and appeared confident to express her views of their perceived difficulties.

Pamela also recognised that dying at the same time as her husband was unlikely:

"my husband and I used to talk about what would happen if one of us died, because you don't very often die together, you know" (Pamela, 2/5/35-37).

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Yet in contrast to Aileen her interpretation of her situation appeared more emotional and personal. She ascribed her feelings of grief as being inversely related to her relationship with her husband:

"... as I say we were lucky we had fifty years so, lot of people don't get that, and my brother said I think "you pay the debt for the amount of pleasure you've had together," the better you got on together the harder the price is you know but it is you know" (Pamela, 1/15/2-5).

Both Aileen's and Pamela's comments reflect an acceptance of what has occurred and an acknowledgement that life continues; and this was evident amongst all of the participants. The challenge for them at this point appeared to be to identify how to begin to re-engage with the world and to find meaningful ways to organise daily life and occupations. Practical concerns about coping alone frequently focused on the often overwhelming demands of domestic chores. Ernest described how busy his days felt now he was on his own and his belief that he would never be able to do everything:

"when there were two of us there was first of all there weren't all these jobs somehow and secondly there was always somebody there to help you" (Ernest, 2/4/26-27).

"there's always something crops up that needs doing I mean maybe something in the garage for the car like when you've got the cold and snow to make sure that it will start the next day or clearing the drive a little bit on the side so I know where the borders are to get out you know every day there's something or could be something, sometimes I don't get around to it ...I mean I never go to bed thinking well I've done everything I want to, that's the day I long for ... and I doubt it will ever come. What does happen is as I go to bed I think now what am I gonna do tomorrow and I set myself a target but I never achieve it or very, very rarely, then that target is not the complete thing that I need to do but just part of it that I think I can achieve that day" (Ernest, 2/3-4/39-50 and 1-5).

Whilst Ernest's spoke despairingly about the amount of work for one person, he did not appear so troubled by the lack of confidence which other participants identified. This may have been a gender-related issue as many of the female participants such as Davina foremost emphasised the struggle to feel confident to do things alone having previously rarely had to do so. Female participants frequently expressed worry related to dealing with financial and household maintenance matters; for male participants, domestic chores and finding opportunities to be with others socially were highlighted. These may reflect traditional gender roles within marriage for this age group where responsibilities were more likely to be divided into male/female roles.

"I've never been alone until my husband died" (Davina, 1/4/2).

*"I like to do some walking [but] 'cos it's not very safe in this day and age to go out walking on the *** alone or anything like that. But down at the seafront ... it's perfectly safe to be alone in the daytime. So you've got to sort of work out what's right for you" (Davina, 1/3/26-29).*

"I feel alone here, like when you go I shall be alone, it's not a frightening alone. When I get in the car to make my first long journey, it'll be a frightening alone, in case the car breaks down" (Davina, 1/9/11-14).

"I would say the hardest thing is the loneliness, being "alone"" (Davina, 1/10/22-23).

In the weeks following her husband's death Davina had needed to employ several trades people to make repairs around the home; this appeared to have particularly emphasised her situation. The weight of responsibility for managing such issues bore heavily on Davina and was multiplied by the fact she felt alone in having to bear this:

"I think a lot of it is because you're alone and it all rests on your shoulders so whatever's going to go wrong there's only you to solve it" (Davina, 1/18/38-40).

Geraldine's reflections on starting to socialise without her husband suggested a loss of confidence following his death; her husband had been very sociable and without him she worried what others would think:

"we were always together; we only went places together. So that was the difficult thing. And I suppose another thing, because my husband was ... such good fun, I suppose sometimes I used to think, "Well maybe they don't want me on my own." You know, they ... it was my husband. I mean I'm exaggerating, it was ... 'cos he was such good company, you know, and always a laugh, we were always laughing. So that was probably, you know, what I thought originally" (Geraldine, 2/25/16-21).

Lorraine described the challenge of re-engaging alone in some of the familiar occupations she had previously participated in with her husband. They had been members of a sailing club and had enjoyed the social activities linked to this. Returning to the club alone felt very difficult and so she had adopted strategies to enable her to re-engage in an occupation which was important to her and which had played a significant role in her previous life with her husband:

"it was quite hard to go back on your own and ... the first few times I found it very difficult even though I knew people there and they would talk to you, you felt, you felt odd because there was only you, you know, only half of you ... But it gets better and so I quite often take my other friends down and we'll go and have a ladies lunch or something like that ...

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I make myself go to things, I did have to, initially I think I had to make myself go out because I said for the first two or three months I didn't want to go anywhere and then I had to make myself go out because I thought I must, I mustn't sit in and vegetate ... I felt I must start going out again and start having a life, you've got to move on and I didn't always want to go but I used to make myself go out, and it would be hard to begin with and then it would get a bit easier" (Lorraine, 1/23-24/37-4 and 1-10).

As well as finding ways to manage her own anxieties about returning to the occupations she had previously engaged in with her husband Lorraine also identified concern about how others would view her new widow status and explained how she had felt conscious of this:

"and the other thing I sometimes thought about is that I'm a ... you know you're a widow now and you have to be a little bit careful with people, you know with couples because they're couples and you're not a couple anymore. You mustn't try and sort of muscle in a bit I used to think you know you must be a little bit more circumspect but maybe that was just daft, I think it was just I felt I hadn't got my partner anymore you know, and you hadn't got your other half and it is more a man's world down in the Club, although there are a lot of ladies and I know lots of ladies there and I've been on the Committee, it is a man's world so you're a little bit more circumspect because I didn't want to ... not flash your widowhood but you know you didn't want to do anything like that, so you, you anyway you just wanted to keep a low profile"(Lorraine, 1/23-24/27-49 and 1-35).

Lorraine described how she first began to venture away from home and take on new challenges alone. She justified this in part by explaining that she felt she needed to do this in recognition of the support she had been shown by others. Lorraine described a process of gradually increasing steps which allowed her to build her confidence at each stage:

"... the other thing is I think the first few weeks you have this wonderful support from everybody but you can't feast or rely on that forever you've got to go half way yourself, you can't take it all, and they had been so good, they had been so kind throughout last year. I just felt I must give something back, I've got to go out so I would start inviting people in for coffee and things and they would start inviting me but to begin with they would say "It's not too soon for you is it?" Just making sure that you were quite ready to come, and I would say "No it's not too soon, I'll come" and even if you didn't you'd make yourself go, but you have to go out yourself, you've got to, you've got to sort of somehow you have to make yourself, like go to the shops or go down as I say go to a lecture or go and have a drink or just go lunch time and have a sandwich which is less traumatic because there's not quite so many people there ... I've just found people are just so supportive and if you go half way they'll meet you and then you can, it gives you that bit more

confidence to go on to the next bit because you can't, confidence does undoubtedly takes a knock." (Lorraine, 1/24/11-44).

Learning to be alone was a significant step for the majority of participants following the death of their spouses. For those who had close family nearby this was sometimes less noticeable within the sphere of the home; participants with no close family often had few, if any, visitors and so their cognition of being alone was more acute. As time progressed and there was a need to begin to venture away from the home the sense of being alone was further emphasised. Some participants had, or developed, resources to manage this but where additional constraints were experienced such as health or financial issues this remained a significant concern.

To be alone is a multi-faceted experience encompassing the need to learn how to do things as well as how to "be". Issues of confidence were significant in how participants attempted to overcome hurdles and for some their past experience of having to cope alone appeared relevant. Aileen, Norma and Pamela had all spent long periods alone during their marriages whilst their husbands worked abroad; this appeared to have provided opportunity to have to deal with problems alone and as such they all presented as being less concerned about managing alone in widowhood.

5.6.2 Adapting to a different pace

In widowhood time appears to take on a different perspective. This may simply reflect daily life returning to a more realistic pace after an intense period worrying about and caring for a sick spouse; it might also be a result of participants adapting their routines whilst they recover their energy. For several participants however slowing life down was due to necessity. Rose had long-term health issues which whilst her husband was alive had been manageable with his support. After his death these became a significant challenge for her. She described how she had learnt to her cost that she needed to pace herself in order to avoid illness. She described how she had had to adapt how she managed in order to continue to look after her garden:

"I learnt to my cost that I, whereas I would normally say that I was going to finish that, if I get a pain in my chest I don't finish that I come in ...there and then, then go back and finish, but it, it took me a long time to learn that. ...After the operation I had last year, I've been back into hospital once because I didn't do what I should have done, and I'll not go back again for the same reason" (Rose, 1/4/15-25).

For other participants their spouses' death provoked clearer recognition of the constraints that together they had worked to manage. For Brenda this related to her potential isolation and lack of independent occupation. She described having done most things with her husband and having

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never driven she found difficulty to engage in occupations due to inexperience in using public transport.

"I think we were that sort of person, we were, we worked together erm we did everything together ... My husband was always in charge (laughs) but unless he felt it was something he couldn't be in charge of and then he would turn to me, and we'd work it together and things, we'd work things out. Sometimes I would turn round and say "Well, what do you think, if this would be better or don't you?" and he'd say "Oh you were right about that" (Brenda, 1/8/1-11).

Since his death she described frustration at having to be dependent on others and the lack of spontaneity this created. She spoke about the difficulty of completing routine domestic tasks such as having things to take to the recycling facilities but having to wait until her daughter had a day off work to drive her there:

"there is frustration that you've got to, can't get rid of it, you can't do it because you haven't got the amenities to do it. I haven't got a car, I've got to ask other people, and I don't, I try not to do things like that" (Brenda, 1/17/5-7).

Although Rose had cared for her husband during his illness she had a health condition which he had supported her to manage during their marriage. After his death she struggled to complete those occupations he had previously helped her with:

"there wasn't anything other than fishing, there wasn't anything that we didn't do together" (Rose, 1/14/26-27).

"I mean there are a number of things that he did for me like the fork er that he's done with gardening tools that have made it easier for me to use it but it wasn't with an idea that he wouldn't be here, it's just something he did to help me and I mean if I can't cut something with my fork I, I tend not to have meat unless it's chopped or what have you" (Rose, 1/19/10-14).

"it's this blessed tremor that's the thing that stops it because I can't, I can't carry hot things or at least I'm frightened to carry hot things and within the last three weeks I've got, my husband used to do all the cooking, and I've got my dinner ready and I've had to eat it stood up at the counter in the kitchen because I can't carry it across to the table" (Rose, 2/1/29-33).

Harry also experienced difficulties in getting around as due to failing vision he had decided to stop driving in the year before his wife died. Not having any close family he was reliant on using taxis as he did not feel strong enough to manage on foot or public transport after his wife died. Harry had cared for his wife for twenty years during which time he had little opportunity to continue the work and leisure occupations he had experienced as meaningful. More recently his

visual impairment meant many occupations had become very difficult if not impossible to do and so he found it difficult to fill time and structure a routine which felt meaningful to him.

"I think it's the fact I can't occupy myself as well as I would have done particularly since this eyesight it's difficult" (Harry, 1/19/15-16).

"To read a newspaper, it takes ages. Now you might say well that will occupy some of my time but it's tedious ... And just as a time killer it's not enough so I'm afraid reading is not high on my list at the moment, it would be if I could" (Harry, 1/19/34-40).

"I had plenty to do as a result, although now I've got nothing to do, really. And ... so I've got time on my hands, as they say" (Harry, 2/14/8-9).

Transport issues posed challenges of various kinds to participation in occupations outside of the home environment including the issue of funding; Ken had his own car but after his wife died could not always afford petrol for it.

The pace of life and capacity for engagement in occupations was also affected by the emotional and physical strains which appeared more noticeable. Brenda felt that she had aged over the period since her husband became ill and died and the changes in her routines which this had provoked:

"Yes, slowed up ... I don't know, I just feel age has caught up on me all of a sudden. Might be because I'm not doing all of the things I was doing before, all the things I was doing with my grandson, I used to go up, I used to do the school run, used to talk to the young mums and there's nothing like, I think the best thing in the world is to be with young when you're getting older ... and it was lovely and I think they did, it does keep you going. I mean it's just now because I'm dependent on my daughter and ... I think that's what it is really, it's just that you get, suddenly you start to feel old" (Brenda, 2/5/11-36).

For Pamela life had taken on a very different temporal pace in widowhood. Feeling unable to return to her previous leisure occupations involving membership of several groups and organisations she instead preferred to stay at home and actively avoided seeing people she had previously socialised with. This change persisted even through to the second interview by which time she had begun to go out but only with people she had not previously socialised with; she explained this as a means to avoid having to see other people's sadness and discomfort at her husband's death. Pamela felt very anxious about meeting people she knew and who had known her husband both because of the distress it caused her but also because she did not wish them to feel upset as well. She avoided face-to-face contact with friends and instead participated in similar occupations at home on her own. Instead of being on the Committee of a Gardening group

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she preferred to garden alone at home; instead of re-joining her reading group she read alone at home; and instead of resuming her role as Secretary of the Residents Association she followed local news on the radio. Whilst she was happy to maintain contact with her friends she did not feel able to actually meet them face-to-face either for fear of experiencing anxiety.

*"I've got two of my friends who write to me every week – they only live not far away – but they, they quite accept my peculiarities, and so they write to me every week, or every fortnight ... and tell me what they're doing, and all the family. And I write back, and I think ... and each time they say, you know, we will have that coffee together won't we ***? But I can't quite get there yet" (Pamela, 2/36/34-42).*

She concluded:

"... perhaps I've retired, you know ... Perhaps I'm 80 and I like just being at home, and ... I can't believe that ... I still can't get used to the idea that I can do what I like today" (Pamela, 2/27-28/37-40 and 1-2).

For Harry too bereavement appeared to have marked a point where certain things appeared no longer realistic and were relegated to the past:

"Well certainly local village if we were going to swim, and they er, but as you get older, various things, limitation factors and you gradually do it less and less and less until it becomes just the things you look back on. But I don't expect I'll be able to go swimming again, you know but I'm not worried about that. I'm quite, I think you've got to be realistic about it. I'm eighty-four years of age this year so you can't, you can't turn the clock back" (Harry 1/3/21-26).

5.6.3 Learning new ways

As the participants began to consider resuming participation in occupations there was a need to find a way to adapt familiar occupations or to fit new occupations into their repertoire; these were generally those that their spouse previously did and which now fell to them. Both male and female participants spoke of the need to learn how to manage the household finances. For some of the female participants managing the finances was completely new as their marriages had been based on traditional roles; whilst for some of the male participants their wives had managed these whilst they worked and had retained the role into retirement. Martin's wife had always dealt with their financial matters and he acknowledged it may have helped to have had more involvement before her death; he was being helped by his step-daughter and a solicitor:

"Well I think it would have helped because I can't, it's a question of finding where the various records and that sort of thing are and that is most difficult, I've got my stepdaughter and I have taken all the papers down to my solicitors and he's sorted through things but it's still, it's going to

be a heck of a job sorting the tax out for example this year, yes it's most difficult ... but I expect I'll get through that" (Martin, 1/8/4-9).

Davina identified driving as challenging for her; although she had driven whilst her husband was alive she had not driven alone beyond trips within the local area. Her anxiety about driving was related to being alone in the car in case something happened rather than to driving itself:

"When I get in the car to make my first long journey, it'll be a frightening "alone" in case the car breaks down, and that's another thing I'm not very good at, I've got a mobile but I'm not very au fait with that sort of thing, I'm not, it's just my brain doesn't tick in that line and I've got the numbers put on and they've done things to make life easy [her children] but then I would worry is it going to work and that sort of thing. You see you worry about things before they happen" (Davina, 1/9/12-18).

Similarly Norma had driven for many years and was not concerned about driving but as for Davina being alone in the car was a novel experience; in particular her husband had always navigated on their trips and she recognised she would have to do this for herself in future as well as drive the car:

*"I'm perfectly happy to drive, it doesn't bother me in the slightest. It's strange because I do plan to be away and I'm going up to *** (town in South) and it's years since I've driven by myself ... any kind of distance, I think the last long distance I did was coming down from the North way back in the early eighties or something like that so it's interesting, I keep saying I've just got to get this behind me and even then when I drove I always had the dog with me ... I'm going to find it interesting, he's not there, I'll have the radio on, when I was younger I didn't like the radio in the car, I just found it distracting but I shall have the radio on now ... It's going to be a little bit of a challenge yes I'm going off on Thursday and I mean let's face it, it's a hundred and twenty miles or something, it's no great distance, it is just the thought that I'm ... there won't be somebody there saying "you're coming to a railway" "you're coming to a railway bridge" or something, "you're coming to a crossing," he was very good at navigating, I mean it was detailed navigating, he used to like to have the map there and he'd say] "you should come to a roundabout," second on the left style of thing, I'm going to have to do this myself. ... I've just made a list and that'll be it, yes. It's just lack of company I think that I will notice, although I say I like my own company, it's just being on the road. I shall have my mobile phone ... I've never received a call on a mobile phone yet but I have it there for emergency purposes" (Norma, 1/11-12/41-50; 1-11 and 19-22).*

For the participants the process of considering how their life in widowhood would be structured by necessity included having to make some changes. The rationale for these changes related to age and health reasons as well as acknowledgement that trying to do everything that between

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them the couple had managed was not realistic. For some it was possible to employ someone to help them with the more demanding physical tasks such as gardening; for others changes meant resolving to let things go in order to look after themselves better. Jackie described changes she had made in order to *“try to make my life as easy as I can” (Jackie, 1/1/35-36).*

She described an early change she made when speaking about returning to driving on her own: *“I would say on the whole I enjoy it and I sold both cars and bought a smaller, automatic. Wasn’t bothered about that but I thought I must make my life as easy as possible and it’s a nice car to drive, and reliable and safe, so all that’s helped me” (Jackie, 1/4/34-37).*

As with other participants Ernest also expressed concern about being alone and worry about who would deal with his things when he died. To this end he planned to sort and tidy his affairs to make everything as straightforward as possible. Anxiety about being alone and ill had led him to acquiring a call alarm; although this in some ways reduced his sense of independence it helped him to feel reassured that should he become unwell someone would help him.

“well what I was thinking you see, there initially as I probably told you then it was of getting my wife’s affairs settled. Having settled that I found gradually that my physical health deteriorated and that brought about the thought that latterly that I have to face dying too and the prospect is a daunting one from two aspects, first of all how it will be and secondly when it will be because I want to have an orderly death if I can which brings me back to the financial aspects of it and then a lot of the worry then arises of if I should become physically incapable of cleaning, cooking and all the other mundane things. I haven’t gone into that yet, I haven’t at the moment sort of researched it but I’ll have to because it’s going to mean considerable financial implications I mean if I have to employ a cleaner or you know” (Ernest, 2/2/39-49).

Ernest was not alone in this endeavour, the issue of sorting personal possessions and affairs was spoken about by many participants. Those who had no family were concerned about who would deal with their belongings whilst those with family, such as Brenda, wanted to make things as straightforward for them as possible when the time came:

“I live in fear now, I’m going to leave all this for them to do. And they’ve got their lives, they say “Oh don’t worry mum, plenty of time” and I say “But there isn’t plenty of time”. So I’m trying to do that gradually, but I’m not doing very well, (laughs) I get it out and I put it back again” (Brenda, 1/4/29-32).

It is perhaps significant that this sense of one’s own death had arisen after their recent experiences. Whilst several spoke of having discussed their funeral arrangements with their spouse before they became ill; making plans for the disposal of possessions and arrangement of

finances had not been considered. Many spoke of the impact of having to do this for their deceased spouse and how they had not realised how demanding a task it was.

Learning new ways of doing things and how to do things they had not previously done presented different challenges to the participants. There was no evidence from the interview material that participants had completely avoided or ceased specific occupations, rather that alternative means to accomplish them were found.

The theme of *taking stock* reflects the experience of participants as they began to identify how their life as a widow/er would be. Issues of confidence and previous experience were relevant, as were health status and available support. The significance of these grew as participants began to consider the resumption of occupations. *Taking stock* appeared to mark a turning point at which participants paused in order to reflect on what had been and what was no longer relevant.

5.7 Theme 3: Taking yourself forwards

“no point in feeling sorry for yourself, you get up and do something because no one else is going to knock on your front door and do it for you” (Aileen, 1/3-4/49 and 1-2).

The third and final theme – *taking yourself forwards* - referred to participants' engagement with occupations not necessarily related to their deceased spouses. The two previous themes explained participants initial response to returning to their previous routines and occupations, and the adaptations that participants made in how they organised their occupational repertoires and routines to accommodate widowhood. The final theme primarily reflected engagement in occupations beyond routine personal and domestic activities of daily living. Engagement in these occupations occurred throughout the data and was not just something that was found as time progressed; excerpts from the interviews with participants included in this section therefore span both sets of interview data. Some of the participants returned to occupations outside of the home very quickly after their husband or wife had died. Whilst for others this occurred later or was thwarted by constraints such as those related to health and aging. Various reasons were offered for these differences and these are explained in this section and then aspects are explored further in the discussion in relation to current literature.

Four sub-themes were identified which related to the experience of *taking yourself forwards* within the widow/ers daily lives: *staying in touch*; *taking ownership*; *(re)filling the day*; and *revising occupation*.

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For the majority of participants engagement in their personally meaningful occupations were put on hold whilst their spouse was ill and resumed again afterwards. Some of these participants spoke of needing time to recuperate and recover their energies in the immediate aftermath of their spouse's death. The point of re-engagement was often a challenge and cause for anxiety for fear of how they would cope. For many participants re-engaging in occupations involved some form of decision process regarding if and how they would return to these. There was though a keen sense of wanting to get back to occupations which had previously been meaningful and which brought them into contact with other people again.

Aileen and Norma differed to this in that they had been able to maintain their engagement in the occupations that had played an important part of their lives throughout their husbands' illnesses and afterwards. Both of their husbands had worked abroad for long periods during their marriage and they described how they had had to carry on independently in their absence. Norma described her passion for gardening and how she had made changes to enable her to maintain this whilst caring for her husband:

"I just got on, I and I had a little radio bell in my pocket that he had the bell if he wanted it, and then if I wanted to go, cos I still had to do things outside otherwise it would have got out of [hand], and he wanted me to ... but he never, I think he only rang the bell a couple of times and that was only to tell me that the telephone was going and I had the telephone in my other pocket anyway" (Norma, 1/6-7/50 and 1-5),

For two participants the early period after their wives died brought about a period of uncertainty relating to how they would spend their time. Both Harry and Ken had been long-term carers for their wives and in undertaking this role they had forgone many of the occupations they had participated in earlier in their lives and which had brought them into contact with others. After their wives' deaths they found themselves under-engaged. Ken found this difficult and was made worse due to financial difficulty which precluded participation. Harry did not identify financial difficulties; he tackled his loss of occupations by setting about trying to identify organisations to join where he could be of use; possibly replicating his former carer role:

"Yes, oh I keep my eye open, I've got a different thing, if I think it's er the sort of thing I could contribute to. I don't like joining something just for what you're going to get out of it, when I joined this professional, chartered engineers association, I'd only been a member about a year and I was made treasurer but I felt I was doing something useful as well as being a member. ... So that's why, if I look for something to join then I try to look for something where I could maybe help a bit as well" (Harry, 1/21/20-29).

5.7.1 Staying in touch

Contact with people is a key driver for participant's engagement in occupation and a lack of opportunities to be with others was experienced negatively by almost all of the participants. Participants who were able to return to familiar social and leisure occupations after their spouse died reported one of the benefits was the opportunity to be with and talk to others. Jackie had returned to her choir group and floral art society and both the act of singing and being with others felt supportive:

I stopped going to my choir, but I was able to take that up quite quickly afterwards and sing in the Carol concerts fortunately. I made myself do it, and I found it quite uplifting" (Jackie, 1/8/32-34).

"And by going out we do lots of things connected with it. From our choir we have two social evenings a year at a restaurant and it's usually very jolly and I managed to go while he was in hospital in July and again in January after he'd died, and you know friends drove me and I sat with friends and that was all, it all helped that they were aware" (Jackie, 1/9/40-44).

"I think I realised you know that was all going to help me get back to normal" (Jackie, 1/9/35-36).

Some participants recognised that their behaviour changed as a result of spending lengthy periods alone. Norma described how when her husband was alive but working away she had realised that she tended to "talk at" him when he returned due to lack of opportunity to talk to anyone for extended periods of time; she acknowledged that she did the same since his death. Similarly Ernest found the lack of conversation and interaction with others very difficult to manage since his wife had died; he too recognised a tendency to talk excessively when the opportunity arose. He felt this was made worse by his hearing impairment which meant he sometimes struggled to hear what people were saying:

"if the phone rings you know and there's somebody there and I, I talk to the people, even while I'm talking to them I think "my god I'm going on a lot here" you know this is and it's only intended originally to be a very brief phone call, but it gives, or it gives me the opportunity you know to talk ... without talk it's like a handicap, I mean as though you haven't got a leg you know, a physical handicap, if you, well as though you can't talk you know?" (Ernest, 1/17/20-30).

"Yes, yes, keeping you a social animal, yes. I mean you're not an outcast you know, you're sort of vegetating there on your own you can't talk, I can't hear" (Ernest, 1/18/6-7).

Ernest set about remedying his situation by making concerted efforts to invite friends and distant relatives to tea. This initially provided enjoyable company and something to look forward to each week; he also enjoyed the preparatory activity it required such as planning the food and shopping.

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"I try to think ahead of what I can do at some future date, and I try to keep some odd days, not any specific day but for a whole day to either take somebody out that I know or ask somebody to come and have tea with me" (Ernest, 1/1/38-41).

"I say "Well how about coming over to tea?" you know it's a kind of but it's again, it does impose, not impose, it does give me an opportunity to do something other that's social and I think it's perhaps social contacts that you want and the older you get of course the fewer relatives you have, if any" (Ernest, 1/18/37-41).

"it also gives me something to do, I have to get shopping, get something in to give them and I know perhaps more what they want, or give them a treat in some way and it if they enjoy it, it's a pleasure for me" (Ernest, 1/9/39-41).

However during the second interview he reported how this had begun to pall as the topic of conversation tended to be his wife and her death because the majority of his visitors were her relatives and friends.

"But that I find very difficult and I think well people must be getting sick of me because they ring me up and "How are you?" well you know. They're not genuine friendships if you know what I mean, they're not built up over the years, they only have one thing in common and that's something that really you want to forget or not talk about because it gets stifling" (Ernest, 1/12/21-26).

Frank regularly attended a club where he would chat and drink with a small group of friends; this was an occupation he particularly looked forward to because of the companionship it offered: *"as I say I look forward, as I say [to] the Club days because I know there's gonna be people there"(Frank, 1/18/41-42).*

Even where participants chose to avoid engaging in familiar occupations which they had enjoyed before widowhood, the need for interaction was evident and provoked new occupations. The need for interaction with others was such that Pamela chose to use the bus to get around rather than drive her car:

"I mostly just go out on the bus – I tend to not go in the car so much because I like to meet people" (Pamela, 2/2/14-15).

It was of note that Pamela had a group of good friends and had previously engaged in a range of social groups before her husband's death but felt uncertain about returning to these and resisted pressure from others to do so. She was nevertheless keen to maintain links with friends and so instead of meeting them as before she had changed her telephone contract to allow her to make

longer and cheaper telephone calls and she used this as a means to stay in touch with friends instead. This also had the benefit that when she had had enough she could end the call:

"... the new deal I've got with BT you can talk to anyone anywhere up to an hour ... and I actually do have conversations with friends ... up to an hour, and we laugh because you can't believe that you can talk to anybody for an hour. And I thoroughly enjoy that, because I keep in touch with a lot of people on the telephone ... now I, I just ring them up and we just have a good old gossip. And they've been marvellous, they really have. And that's ... it's back to the sort of control word; I mean I could sort of like say, "I've got to go now," and, I try not to tell people lies, but you know, I could stop when I wanted to (Pamela, 2/31/6-23).

Similarly Pamela maintained her interest in politics and local events by regularly watching the news on television, listening to the radio and reading local bulletins but resisted encouragement to return to the local Residents Association where she had been Secretary for many years:

"I still like to follow politics because I'm interested in ... I've always been interested in politics, and I do like to follow that on the news. But newspapers irritate me because they're so biased, you know ... I watch the news regularly ... And I listen to the radio, the local radio I quite like because they do sort of local topics, because I haven't lost my interest in local affairs, but I don't want to be part of them ... and I find topical affairs, I quite like to follow, and know what's going on ... And I read all the information I get about local things that are going on" (Pamela, 2/30/15-36).

For Frank *keeping in touch* with the world beyond his home involved both reading a daily newspaper and spending time on the internet and responding to emails from relatives abroad and friends made during holidays he had taken with his wife. Initially reading the paper version of his newspaper formed a key part of his daily routine:

"I have the newspaper every day, and that's up, washed, changed, kettle on, cup of tea, down to me paper once I've checked the computer see if there's any messages, messages don't always come through the phone do they now?" (Frank, 1/1/16-18).

By the time of the second interview he had changed this and subscribed to an online newspaper:

"Well I take me tea into the computer now ... see what the world's doing" (Frank, 2/10/23-27).

Soon after his wife died he also registered with an internet dating organisation as a means to develop contact with others:

"but I, I'll tell you I were on a dating [agency] on the computer ... Yeh, I'm not, don't get me wrong I'll never forget my wife, that's a certainty, I mean I'm chatting to a couple of people now you know what I mean, but I was still a, when I say I'm a loner, I don't mean a loner, I'll soon be talking to somebody you know, I'm outward in that respect" (Frank, 1/23/12-20).

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Oliver maintained links with the outside world through his involvement with his former military regiment, the Coldstream Guards, and through watching the news on television to keep up-to-date with military action. Having spent his working life involved with military affairs these continued to contribute significantly to the occupations he preferred to engage in. His involvement with the Military through his career and afterwards formed the cornerstone of his life and continued to provide an important form of occupation since his formal retirement. Age and some health issues threatened to make this more complex but keeping in touch with events remained as important as ever to him. He spoke about attending reunions:

“they’re often a tremendous sort of reunion; you see people you haven’t seen for years ...

I’m the President of a Branch of the Coldstream Guards Association, so there’s that. I organise a periodic gathering of my chaps, Sandhurst bunch, Waterloo Company, Intake ...” (Oliver, 2/14/7-13).

He continued to follow military activity via the news and television and described his feelings towards what he saw:

“Pride, wishing I was still part of it ... they’re going through a harder time at the moment than I ever had ... because active service in my day, apart from Korea, and Malaya, you got, odd burst of activity, and so on. Most of it was rather boring – a lot of war is - but I mean Afghanistan today, the soldiers are involved in constant fire fights and so on and so forth” (Oliver, 2/26/26-29).

Keeping in touch with life beyond their home was important to all of the participants; as was opportunity to talk to and to be with others. They had made a range of adaptations to their daily occupations to try to ensure they saw others regularly. Where this had not been possible it was a notable cause for concern for the participants.

5.7.2 Taking ownership

At various stages of their bereavement journey participants began to take on roles and occupations previously undertaken by their deceased spouse. Perhaps the most frequent of these was dealing with financial issues. For most the challenge was to learn how to manage the household finances and pensions in order to reduce day-to-day worry. Jackie reflected on how she had been aware of her husband’s actions in this regard but confessed to not necessarily taking it all in and finding it difficult to learn how to do things later after his death:

“He did all the paperwork, he would always show me, but whether I took it in or not, you see, you think your husband’s immortal so you don’t always take it on board but I did take some of it on board obviously and he never kept me in the dark about things” (Jackie, 1/4/7-10).

"Yes, the paperwork and standing [orders], all the intricacies of the money side of it, you know shares and things like that. I find that difficult but I've learnt a lot in the five months" (Jackie, 1/5/11-13).

"I've had to sell some shares and deal with things I never did before. I'm not wonderful but I'm learning ... And I would advise anyone to do it while their husband is alive. My husband always showed me things – he never left me in the dark, and if we had to move money around he always informed me. But because he did it, and you need one person handling the money, I didn't take too much interest. Now I wish I had" (Jackie, 2/5/20-29).

For Aileen however it was something of a welcome challenge to be able to manage the finances; she had done so earlier in their marriage when her husband worked abroad for long periods of time and had reluctantly handed it back to him on his retirement. She relished the opportunity to reclaim this aspect of life and to make it her own. Her manner in describing this suggested a sense of personal achievement:

"[He] did the lot and it's because I wouldn't share it. I either did it myself or he did it but there was no point two of us doing it. So I suppose really I like to be king pin, so I did the accounts when he was away but the moment he came back he did the lot So suddenly I'm confronted and at last it's my baby. And am I doing it the way he used to? No I'm not. Doing it my way, do you see? (Aileen, 1/16/9-15).

Charlie also made changes to the way his wife had managed their home. In the first interview he described his belief that he had earned the opportunity to spend time engaging in his interest in aviation after caring for his wife during several illness. In order to do this he had relaxed his approach to housework to allow more time to do what he wanted to do.

"My housework is moveable ... I don't say "I can't come because I've got to do the housework." If it's not done one day it's done the next" (Charlie, 2/32/12-17).

This had allowed him the time he needed to help a friend who was writing a series of books about the history of aviation. Charlie rather proudly showed the acknowledgement of his help that his friend had written in the introduction to the first volume:

"So it's for the work I done for him, which is all contained in the information you see" (Charlie, 2/22/39).

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For Davina opportunities to take ownership of her actions occurred in the social groups she attended through her church. In particular a widows group had provided her with confidence to make suggestions and initiate popular activities for the other group members.

Well the two that run it, they're not widows and they are responsible for putting things on but I must admit you've hit the nail a bit on the head you know because they always say now are there any places you'd like to go and one of the places was Aylsford Priory, my husband and I used to love going there ... I wanted to go back there so they arranged that, everybody was so thrilled because they'd all heard about it, some had been, some hadn't, we had a super day there, they organised a coach for us to go, that was lovely. Then a couple of places I wanted to go, gardens I mentioned that I thought would be nice places to go so I probably I am, I mean they run it, if I get an idea I will put it forward though probably more than anybody else" (Davina, 2/14/14-23).

She identified that she also initiated activities amongst her friends; this was in part to manage her own loneliness and avoid dependence on her family but the act of taking ownership of her time in this way appeared to provide a sense of increased confidence which was notable during her second interview.

5.7.3 (Re)filling the day

Despite feelings of fatigue and exhaustion being commonly described by participants there was a strong sense that it was important to be busy; inactivity was experienced as negative.

Engagement in occupations offered a means to feel busy even when sometimes the occupations themselves were less meaningful. A contradiction was noted whereby some participants found they had little to do and so worked to create occupations to engage in; whilst others struggled with the amount they felt that had to manage in order to complete the tasks that they had managed with their spouse. Establishing a balance could present a challenge. Unlike Ernest who as described previously experienced difficulty fitting everything into his day, Iris found herself creating tasks to fill her time particularly during bad weather when it was difficult to get out:

"Very depressing, well yes because you don't go out so much do you? Or I don't anyway you know when it's cold and wet I tend to stay here and then of course you've got to find things to do. I have been logging all my husband's books because we've got to get rid of them you know there's just so many of them, he loved his books but you know we don't need them anymore so I've got to try and find a place to get rid of them ... No I did it while it was so miserable over the weekend and the weekend before. Weekends aren't so good if you're not busy you know they can be a bit of a drag" (Iris, 2/8-9/48-50 and 1-18).

Rose also struggled to fill time; this was exacerbated by health difficulties which had felt emphasised since her husband's death:

"I didn't know what to do with my time and I can't do any voluntary work really because I can't guarantee to be able to go and whereas throughout my life I've done voluntary work, it's not exactly boring but a loss of what to do with my time ... but since he's gone it's not that I'm bored with the day, it's just what can I do to fill it especially when the weather's horrid ... there's a limit to how much, well I can anyway, watch that, or read, or ... so I do it in phases when it was, I was in here a lot, I would watch a bit of television, I'd read for a bit and then I'd Sudoku for a while you know? ... but no I s'pose I'm still not bored, it's just that I don't always know what to do and I really fuss around until I find something to do but it's, I've never been so bored that I want to pick up the polish and duster." (Rose, 1/4-5/35-50 and 1-12).

Norma described how her upbringing had resulted in her need to be busy and to be "doing" things and tended to dismiss the more passive leisure occupations adopted by other participants as less important:

"I have this I think, an unfortunate kind of work ethic, I think I have to accomplish something, I cannot sit and ... and sitting reading is sitting doing nothing as far as I'm concerned, I just have to be doing something practical ... I wrote this in an email to somebody, I think one day last week it's just one of those days when it's either wet or there was something and I just fiddled most of the day and really it quite bothers me to get to the end of the day, I think it's a kind of Calvinist background that I've had and that you've got to work and accomplish something ... But I just have to be doing something, accomplishing something ... I just cannot sit, no.

*... well my mother would have been a bit upset I think but my mother was a Scot and she, she did have, she had this business too and I don't know perhaps during war and whatnot there, everybody had to get on and there was always something to do, she had to go out to work and so therefore I would have to help as well which was fair enough but and I think perhaps even my, my training and my work you just have to do something I mean I have an old school friend up in ***, I know she sits around and then she doesn't ... feel right and she's got all kinds of complaints but I think to myself, if you'd only get up and do, you'd feel better about it yes so yup I'm a doer"* (Norma, 1/9-10/25-50 and 1-10).

Charlie had experienced motivation for change quite soon after his wife died; having placed his interest in aviation in second place to his wife during their marriage he reconciled his sadness at her death by interpreting it as providing him with time to re-engage in his hobby as his reward for having cared for her for so many years:

"... never a time when I thought what am I going to do. I've got so much in my hobby to do that it was a relief. Once I got over the grief of it, the initial grief is terrible, but I realised it was for my

good. The way I looked at it, God as we say, took my wife, and my remaining years are my reward for looking after [her] and her mother” (Charlie, 1/8-9/47-49 and 1-2).

Pamela reflected a very different experience in that she had not returned to the occupations she had previously enjoyed before her husband became unwell. She had ceased engagement in them when he became ill with the expectation that she would return after his death. However she had not been able to do so and spent her days quietly at home and pondered on the reasons for this: *“I still haven’t taken up really any of the things that I used to do; I haven’t been able to ... I haven’t felt ... I can’t quite know why I can’t do any of it, but I just don’t seem to be able to do anything” (Pamela, 2/1/30-33).*

“... as I said to our Chairman [local residents association], I think maybe I’ve just retired ... You know, not so much like grief struck, but it’s just that it was a natural ending and it meant that I didn’t have to resign, you know, that I can keep in touch with them. So I haven’t felt, I haven’t felt any wish to go back to it at all” (Pamela, 2/5/20-26).

A further aspect of re-engaging in occupations and re-filling daily routines reflected the effort often required by participants to do so. There appeared to be a common understanding that it was good to do things but participants often spoke of having to make themselves do so. These were both new occupations and those they had previously engaged in but which felt somehow different as a widow/er. In some instances the difficulty related to being a single person in a group of couples; for others it was caused by anxiety about breaking down in front of others; or to worry about making others feel uncomfortable. Geraldine spoke of several of these when speaking about returning to social events with people they had known as a couple. Her comments indicated some conflict between recognising she should start to engage in social occupations and the demands of presenting in a way which did not deter people:

“And we had a party; we had our New Year’s party – we didn’t have one last year, but I said to my daughter well let’s do it. So that was nice. And of course I suppose in a way that’s why, like, I’ve friends, you know ... we were quite sociable I would say, and I try to, you know, I have had people around for a meal. Yeah, and I feel you’ve just got to make the effort, otherwise you, you just drift into solitariness don’t you? I could see ... like I can see that with my friend, you know, she didn’t seem to ... I mean my friend said something to me once, and she said “Well people ask me how I am, and I tell them.” And I said “Well sometimes people don’t want to know” you know, they don’t want ... and I tried to say, Well if you’re moaning all the time people get fed up don’t they? They don’t want that” (Geraldine, 2/13/1-14).

Whilst acknowledging some anxiety she also acknowledged a more reckless attitude; it was this latter approach which perhaps facilitated her engagement.

"... Yes I felt a bit, you know, apprehensive there, but then I, I get into a frame of mind, Oh what the Hell, you know, and ... and just go for it, and think well if I say anything people don't like, too bad, you know" (Geraldine, 2/25/31-33).

To take this approach perhaps indicates a deeper confidence which might be a response to having coped with such challenging experiences in more recent times; a sense that having coped with the worst life can throw at you nothing else can be that important. Like other participants Geraldine made herself do things even when she did not really feel like doing them, with a sense that to do so was ultimately going to be helpful:

"I've tried not to turn down any offers that there have been, even if I maybe didn't feel like going, or like my daughter would say, "Oh well, go on Mum."" (Geraldine, 2/26/10-11).

5.7.4 Revising occupation

Taking yourself forwards after bereavement involves a form of re-appraisal of how life is organised and lived. For some participants the routines and occupations which were undertaken after the death of their spouse were very similar to those engaged in before; whilst for others life felt and might have appeared to others to be very different. Ultimately a re-organisation results in a revised occupational identity as participants begin to adapt to their new situation. Frequently participants' strategies for moving forward with life, incorporated skills, resources and occupations they had previously used and which enabled them to devise an identity which encompasses how they were before but acknowledges their new identity as a widow/er.

Initially Brenda had found herself dependent on her children for help in carrying out occupations away from her home due to her lack of transport after her husband's death. As she had relied on her husband to drive her wherever she needed to go, she had rarely done things by herself and so struggled with a lack of confidence initially. During her second interview she had begun engage in some occupations more independently and had decided that she would use money gained from a legal case as a result of her husband's death to help her to do this. She had begun to visit the supermarket by taxi occasionally:

... doesn't make shopping cheap but then you see as everybody knows, everybody knows that if you have these illnesses you have a claim and all the claims been through and the money's been out, it's been put in my account and I look upon that account, is taking [the] place, as nothing ever will but things that my husband and I can't, I haven't a car, so I don't pay out on a car, so the money goes to support me, you know ..." (Brenda, 2/15-16/48-50 and 1-3).

She described starting to buy herself things and explained this as being a way to look after herself:

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"I didn't do it just because my husband used to do it, I did it because I thought I'm gonna have some flowers, you know? ... I treated myself and I've been out, I bought two skirts last week ... I bought this jumper ... but I've got to buy myself ... I try to keep myself okay you know, I try to do things I would have done if my husband was alive ... Because he would have expected me to have done. I'm not going to let myself go" (Brenda, 2/17/4-20).

For Norma, widowhood had emphasised her natural resilience and independence developed over many years of being alone whilst her husband had worked away. She recognised that over that period she had learnt to cope with whatever happened and this appeared to offer a sense of confidence that she would continue to cope. To this end she was very determined to remain in her house where she could continue her passion for gardening rather than have to consider joining activities which she did not want to do but which her family suggested to try to reduce her isolation:

"But I'm not prepared to give this place up. And if I had this, go into this apartment, well I can close the door and walk out, I realise that, and go off [on holidays]. But on the other hand I wouldn't have a garden to go into, and potter, and I would be shut up in a box, because maybe I'd join things... I think it gets, as one gets older you don't particularly want to join things. I've never been a kind of organisation person, I don't think I'd want to start now. A lot of women twittering on. I don't think it would be for me" (Norma, 2/15/32-37).

Lorraine was prepared to venture out and in line with her lifelong involvement in craft work and sewing she joined a local craft group where found a new role for herself when her skills were noticed by others and she was encouraged to take a lead in preparing for a craft sale:

"And I joined about last September, I'd heard of this group, and I love making things. I love making things, I always have all my life I've adored sort of craft work of any sort; I knit, I crotchet, I sew ... So I tried to turn my talents elsewhere, and they were absolutely delighted, because the first thing they said to me was "We've got a Christmas Fair coming up in November," this was September when I went, "do you think you can think of small things to make" ... And so, there we are, I started making lots of things for the Christmas Fair." (Lorraine, 2/2-3/37-41 and 1-8).

As well as returning to former preferred leisure occupations Lorraine also reinstated a strategy from her past to ensure she stayed on top of her household administration; she had kept lists before she married and had begun to do this again whilst her husband was ill:

"I've more or less always kept a list of letters that come in and ones I send and 'phone calls; even before I was married I used to do that, so that I wouldn't lose track of anything, and once, I mean,

when I was married I didn't do it because there were two of us I didn't need to, but since my husband has died I've taken that up again, and yes, I do, I keep a record of all 'phone calls in and out, and all letters in and out, so I can keep track of ... And I find that's quite a good discipline really. So that I can, you know, keep in touch and everything, because sometimes your memory can play you tricks, so it's nice to have that" (Lorraine, 2/19/32-38).

Lorraine described how she worried about the thought of her first Christmas after her husband died; but it had not been as she had feared and described it as a turning point; after which she decided to make plans to go on her first holiday without her husband.

"I thought it would be terrible at Christmas time, but it wasn't ... Do you know, it was a lovely Christmas ... But it was just a lovely, happy, family Christmas, and it didn'twe had to make our own entertainment, and it was such fun. You just did daft things, you know, together; we did crosswords and all sorts of daft games, and we all mucked in, and it was lovely. And it wasn't unhappy at all. It was just very happy, and I was amazed afterwards how well it had gone ... I didn't know how it would go, or how I would feel, and it just, it just felt normal really, which was fine...I wasn't sure it was right to feel normal, but it just was. And it was happy. And that seemed to be a milestone point to me." (Lorraine, 2/16-17/18-41; 1-2).

Quentin also returned to former leisure interests in widowhood; for him this was preferable to trying to do the things he had previously done with his wife which he found difficult due to the memories it triggered. He had therefore ceased watching the same television programmes, attending philatelic society meetings and instead resumed his interest in photography. A renewed relationship with his son who has computer expertise had enabled Quentin to bring his hobby up-to-date and share photographs with friends via email. He spoke about a trip he was planning to take photographs:

"So that's why when I go to Bruges I don't necessarily want anybody to come with me, I shall just quietly go along and look at the ... what I can see and take some pictures you see" (Quentin, 2/8/9-11).

Quentin summed up the changes he had made since his wife died by saying:

"But I think if you're on your own, you've got to take yourself forward, you can't, you can't sit in the sea of despond for a long time can you? ... But I think it's coming to terms with what you've got, and knowing you can't change, and just hope one day, you know, you'll be together again" (Quentin, 2/36/10-18).

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Similarly Spencer also made changes in the occupations he participated in as a widower. His wife had not liked to travel and so they had rarely taken holidays or trips away. Since her death Spencer had made frequent plans for trips he intended to take.

“that’s another thing I’m doing now, you see my wife and I, she didn’t travel a great deal, in her early days we got about and that sort of thing, we used to fly off to the Channel Islands, Scotland or something but then as she got a bit older, I realise her frailty became increasing with her” (Spencer, 1/6/15-18).

Initially his sons were concerned that he was avoiding being at home and tried to encourage him to try to stay at home to get used to being alone:

“That’s the hardest thing, cos initially I was away for so many times they would say “Dad, you’d better have a couple of days at home and then we’ll whisk you off somewhere else and then you can come back and have two or three days at home,” and they did that wonderfully, but then and increasing now I’m spending, well even now I’m only home for about a couple of weeks” (Spencer, 1/12/38-42).

In contrast Pamela found her widowhood opportunity to reduce her occupations and revelled in having an empty diary and no responsibilities. Whilst her husband was alive she had engaged in a range of clubs and groups outside of the home but had ceased attending these when he became ill.

“... perhaps I’ve retired, you know. Perhaps I’m 80 and I like just being at home ... I still can’t get used to the idea that I can do what I like today.” (Pamela, 2/28-29/37-40 and 1-2).

“but I think really, I’ve always done such a lot of work that there’s almost sort of like a, it’s quite amazing that I, I quite like the fact now that I haven’t got all these commitments” (Pamela, 2/5/8-10).

It was of note that the new home-based occupations she enjoyed engaging in were similar in some ways to the clubs she had previously belonged to but did not carry the responsibility of commitment to others. Although Pamela described her new role as “retired” perhaps she had scaled down and adapted her engagement and commitments.

For other participants their experiences over the first year as a widow/er reflected a gradual adaptation to their new situation. Aileen identified lifelong occupations which she used to help her to manage in difficult times and was confident would continue to help her:

“as far as I can I will jog along as I am doing my thing which means that I’m obviously reasonably contented with this, I don’t, I mean when I hear of people going on coach trips to this or that or the other, oh my goodness eugh you know it’s just not me. I do know if I wanted, I was really

down, but I'm not a down person, but if I was really down I've got people I can phone but I er, if I was really down I would get myself into a good book and ... I think that stems from being an only child" (Aileen, 2/24/4-10).

The theme of *taking yourself forwards* offers an interpretation of how the participants returned to engagement in occupations. In widowhood occupations were frequently revised to meet their new situation or needs as a widow/er and consequently contributed to a revised range of occupations; accommodations for age and changes in practical circumstances were largely integrated into those occupations in which they formerly engaged.

Occupations were seen as providing an important opportunity for companionship and conversation; as such they were considered essential and necessary to wellbeing and a means to avoid isolation. For most of the participants being alone was a novel experience; having to do things alone for the first time as a widow/er was therefore a significant change for these participants. All of the participants indicated insight into the fact that their life had changed and the way they organised their routines and occupations would also change.

5.8 Superordinate theme: Recovering occupation

A superordinate theme – *Recovering occupation* - was identified which drew together the three themes. *Recovering occupation* provided an overarching perspective of participants' experiences of engaging in occupation across the first year of widowhood from the period immediately after their spouses' death to the end of the first year; the period explored during this longitudinal study. This section of the chapter will explain the interpretation of the experience of recovering occupation, integrating the three themes identified. This is portrayed as a journey which the participants undertook. Each journey began with the death of a spouse after which their route became individual and personally meaningful, and would ultimately end in the recovery of occupation.

In the immediate period before bereavement the majority of the participants spoke of ceasing engagement in their usual occupations whilst the demands of caring for the sick spouse were met. They spoke of the significance of doing this as being of the utmost importance and that other occupations paled in significance in comparison. Changes to occupations and routines were made deliberately in order to spend the time remaining together. As their illness progressed occupations became increasingly focused on the dying spouse; although this varied between participants. Subsequently after their spouse had died they were in some ways in a form of hiatus in terms of their engagement in occupation. Their former occupations in a sense related to a previous life; energies with which to identify new occupations and routines was depleted.

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Initially participants spoke of appreciating the opportunity to rest and recoup their energies, and so avoidance of past occupations was apparent. Routine occupations were maintained, often with difficulty or reluctance; these were primarily personal care and domestic activities. Leisure occupations either brought painful reminders of the past because of their links to their spouse; or lacked meaning in the aftermath of their spouses' illness and death. Social occupations were largely seen as particularly challenging as they provoked others concern or caused anxiety about becoming distressed in front of other people.

Participants referred to needing time to retreat to what were perceived as familiar ways of organising their time. The formation of a continuing bond was common amongst the participant group. These largely reflected traditional forms of continuing bonds but were often described in relation to occupations that the widow/er engaged with. In this way their spouse appeared to be engaged in the occupation with the participant. This form of bond was seen in the ways that participants described ongoing conversation with their spouse throughout the day; greeting the spouse as part of their morning or bedtime routine; and seeking their advice about aspects of their occupations which they were unfamiliar with. A novel form of continuing bond was described by the participants which involved the maintenance of the former routine which they had had whilst their spouse was alive. This further appeared to facilitate the sense of returning, or retreating, to a time when life felt more secure and familiar.

Some of the participants described having long-term, personal leisure occupations. These participants described being able to return to these quite soon after their spouses' death but this again may reflect a retreat to what felt familiar. Engaging in occupations at specific times of the day or week, with familiar people provided opportunity to retreat to what felt a more secure experience and environment. These occupations were described as affording a means of coping with the challenges outside of the occupation. Such personally meaningful occupations included gardening, walking the dog, craft work and membership of a choir.

The support of others at this time was important for the participants and offered another means of emotional and practical support. This was often provided by family, close friends, well-known neighbours and organisations such as the Church. This means of support enabled participants to ensure that necessary, but less familiar occupations were completed. During this early period when participants felt less able to take on new occupations and responsibilities; this form of support was welcomed although was also seen to create conflict where it was felt to imply dependence.

With time the participants regained energy and with it some motivation to begin to re-engage in occupations beyond those necessary to get through the days. As their vision began to be turned outwards again there came recognition of how life had changed. Except for one participant who

had been widowed three times and married for approximately ten years to her spouse who died just before this study; the participants in this study had all been married for several decades. Most had not lived alone and there followed a period of adapting and learning to be alone.

It was as they began to re-engage in occupations that various constraints to engagement became clearer. These included health issues which felt amplified in the new situation where there was no immediate support and the participant had to cope with these alone. Other participants felt the impact of not having easily accessible transport to enable them to access community facilities and social interaction as they previously had. For these participants, their spouse had been the driver. Such constraints complicated re-engagement and participants expressed concern that they had to rely on others and fears that they would lose their independence.

For participants who had been long-term carers; adaptation was complicated by struggling to find meaningful occupations to fill their day. Whilst other participants had experience of engaging in varied occupations which they were able to choose to return to; those who had been carers had previously spent their time caring for their spouse and in order to do this had ceased engagement in independent occupations. They had retired early to care for their spouses and not had opportunity to develop independent occupations in retirement. During these years the meaningful occupations they had engaged in had related to caring for their spouses. With bereavement came the secondary loss of purposeful and meaningful occupations. One spoke of wanting to find social occupations which would provide a sense of usefulness and purpose, perhaps replicating his former caring role.

Many participants spoke of changes in the sense of time passing. Some felt there was not enough time in the day to complete all of the things they needed to do; whilst others found difficulty filling the day. For some there was a sense of having slowed down as a result of bereavement and ageing. There was a need to adapt to this new temporality.

In this period participants experienced a sense of needing to adapt to their new situation; being alone and having to do things alone; and also to learn how to do a range of new occupations. In accordance with traditional gender stereotypes more typical of the generation represented by the participants, for the women the new occupations related often to dealing with finances and the responsibility of household maintenance; for widowers the new occupations were frequently linked with housework and cooking. The process of developing the skills to take on these new occupations was generally either by asking for help, or by trial and error. Whilst many participants expressed anxiety or concern during this period, particularly in relation to taking on new occupations and responsibility; some reported a sense of enjoyment or pleasure at having mastered new tasks.

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So far it can be seen that the journey back to engagement in occupation involved a return to the past and familiar occupations; this was followed by a movement back to a neutral position. This appeared to prepare the participants for a move forwards into a new, revised repertoire of occupations. Although none identified their experiences as positive most identified having managed to cope with the events and situations which occurred whilst they had begun to resume participation in occupations. They felt more confident having done so and used this renewed confidence to support the steps made to go forward. This saw effort expended to re-engage with social occupations and more generally through renewed interest in the wider world. The need for contact with others and opportunities for social interaction and conversation with others was felt to be imperative.

There was a strong need to be active and busy within the constraints imposed by age and health concerns. This appeared to derive from a strong sense that being active was good; and lack of “doing” was seen negatively. To this end participants worked hard to ensure their diaries were full. Where this was difficult some described creating new occupations to fill the time such as reorganising bookshelves and other items. Whilst some avoided using a computer due to a lack of familiarity or confidence; others welcomed the opportunity for filling time that it offered.

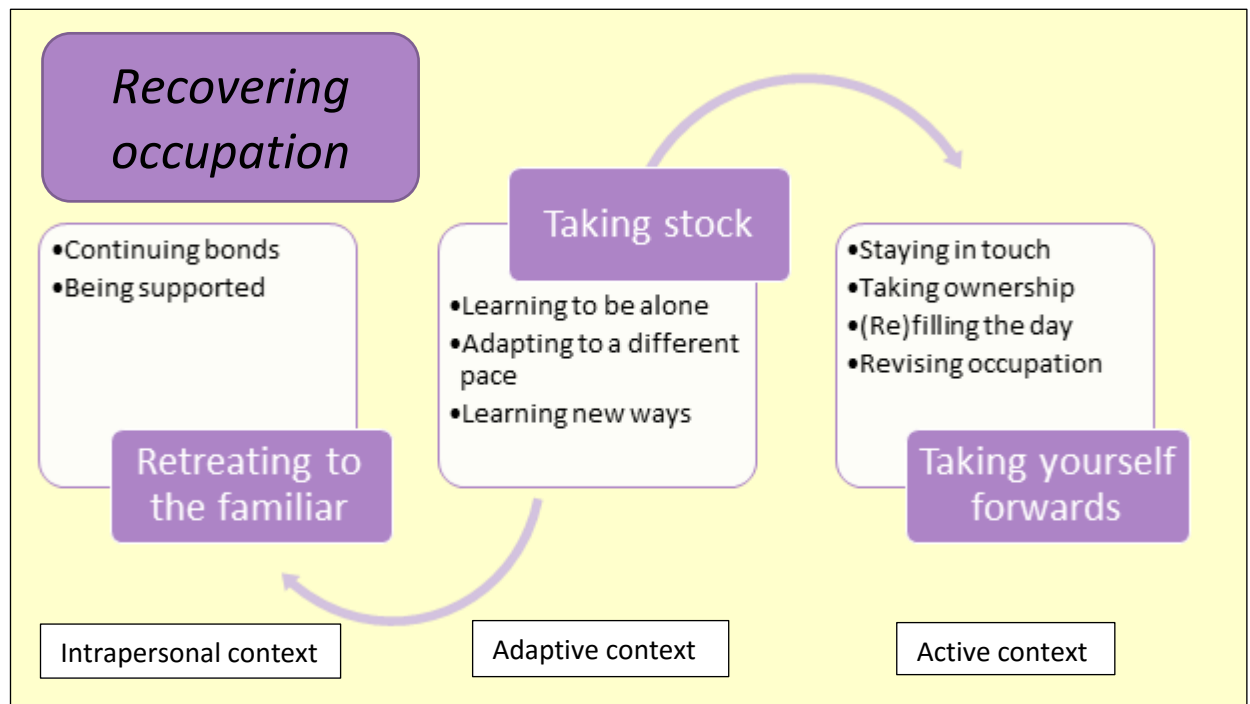
The final stage of revising their occupational repertoires and routines could occur as a result of successfully negotiating the challenges they had faced throughout the year from the point of their bereavement. Participants were able to acknowledge that they had coped with challenges they would not previously have thought they would cope with. Confidence continued to grow such that participants who initially had stated they would not be able to undertake some occupations again, such as taking a holiday; reported that they felt they would be able to return to those occupations. The sense of renewed confidence and engagement in varied and meaningful occupations indicated that adaptation of occupational identity had occurred or was in the process of doing so.

The model of recovering occupation (Figure 5.1) indicates the journey that participants undertook. The diagram representing the model is depicted in temporal order; commencing with the past on the left of the diagram; the present is sited centrally and the future on the right hand side. Participants initially travelled back to past occupations and routines which represented safety and security. They were accompanied on this journey by the intrapersonal support afforded by their continuing bonds to their spouse and the occupations they had shared; and by practical and emotional support provided by family, friends and organisations to which they had affiliations.

The next stage of their journey involved a move to the present where they had opportunity to take stock of their new situation and identify the next steps they needed to take in order to

resume occupational engagement. Finally with renewed confidence and new skills they moved their focus of attention outwards and forwards to recover occupation.

Figure 5.1 Recovering Occupation



5.9 Summary

This chapter has introduced the superordinate theme, three themes and the sub-themes identified in the analysis of the data collected during both sets of interviews. These have been explained using extracts from the interviews with the participants. The superordinate theme links the three themes and draws together the interpretation of the whole experience of engagement in occupations. The superordinate theme allowed for an understanding of re-engagement in occupations as encompassing three temporal contexts which further help to explain the process of re-engagement in occupations in spousal bereavement.

The next chapter will discuss key issues drawn from each of the themes identified; relevant theory and empirical work will be considered in order to establish the contribution of the current study to the experience of engaging in occupations by older widow/ers. These will be considered in relation to the anticipated outcomes of the study:

- Development of an understanding of the lived experience of engaging in occupations during the first year of widowhood in older age.
- Identification of how older people who are bereaved perceive their daily routines and activities.

Chapter 6 Discussion of the themes and superordinate theme

6.1 Introduction

This study aimed to explore the lived experience of engagement in occupations by older people during the first year of widowhood. As argued earlier in the thesis this is a novel area of research and as such no significant body of research literature exists which attempts to explain the experience. The previous chapter introduced the superordinate theme and three themes which linked and contributed to this. This chapter will discuss key issues pertinent to each of the three themes and the superordinate theme. These will be considered in relation to current research understandings and theory; and to the initial research question and outcomes identified. In this way the hermeneutic circle will again be reflected in the bringing together of pre-understandings and the new understandings provided by the current study. The research question was: how is engagement in occupation perceived by older, bereaved spouses? Two outcomes were anticipated and will be addressed towards the end of the chapter:

- Development of an understanding of the lived experience of engaging in occupations during the first year of widowhood in older age.
- Identification of how older people who are bereaved perceive their daily routines and activities.

Unlike in the previous chapter specific participants will not necessarily be referred to here; instead the focus will be on the broader issues identified in the data. Literature which will be drawn on in the following discussion is therefore drawn primarily from research and understandings of the experiences of older people; occupation; and bereavement.

6.2 Retreating to the familiar

The theme of *retreating to the familiar* encompasses two sub-themes which relate to both intrapersonal (*continuing bonds*) and interpersonal support (*being supported*). These will be discussed in relation to the following key issues relating to engagement in occupation in spousal bereavement drawn from this theme: the role of continuing bonds; impact on routines; and support and help-seeking behaviour.

Intrapersonal support was evidenced by the presence of participants' continuing bonds with the deceased and provided a form of symbolic support. Interpersonal support was provided by family, friends, neighbours and organisations such as the church, and was both sought by the bereaved as well as being initiated by the provider. Participants primarily discussed interpersonal support as relating to the provision of practical support but emotional support was also experienced. These two forms of support appeared particularly significant to participants in the earlier period of

widowhood and together appeared to provide support for the widow/er to re-engage with occupations. An ongoing bond with their deceased spouse appeared to provide an internalised means for emotional support for the participants allowing for gradual adaptation to their new life situation; whilst the support of others enabled them to engage in the occupations necessary to the continuation of day-to-day life.

The frequency with which a continuing bond with the deceased spouse was demonstrated by the participants in this study was notable. It was evident from the interviews that all of the participants who identified an ongoing bond accepted this without concern; none appeared alarmed or concerned about the presence of a continuing bond or what others might think. Neither did any of the participants appear to anticipate that it might be a temporary phenomenon; some of the participants commented that they could not imagine a day when they would not speak to or involve their spouse in their life.

The range of continuing bonds identified by participants reflected those commonly referred to in the body of literature on ongoing bonds with the deceased. No particular form of bond appeared linked with specific emotions or behaviours but their strong presence in this group during the first phase of interviews might suggest they play a role in the early stage of adapting to widowhood. This finding supports those of Asai et al (2010) who examined behaviours and coping in the period immediately following spousal bereavement although with a Japanese participant group who were much broader in age than those recruited for the current study. Findings from Asai et al (2010) drawn from data reliant on participant recall of their early experiences of widowhood from up to 9 years earlier, supported the role of continuing bonds in coping early in grief. Asai et al (2010) proposed that whilst the bereaved utilised a range of coping strategies; continuing bonds appeared to represent a coping strategy specific to bereavement. They concluded that the continuing bonds claimed to be utilised by the participants reflected both cognitive bonds, such as having inner conversations with the deceased and recalling memories; and behavioural bonds, for example visiting the grave and making offerings at the family altar, and in this way provided a means of comfort which enhanced coping. Whilst the current study did not explore coping strategies used by the participants, these behaviours were most frequently discussed in the first phase of interviews, and were described by the majority of participants as a source of comfort. Nevertheless ongoing bonds identified by participants in the current study appeared to have longevity as their continued existence was noted in the second interviews with participants in the current study. A finding which differs to that reported by Field and Friedrichs (2004) who identified a reduction in the use of continuing bonds over time.

It should also be acknowledged that the majority of examples of ongoing bonds identified in the current study meet the criteria included in Pierce's (2001, page 139) definition of occupation.

Behaviours such as conversing with the deceased spouse; seeking their opinion and interacting with their possessions can be interpreted as *“a specific individual’s personally constructed, non-repeatable experience ... a subjective event in perceived temporal, spatial, and sociocultural conditions that are unique to that one-time occurrence. An occupation has a shape, a pace, a beginning and an ending, a shared or solitary aspect, a cultural meaning to the person, and an infinite number of other perceived contextual qualities.”* As such the use of continuing bonds with the deceased can be described as a meaningful occupation for the bereaved.

Findings from the current study potentially extend those of Asai et al (2010) in that the participants’ use of their continuing bonds reflected occupations which *involved* their spouses rather than just *related to them*. These included activities such as asking their spouse for help with new tasks that the deceased had formerly undertaken and which the widow/er was now required to take on; involving them in conversation as they went about their daily occupations as they might have done when they were alive; and interaction with their spouse in the continuation of leisure occupations previously shared. In this way the participants identified a sense of reassurance about how they were managing the necessary occupations of daily life; reflective of findings from Carnelley et al (2006) who identified that continuing bonds demonstrated as ongoing conversations and thoughts about the deceased appear to provoke positive, happy feelings in the early stages of grief; and possibly thereby constituting a coping strategy. Participants in the current study also reported sensing the presence of the deceased; although one person reported this to be upsetting, for the majority this was a reassuring experience. This finding reflects those from studies of early widowhood by Conant (1996) and Nowatzi and Grant Kalishuk (2009) who reported a sense of comfort and connectedness associated with the sense of presence phenomena.

In contrast Stroebe et al’s (2012) study of early widowhood concluded conflicting findings suggesting that continuing bonds do not facilitate adaptive coping and that bereaved people who developed continuing bonds were more depressed than those who did not. Results from Stroebe et al’s (2012) study suggest that those who have stronger bonds to the deceased experience more distress initially but improve over time; although this might be the anticipated progression of the grief response. Whilst mood was not measured in the current study these findings do not reflect the impression given by the participants in the current study. Two of the participants who did not identify any ongoing bonds appeared outwardly during the interviews to be the most distressed of the participants compared to those who reported bonds. The range of, and response to, continuing bonds in the current study differ to those identified by Stroebe et al (2012) in that the participants experienced the ongoing bonds with their deceased spouse as positive and comforting with most able to deliberately create or summon their appearance.

No conclusive consensus was found in the literature reviewed to indicate whether bonds were a positive or negative coping strategy in relation to mood; whether participants initiated the presence of the bond to provoke more positive feelings and thus improve mood, or does the experience of the bond cause lower mood and higher levels of distress. The experience of participants in the current study and the forms of ongoing bonds reported does however suggest that the existence of an ongoing bond to their spouse enabled participants to begin to engage in daily occupations and routines. Participants described how they called on their spouse to help them to overcome inability to deal with day-to-day problems; and for reassurance when they had to make decisions. Others described wanting to do things as a means to continue the positive achievements and occupations of their spouse.

Richardson (2014) explored the role that interaction with the deceased's possessions played in the ongoing life of widowed, older people and considered this in relation to continuing bonds. As in the current study, participants in Richardson's work spoke of ongoing interaction with their spouses' possessions particularly items of clothing and continuation of habits and regular behaviours that their spouse had performed. Richardson (2014) interpreted these as a continuing bond in the sense that they enabled the couple to continue to exist. Without the material body of the deceased, their relationship and identity as a couple was interpreted as potentially under threat and even though externally this might still be how the situation is understood, for the participants the continuity of their relationship and marriage was key.

Richardson (2014) referred to this kind of bond as a metonym. In contrast to a metaphor which acts as a symbol of something, usually used in relation to language and vocabulary; a metonym acts as a substitute for something to which it is closely associated. In this way the possession acts as a substitute for the deceased and as such can trigger both positive and negative affect, although Richardson's work did not explore this. She gives the example of a spouse's signature as a metonym for them, whilst a photograph is a representation of them. Richardson interpreted the behaviours which her participants described having taken on in widowhood and which previously had been performed by their spouses in the same way, as metonyms for the physical body of their spouse.

Although Richardson (2014) focused on interaction with the deceased's possessions and continuation of their habits, this could also reflect the descriptions of maintaining their routines as described by participants in the current study. Routines are a form of embedded practice and as such might be described as metonyms for the physical "couple" that once was. By repeating the shared routines, the participants recreate the life that was disrupted by bereavement.

Connerton (1989) describes repeated practices such as routines as “incorporating practices” through which memory is maintained. By repetition routines and habits performed with another person create a durable memory which endures even after the removal of one of the “actors” through death. In widowhood this possibly plays a role in the maintenance of memories of the previously shared life. This interpretation might also be applied to participants who reported engagement in occupations which had been personal to them, rather than to them as a couple; this perhaps enabled maintenance of the memory of their past life. This was particularly noted in two participants whose husbands had worked abroad for long periods during their marriage; they had both established independent routines to which they returned after bereavement.

The notion of maintaining the presence of the deceased as a facilitator to engagement in occupation speaks to Wilcock’s (1998b) model of “doing, being and becoming” which was later extended by Hammell (2004) to include the concept of “belonging”. Engagement in occupation, or “doing”, is proposed to offer a means to maintain occupational identity. Early during grief, engagement in the occupations undertaken when the spouse was alive potentially help to maintain the identity of husband or wife until such time as identity reconstruction occurs. Participants in the current study perhaps retreat to familiar occupations in order to avoid the challenge inherent in revising identity at a time when resources may be depleted. This may relate to the restoration phase of Stroebe and Schut’s (1999) dual-process model of bereavement. Although this part of the model is often described as time spent developing new skills and occupations as a way of preparing for new challenges ahead; it might also refer to time spent engaged in familiar occupations which avert overwhelming emotional responses. In this way the current study might indicate a role for continuing bonds in identity reconstruction; in particular the reconstruction of occupational identity in widowhood.

In considering the potential role played by the continuing bonds identified by the participants in the current study, Root and Exline’s (2014) proposal regarding the relevance of temporal aspects of the bond have relevance. They suggest that ongoing bonds involving memories and reminiscing might indicate the view that the relationship is in the past and identity has been revised to that of *widow* or *widower*. Thereby ongoing bonds which relate to activities in the present such as those participants in the current study who spoke to their spouse about daily events, might imply the continuation of a *wife / husband* identity; and suggest identity has not yet been revised. As was explained in the previous chapter, the participants in the current study reflected both forms of bond – those which maintained the marital relationship as it was; and those which suggested adaptation of identity had occurred. This implies that for some of the participants the deceased continued to play an ongoing role in their life; the relationship remained unchanged and the deceased’s presence is apparent in an ongoing way, as part of the continuation of life. This

indicates that for the participants the relationship remained current and perhaps consequently their identity remains as a *husband* or *wife*, rather than having been revised to *widow* or *widower*. There were also some participants who described both reminiscing and forward-facing bonds; if the current study reflects Root and Exline's (2014) proposal this may suggest the process of adaptation is occurring and might be viewed as a gradual loosening of the bond as proposed by Stroebe et al (2012) and Root and Exline (2014). Further investigation of this finding is therefore warranted. Again if this proposition is considered in relation to the dual-process model of bereavement (Stroebe and Schut, 1999; 2010) it would suggest that as the widow/er gains familiarity, confidence and competence in their new situation they rely less on direct engagement with the deceased who move to a more removed position within the relationship.

Whilst the longevity of ongoing bonds remains uncertain it is acknowledged that not all are permanent and the experience of participants in the current study, captured in the focused code, *making blind changes*, may be a demonstration of how the loosening process occurs. Some of the participants outwardly described their daily occupations during the first interviews as replications of their former routines with their spouse. At the same time they spoke of changes they had made for various reasons but largely to make life easier. Although they did not describe these as changes and they were related at different times in the interviews, they were clearly changes they had made deliberately. This perhaps also speaks to the gradual loosening of the bonds with the spouse, and may again refer to adaptation of occupational identity. Bennett (2010) espoused that whilst initially engagement with the deceased spouse is experienced as a significant means of strength and support; over time this becomes less important as other means of support are identified. In the current study this can be related to occupation whereby making changes to occupational repertoire indicates renewed strength and a gradual loosening of the bond. Adaptation to a revised identity is demonstrated both by the unnoticed changes which occur and through the relocation of the deceased in a revised relationship which is facilitated by the continuing bond.

If a continuing bond can facilitate the process of a gradual adaptation in occupational performance to reflect the transition to widowhood; the existence of practical support from others enables the recently widowed person to maintain engagement in personally meaningful, everyday occupations throughout this process. A key issue identified by participants in relation to the issue of support from others is concern with being seen as a burden or as unable to cope. Research indicates that fears of appearing dependent are a cause for reluctance to seek or accept help (Alea and Cunningham, 2003; Ward et al, 2012). Alea and Cunningham (2003) identified that younger people may interpret seeking help as a positive strategy to enable best outcomes to be achieved; whilst for older people asking for help may be experienced negatively as an indicator of

inability unless the rewards for doing so are interpreted as significantly worthwhile. This provides an interpretation of the experience of some of the participants who decided against asking for help with practical tasks after concluding that the issue they needed help with was less important than maintaining an impression of being able to cope. Being seen to be able to manage was important to the participants; some spoke of avoiding people and places which might cause distress in order to avoid appearing upset and weak to others, even though this meant reduced interaction with others.

Conversely earlier work by Baltes and Wahl (1996) suggests that when the help-seeker is seen as dependent help is more likely to be offered; where the seeker is identified as able to manage independently then help is less likely to be made available. Utz et al (2004) reported more specific outcomes indicating that older widowed women are more likely to receive practical help than their male counterparts from adult children. Reports of support and help provided by participants in the current study indicated support for Utz et al (2004). As inclusion criteria for the study was that participants should be able to live independently it is difficult to say whether Baltes and Wahl's (1996) proposition was replicated in the current study. However where participants had children all reported some degree of support and where participants had health issues which made engagement in occupations more challenging after the death of their spouse the amount of practical help reported was often notable. In the current study it was notable that where participants reported anxiety or lack of familiarity in undertaking household tasks and financial management, adult children appeared to provide either help or to take over this task for their parent. It is also possible that participants who did not seek help may have been seen as competent and so were less likely to receive offers of help. This might also explain the experience of participants who were felt to be competent due to their history of having been carers and who after bereavement identified receiving little support; whilst others who were less confident and who had perhaps been seen as more dependent on their now deceased spouse were more likely to receive support.

Contextual issues also come to play in help-seeking behaviour. Margrett and Marsiske (2002) found that older adults have a preference for working to solve a problem with someone they know well, particularly a spouse. Some of the participants in the current study had small support networks, largely composed of family members, particularly adult children. Several spoke of not wanting to be a burden to their family but acknowledged that without their help they would struggle to undertake everyday occupations such as shopping and household maintenance. Utz et al (2002; 2004; 2011) and Caserta et al (2004) reported studies of the impact of spousal bereavement for older people on occupations and recognised the positive impact of practical support. For the participants in the current study although the support offered was valued it was

accompanied by concern of being a burden to others having been used to their spouse being their key problem-solving collaborator. Participants spoke of two forms of support; the first being where they asked someone to help them to do something; the second where they required someone else to complete a task for them. Alea and Cunningham (2003) describe these behaviours as “accommodation” and “compensation.” The current participants mostly claimed to attempt accommodation first before resorting to compensation. Against a background in which participants were trying to assert their independence it can be understood that compensation might be seen as a last resort for many. Although not investigated in the current study it is possible that these behaviours might illustrate the experience of participants whose continuing bond with their spouse entailed seeking their spouse’s advice to resolve difficulties.

Concern about how others might perceive them may increase the significance of the potential challenges to and implications that seeking help can have on self-identity (Ward et al, 2012). In considering occupation and the adaptations to occupational identity demanded by spousal bereavement this is of particular importance. Several of the participants in the current study experienced age-related constraints on their engagement in occupations, including health issues which might previously have been compensated for by the deceased spouse, lack of transportation and financial concerns. Combined these created a complex barrier to engagement in occupations and posed a risk of isolation as they described making decisions to cease participation in occupations because this option appeared more straightforward than to try to participate.

The experiences of the participants in the current study in relation to seeking and accepting help reflect those reported more generally by older people and do not appear specific to bereavement. Older age, as bereavement, is a time of change and identity adaptation and so the potential for anxiety and distress may perhaps be more likely; coupled with the impact of the loss of a life partner, the potential for difficulty potentially poses additional risk.

The transition to widowhood may reflect outcomes cited in Carnelley et al’s work (2006) which found that over time widows recognised having grown in self-confidence and that they felt stronger as a result of dealing with their grief; developments which may explain their increased capacity to cope and to make changes independently. The participants in Bennett’s (2010) study identified this process as a personal struggle, but as it occurred they too recognised a sense of personal growth – this was expressed in terms of making the transition from the identity of *wife* to the new status of *widow*. The widows continued to see themselves internally as a *wife* but were able to present a revised identity as a *widow* externally.

Studies which consider the use of continuing bonds in identity reconstruction provide compelling, but incomplete explanation of their role in personal growth and self-confidence, which facilitates transition to a revised identity of widow or widower. Studies tentatively imply that in order to facilitate identity revision a continuing bond should allow for the relationship to be relocated to the past tense (Root and Exline, 2014); should provide opportunity for positive self-appraisal (Bonnano et al, 1999; Bennett, 2010); and should reduce in intensity over time (Stroebe et al, 2012; Root and Exline, 2014). *Making blind changes* is a key component identified in the theme *retreating to the familiar*. This refers to how participants appeared to make deliberate changes to their routines without overtly acknowledging them; instead they described how they were trying to maintain their previous routines. This perhaps offers an explanation of how the transition to a new identity of widow/er might occur gradually and in such a way as to avoid causing additional distress and feelings of guilt. The majority of participants in the current study reported established routines and occupations by the time they were interviewed for a second time and made no reference to maintaining their previously shared routines. They appeared to have taken ownership for how they organised their daily life.

Although writing before the formal recognition of continuing bonds as an approach to understanding bereavement, Raphael (1984), a contemporary of Parkes (2010) who established bereavement support services in Australia, and Saunders (1989) who established the hospice movement, both likened the notion of an ongoing bond to the deceased as a demonstration of a denial of reality. Evidence from the current study and the studies examined confirm that continuing bonds are commonplace in spousal bereavement and rather than reflecting denial in fact appear to enable people who have been bereaved to engage with life and occupation whilst making the transition to widowhood.

The expectation of death as apparent for the participants in the current study suggests a potentially important role in relation to intrapersonal support and identity reconstruction. The theme of *retreating to the familiar* describe aspects of participants' early experiences after bereavement and participation in occupations. In some instances the continuing bond appeared to offer a form of symbolic support offering a means to return to what after spousal bereavement feels like a secure place – the routines and occupations of the marriage. Assertions by Raphael (1984) and Saunders (1989) that continuing bonds are a means to deny reality may have some resonance here; but denial does not necessarily preclude a means to re-engage and move on with aspects of daily occupational life. Where widow/ers in the current study did not identify any ongoing bonds this was sometimes a cause of concern for them. Perhaps as life might feel more challenging in ageing and following such a significant disruption as the death of the marital

partner the symbolic support offered by a continuing bond provides a valuable means of dealing with daily life.

In the current study ongoing bonds were noted in the form of recreating the occupations and routines as they had been during marriage even if for some participants this involved the challenge of learning how to do things the way their spouse had in order to recreate the same day-to-day organisation of life. Maintaining the status quo may also demonstrate a respect for the way life used to be.

Retreating to the familiar reflects engagement in occupations during the earlier period of the first year of widowhood as was evidenced by its apparent frequency of occurrence in the first interviews. It particularly identifies the ways in which the participants managed their experiences and the personal strategies adopted to cope and to maintain daily life early in widowhood. With the support of both a continuing bond to their deceased spouse and that offered by relatives, friends and organisations, participants were enabled to retreat to what were perceived to be familiar routines and occupations. This provided opportunity for respite after caring for their spouse and perhaps time to acknowledge the significance of their new circumstances. It is proposed that this theme reflects an *intrapersonal context* of engagement in occupation. Participants adopted an introspective approach in seeking ways to hold onto what felt familiar and could be maintained of their relationship with their spouse, whilst simultaneously making accommodation for needing support from others before they began to venture forwards.

6.3 Taking stock

The three sub-themes underpinning the theme *taking stock – learning to be alone, adapting to a different pace* and *learning new ways* – reflect aspects of early engagement in daily occupations after bereavement which were highlighted by the participants. These were issues that appeared to impact on participants as they began to consider how they might organise their daily life in widowhood. *Learning to be alone* was identified by the majority of participants either directly or in relation to describing their days as empty. The majority of the participants had been married to their spouse for several decades and being alone was a new experience for them; occurring as it did at such a difficult time possibly intensified the experience. This sub-theme also refers to the early re-organisation of daily occupations and the ways in which participants re-engaged with occupations alone. *Adapting to a different pace* linked to participants' perceptions of time and how this varied in relation to different situations and experiences in widowhood. During periods of feeling lonely, time was often described as slowed; whilst when engaged in occupations, particularly new, challenging occupations participants experienced time as going too quickly. All of the participants spoke of having to learn how to undertake or engage in new occupations;

some of these were completely unfamiliar, whilst others were occupations which they had previously engaged in with their spouse or observed their spouse doing. These are integrated under the sub-theme *learning new ways*.

The majority of the participants in the current study had been married for several decades, and except for three whose husbands had worked abroad for periods of time, had rarely spent lengthy time alone. For all of the participants widowhood had brought a sense of being alone; this was also felt by those whose husbands had worked away as being alone in widowhood was felt to be different in that the time apart was not time limited.

Despite many of the participants receiving regular visits and telephone calls from others, most described feeling lonely when at home and for this reason where possible most preferred to have a range of occupations they could engage with outside of the home. Several also spoke of experiencing feeling alone when engaged in activities they had previously done primarily with their spouse; driving and leisure activities were particularly experienced in this way. Although some described feeling lonely, participants spoke more often of the sense of being alone. This perhaps lends further support for the role of continuing bonds as described earlier; talking to the spouse was seen as a way to reduce the feeling of being alone. In a similar way many of the participants preferred to have a radio or television on when home alone; this provided a sense of not being so alone.

All of the participants spoke of the importance of being with others and this reflects findings reported by Ward et al (2012) in a study of older people's experiences and Sherman et al (2006) who reported the importance of opportunities for social interaction as a prerequisite for physical and psychosocial wellbeing. Participants in the current study mostly identified some anxiety about initiating contact with others; often for fear of becoming upset in front of others or of causing others discomfort. These concerns in addition to grief and the loss of self-confidence reported by many of the participants resulted in a more passive approach to initiating social contact. This aspect however differs to the experiences identified by participants in Ward et al's (2012) study which involved older people but not specifically people who had been widowed. Participants in that study identified the importance of creating opportunities to be with others and of inviting others to visit and appeared to be happy to initiate this. The heightened sensitivity indicated by the participants in the current study points to further challenges experienced by widowed older people. In the same way most of the participants identified in the first interviews that although they had previously enjoyed holidays with their spouse, they did not anticipate doing so anymore. This view appeared to shift somewhat for many by the time of the second interviews but largely due to the persuasion of others; for those participants without family or close friends, taking a holiday appeared to remain an activity in their past, associated with their spouse.

In contrast to the experiences presented by the participants in the current study Janke et al (2008) reported findings indicating that widows with more social contacts and higher interaction levels were more likely to experience lower mood. It is possible that reduced interaction serves a beneficial purpose. McIntyre and Howie (2002) and Nyman et al (2014) reported on the importance placed by widows of maintaining contact with close, long-term friends. In considering findings of the current study it might therefore be that large circles of contacts and acquaintances are experienced as less supportive than small, close-knit groups. The challenge of this in older age is that as people age they are more likely to experience the death of friends (Fitzpatrick et al, 2001) and their social group may potentially become very small. This was clearly evident for all of the male participants in the current study; whilst a small number had maintained some contact with a previous work colleague most relied on remaining family for social contact and support. The reduction in the number of friendships for older men was reported by Fitzpatrick and Bossé (2001) who reported that following retirement men more likely to socialise with their wives and their social contacts. When their wives die they potentially lose access to that group as well (Fitzpatrick and Bossé, 2001); as appeared to have occurred in the current study. In reporting results from a large study of bereaved men Fitzpatrick et al (2001) proposed that older men who experienced a close bereavement were more likely to value social and leisure activities as a way to alleviate stress and maintain good mental health. However their results also indicated that as non-bereaved men age their engagement in social and leisure activities reduces. Considering the findings of the current study in relation to these results, the challenge lies in supporting older bereaved men, who may have reduced their social and leisure activities prior to widowhood, to be able to initiate re-engagement in social activities at a time when they may feel less able to do so. An additional issue which older people in the current study identified was a lack of opportunity to go out independently due to a lack of transportation. Some of the participants were able to drive, although most acknowledged they were not sure how long they would continue to do so due to fears about the impact of ageing on their ability to do so. One third of the participants had either never driven or had voluntarily stopped due to health conditions. Of those who continued to drive, half expressed concern that they would one day be unable to do so. Several of the female participants had resumed driving during their husband's illness, and although lacking in some confidence were pleased they had done so for the increased freedom it afforded them in widowhood.

Life became more complicated for those participants whose spouse had been the driver. This group described feeling housebound, with no independent means to get out to do the things they needed to do and being reliant on their children for transport. This reflects findings identified by McMahon (2015) who reported greater risk of social isolation for older people without independent means of transport who were reliant on others, generally family, to be able to

engage in occupations outside of the home. At the point of the first interviews those participants in the current study without independent means of transport were beginning to recognise the difficulties this created. By the time of the second interviews those who were able had largely begun to explore means to get around; however those with health issues appeared to struggle to be able to do this with confidence. Even when public transport was available it was still necessary for users to be able to get to a certain place to commence their journey; this in itself was often difficult for participants and made harder when the return journey involved carrying shopping. As a consequence the practical issue of transportation would imply a further barrier to engaging in occupations which might relieve loneliness and the sense of being alone. A lack of transport further reduced opportunities for autonomy which impacted on belief in self-efficacy and optimism. These findings reflect those produced by Turcott (2006) and McMahon (2015) which acknowledged that opportunities for meaningful occupational engagement can be reduced significantly by a lack of transportation. Penning and Wu (2014) proposed that childless older people are more disadvantaged in terms of support for occupation due to transportation issues; this too was reflected in the experiences of some of the participants in the current study. In the current study several of the participants described a specific leisure occupation which they found particularly meaningful. Of all the occupations that participants either needed to do or wanted to do these were often those they returned to more readily or rapidly after their spouse died. Janke et al (2008) found that engagement in meaningful leisure occupations after a bereavement was linked with improved coping. Participants in the current study who had a specific occupation occasionally spoke of it in almost apologetic tones as if to return to something others may perceive as “fun” might indicate a lack of respect; similarly they expressed concern that other people may view a rapid return to these occupations with disapproval. However these experiences can be interpreted in light of the restoration focused grieving described by Stroebe and Schut (1999; 2010); and as such are likely to provide valuable coping strategies. The current study also reflects findings from Mattock and McIntyre (2016) who suggest that having a specific, personally-meaningful occupation also provides a means to maintain identity following spousal bereavement.

Akin to the feared disapproval of others linked with a return to meaningful occupations in widowhood was concern that certain occupations were deemed unsuitable by others. Female participants were most likely to refer to concerns about engaging in occupations which may be seen as male occupations; and to occupations which they had formerly engaged in with their husbands. During the first interviews participants remained anxious at the prospect of re-engaging alone in these occupations; by the time of the second interviews most reported that repeated exposure to the occupation had increased their confidence; or they had adopted strategies to reduce their anxiety.

In addition to concerns about other people's reactions, more general issues related to ageing which were identified by participants as likely to preclude engagement in occupations such as visual impairment, fatigue, slowing down and difficulties with memory. The consequences of these appeared to have been managed without undue concern prior to bereavement, but afterwards appeared to gain significance for most participants possibly due to the loss of the support formerly provided by their spouse. This suggests that the participants in this study were generally resourceful and able to cope with potential challenges. Previous experience of coping earlier in life is recognised as facilitating the development of resourcefulness and resilience which supports capacity to cope with later challenging circumstances. Schulz and Heckhausen (1996) and Nimrod and Ben-Shem (2015) reported findings which lend support to the importance of earlier developmental experiences and opportunities as contributing to the aging process and the ability to cope with the challenges it can bring. Whilst previous experiences were not explored in the current study this would be a worthy area for further investigation to identify more specifically what kind of experiences might contribute to the development of resourcefulness and resilience, which in turn supports capacity to overcome challenges to engagement in occupations in older age.

Opportunities to make individual choices and to exert control over personal issues, perceived self-efficacy, resilience and optimism have been identified as having significance in relation to coping successfully in older age from the literature identified (McCann Mortimer et al, 2008; Bowling and Iliffe, 2011). Participants in the current study referred to these qualities in providing examples of how they were able to cope. Examples they gave included being able to take over and manage the household finances without requiring help from others; adapting routines in order to allow time to engage in preferred occupations they previously had had to neglect; spending time with friends who their children did not approve but with whom they felt a connection.

For those participants with additional health needs it appeared to be more difficult to demonstrate autonomy; resilience appeared more challenging to those who had previously relied on their spouse's support. In turn this perhaps contributed to a more passive or helpless impression. In struggling to remain independent these participants described reluctantly having to acknowledge they could no longer manage their home and garden alone and had to pay for help with this. For those who appeared more able to cope this was not seen as negative but a sensible and realistic approach to managing alone; perhaps indicating a more resourceful and positive outlook.

Participants in the current study acknowledged that everyday occupations took them longer to complete due to their age whilst some also felt they had grown older since their spouse died. Although some commented on the increase in the number of tasks requiring their attention which could have created a sense of time shrinking; participants in the current study were initially more

likely to comment on time passing more slowly. One possible reason for this could be that the first interviews took place quite soon after their spouse died when the memories of how busy and difficult life had been were still predominant in their minds. This interpretation might therefore highlight a sense of relief that time felt slower. For others practical constraints reduced the occupations they might otherwise choose to engage in and highlighted gaps in their occupational routines and repertoires, sometimes resulting in time appearing to have slowed. Participants in Larsson et al's (2009) longitudinal interview study with very elderly people, aged 85 years and over, spoke of how time and perception of time changed with age. Not only did it take longer to do things due to reduced energy levels as reported in the current study; but there was a sense that time passed more quickly which differed to the experience of participants in the current study.

For some of the participants in the current study re-organising their daily routines to incorporate ways to adapt to their new circumstances also involved consideration of a new occupation, namely how they might organise their own possessions and affairs in preparation for their own death. Ranada and Hagberg (2014) reported this to be an occupation identified by older people, not necessarily widowed people, who referred to a desire to review and downsize their possessions. Whilst Ranada and Hagberg (2014) reported that although this was stated by participants few had done any more about achieving this; some of the participants in the current study had begun to undertake this process at the time of the first interviews. They described this as preparation for their own death in order to avoid leaving their relatives with the task of sorting their affairs. It is possible that having very recently had to do the same for their spouses, they were aware of how demanding a task this was. Participants in the Ranada and Hagberg (2014) study felt that to do so would demand more than they could physically do; whilst male participants in particular identified that they would leave their children to do this after they died. Physical and emotional constraints did not appear to be deterrents for participants in the current study some of whom described having undertaken quite heavy, physical work in order to retrieve items from lofts and sort through reminders of their earlier life. This activity was described in both sets of interviews across the first year of widowhood.

In a study about the experience of downsizing in older age Luborsky et al (2011) suggested a series of stages including one related to the "giving away of heirlooms" which equated to the idea of sorting through and disposing of belongings in preparation for death. Although participants in the Luborsky et al study did not appear to clearly link this with thoughts of dying and were not all widows or widowers there was a strong temporal element running through the report and an indication that it represented a stage in development over the life course. This did not appear to be a factor for participants in the current study who had not considered this as an occupation

they wished to undertake prior to their spouse's death, but one which was prompted by bereavement.

It is possible that the view taken by participants in the current study regarding the sorting of possessions in preparation for death might be part of the aging process. However in the instances spoken of by the participants it appeared to have been triggered by the death of their spouse.

None of the participants spoke of planning to leave this task to their children; the majority who referred to this activity spoke of wanting to avoid leaving such a demanding undertaking to others. For those without any relatives there was some anxiety about what would happen to their things. A lack of transport stood out as possibly the only deterrent to this occupation identified by the current participants; a factor recognised by Ranada and Hagberg (2014) participants.

The occupation of sorting life possessions recalls, and perhaps calls into question, Heidegger's argument that although we might be "being-towards-death" in the sense that we are aware at some level that we will die, it will in a sense always remain a possibility which we cannot predict or plan for:

"Thus if by 'Being towards death' we do not have in view an 'actualizing' of death, neither can we mean 'dwelling upon the end in its possibility'. This is the way one comports oneself when one 'thinks about death', pondering over when and how this possibility may perhaps be actualized." (Heidegger, 1927/1962, 261, page 305).

The experience of another person's death can only be understood in relation to mourning their loss; as Wheeler (2011) explains, according to Heidegger the death of another cannot be experienced in the same way that the person who died would have experienced it. As such making preparations for one's own death in the way that older people appear to aspire to do cannot be an *authentic* action as defined by Varga and Guignon (2015), instead occurring in the state of *falling*, time when people enact socially expected roles and behaviours. However this process of projecting oneself into the future in terms of thinking of one's death also reflects the hermeneutic circle in action; by reflecting on the past the participants can use the experience of having witnessed the death of another to project themselves forwards, both towards their own death and towards how they might wish to organise their future. Heidegger's interpretation of time and temporality comprises what he referred to as the three *temporal ecstases*; Wheeler (2011) concludes that Heidegger defined these as the horizons or limits of phenomena and as such free up consideration of temporality as a purely sequential process:

"Temporalizing does not signify that ecstases come in a 'succession'. The future is not later than having been, and having-been is not earlier than the Present. Temporality temporalizes itself as a future which makes present in a process of having been" (Heidegger, 1962, 350, page 401).

Taking stock explains a range of behaviours which contribute to the process of preparing the bereaved to re-engage in meaningful occupations. The enactment and completion of these

behaviours can be challenging especially as they are likely to occur at a time when the illness and death of the spouse is still clearly and rapidly recalled.

As the key aspects of preparation for re-engagement are worked through the participants began to recreate their occupational identity and this forms the final theme identified – *taking yourself forwards*. Heidegger's definition of time may help to explain the journey which participants appear to make in *taking yourself forwards* – by recalling their past life, *thrownness*; participants return to their *having-been* by retreating to familiar occupations and routines with symbolic support from their spouse through a continuing bond and practical support from others. In a state of *fallenness*, the present, or *gegenwart*, they use the experiences from their past to propel them towards their future, *existence*.

Taking stock reflects engagement in occupation as it begins to change and take on a more outward-facing perspective. It addresses the process whereby participants became acutely aware of being alone; and identified how they adapted to, and managed the occupations they had and chose to do. This element of recovering occupation can be understood as an *adaptive context*. Participants were seen to begin to recognise the need to make changes and to begin to adapt how they went about their daily life and everyday occupations.

6.4 Taking yourself forwards

Taking yourself forwards describes aspects of the process of developing a base from which to move forwards; this may involve reviewing the practical issues involved in engaging in occupations beyond home and family; or it can relate to beginning to do things alone. On achieving this base participants were able to re-engage with occupations which had formerly held meaning for them. Christiansen et al (2015) proposed that participation in occupations contributes to the construction of identity. By learning how to be alone, how to "do" alone, and by engaging in social interaction with others, participants found the means to reorganise and structure their day-to-day life following the significant narrative disruption they have experienced (Unruh, 2004) and by doing so appeared to begin to construct an occupational identity congruent with widowhood. Maintenance of patterns of occupation were found to be an important means to create continuity in identity in studies by Howie et al (2004) and Tzanidaki and Reynolds (2011). Participants in these studies had engaged in creative occupations throughout their adult lives and identified that this contributed to the development and maintenance of occupational identity. Engagement in creative occupations also contributed to the maintenance of a social identity as their creative endeavours were frequently engaged in social groups. Key issues drawn from the findings of the current study which will be discussed in this section are: continuity; the influence

of previous experiences and roles; and the importance of “doing” and keeping busy in relation to successful adaptation.

Except for the two participants who had been long-term carers for their wives and who, in widowhood, struggled for lack of previous occupations outside of their caring role; the majority of participants engaged in familiar occupations. Many returned to the same leisure and social occupations they had enjoyed prior to their spouses’ death. This continuity of engagement in occupations after bereavement was recognised by McIntyre and Howie (2002) in their single case study of adaptation to widowhood. They proposed that by doing the same things with the same people after bereavement as they had done before, occupation supports adaptation to the new life situation. In the current study it is proposed that the familiarity of the occupations provides a feeling of reassurance that served to enhance confidence and create a secure basis from which to begin to move forwards. Although it might appear to be a contradiction, by staying the same, participants appeared able to move forwards towards a new identity.

The maintenance of occupations and patterns of social interaction appeared to provide opportunity for participants in the current study to acknowledge their skills, qualities and achievements over time. These reflect components identified by Howie et al (2004) linked to the maintenance of occupational identity in older age. However in the current study this perhaps indicates two aspects to identity in widowhood; a core, internal aspect which develops through life and which serves to define the self; and a more external aspect which relates to that seen by others and which is susceptible to change. The core aspect of identity refers to how the individual sees themselves whilst the external aspect is that projected towards and experienced by others. This notion goes some way to explain the situation of participants who were, for various reasons, unable to continue to engage in their previous occupations. For these people, both their internal and external sense of identity were affected by widowhood.

The role of continuity of occupations following bereavement was also identified in a more recent study by Mattock and McIntyre (2016) of spousal carers of people with dementia. The authors reported that continuity also appeared to be linked to the caring role in that some of the participants sought out occupations such as voluntary work which enabled them to continue their caring role and occupations after they no longer had to care for their spouse. The desire to maintain a caring role was evident in the current study for participants who had either been carers or who had held caring responsibilities during their earlier life. Being a carer provides a source of identity and when this is lost through bereavement, opportunity to maintain this aspect of the sense of self is of importance. Participants in the current study who had been long-term carers struggled to re-establish new routines and patterns of occupation. Their experience suggested they had already been through a significant reappraisal of their occupations on becoming carers many years earlier. They described having to let go of their previously

meaningful occupations such as employment and interests in order to accommodate their spouses' needs and engage in the new occupation of caring. Although it might be assumed that in widowhood when they lost the occupation of caring and might return to their former occupations, with time these were no longer feasible or available. For these participants maintaining a continuity of occupations was not possible although in seeking new occupations they sought those which offered opportunity to be of use to others; perhaps replicating their carer role and offering a means to maintain their personal occupational identity.

A further aspect of loss of the occupation of caring role was identified by several participants and related to the loss of the relationships built with health professionals through caring for their spouse. One of the participants summed up this experience as feeling as if she was a member of the health care team who had cared for her husband at home; a role which brought a sense of purpose and identity. Several participants spoke of how it felt like a second loss when, often within an hour or two of their spouse dying, all of the people and equipment which had played such a key role in their lives over the preceding months disappeared emphasising their loss. Participants in a hermeneutic study undertaken by Linderholm and Friedrichsen (2010) described experiencing this as a rejection and a secondary loss.

In the current study the majority of participants described how they had made some changes to their routines in order to continue to engage in occupations after their spouse died. For some the changes made involved a significant reduction in engagement and interaction with other people. For others the changes were smaller in scale and made in order to accommodate personal interests and hobbies; or to enable opportunity for social interaction with others. These appear similar to the process of occupational accommodation described by Hoppes and Segal (2010).

A small number of participants did not appear to make adaptations; these were people who had formerly developed a range of personal occupations which did not appear to involve their spouses at all and in which they engaged in the same way after their spouse died. This approach reflects the process of occupational assimilation described by Hoppes and Segal (2010); and refers to how the bereaved assimilate the loss into their occupational lives without making adaptations. In the current study this primarily related to the experience of participants who had developed a strong internal and external occupational identity by which others knew them.

Participants in Hoppes and Segal's (2010) study were mostly younger adults, many of whom worked and none were described as having health difficulties to overcome. The experiences of participants in the current study highlight some of the additional challenges that older people can face when trying to re-engage in occupations in widowhood. Whilst the determination to remain independent and to re-engage can be strong; the reality of doing so as an older person made this

a difficult aim to achieve. The challenges of engaging in occupations in older age might offer an explanation of continuity in occupational engagement (McIntyre and Howie, 2002; Mattock and McIntyre, 2016). Engagement in familiar occupations might prove a less risky act than trying to develop new occupations; if an occupation has previously proved itself of value it is understandable to assume it will provide the same benefits as before widowhood and therefore is more likely to contribute in a beneficial way to the revision of occupational identity which occurs following bereavement. It is also possible that this insight facilitates more successful adaptation of the occupation as the participant is familiar with how the occupation is performed and so can make personal accommodations.

All of the participants in the current study referred to the importance of keeping busy and finding things to do. Reasoning for this related to a belief that being busy was good and provided a sense of purpose; doing things provided a means of distraction from negative experiences and thinking; and also avoided loneliness. They spoke of the importance of being busy and accomplishing goals, and described how this had been instilled in them from a young age. Being busy and “doing” also appeared to be a means by which participants were able to measure how they were and their level of grief. In the first interviews the process of measuring related to how frequently they became upset or were unable to do the things they needed to do. In the second interviews this related more to how much they were able to achieve; participants spoke of measuring how far they had been able to walk, how much gardening they had managed to complete, and how far they had driven alone.

Keeping busy appeared to be something that was actively worked on. Participants spoke of planning the next day before going to bed at night so that they had a reason and purpose to get up the following day. For several of the participants though keeping busy and being active posed a significant challenge; some identified creating things to do which might not really need to be done, whilst for others specific time was set aside to make plans for how they would fill the coming days to avoid the risk of an empty day. Some participants found filling their time harder to do and would use activities such as using the computer as a means to do so. The importance of being busy and planning time was identified by both McIntyre and Howie (2002) and Holtslander et al (2011). Holtslander et al (2011) also described needing to find a balance between engaging with the world and thereby looking forwards, and grieving, which they related to looking to the past; perhaps resonant of the dual-process model of grieving (Stroebe and Schut, 1999 and 2010).

The importance of contact with others and social interaction formed a key aspect of “doing” for the current participants for whom a day without opportunity to talk to somebody else was particularly troublesome. Social interaction was identified as a valuable occupation by the participants. Many acknowledged that this had become more difficult with age and as a result of

their spouse's death. A range of means to communicate was identified; preference was for face-to-face contact, as identified by Ward et al (2012); but communication by telephone and email and skype was also valued. Some of the participants without immediate, or nearby, family valued Church attendance as an opportunity for social interaction and support. Spiritual activities were found by Holtslander et al (2011) to be of benefit by providing a means to establish a sense of balance between positive and negative events. It was also understood to be due to the support and intimacy which may be received from within a church community. Janke et al (2008) reported on involvement in religious activities as providing benefit by facilitating the discovery of meaning in loss which may support adaptation.

Several participants were comfortable using the computer and saw it as a valuable tool to maintain contact with others; however others preferred to avoid it, seeing it a complex and problem-laden medium with which to engage. The age range of participants in the current study spanned twenty years but this was not reflective of computer usage unlike results reported by Chen and Persson (2002) which indicated that older people were less likely to use a computer. As reported by Ward et al (2012) those who had used a computer when employed appeared more comfortable and confident to use a computer, and were more likely to see it as a useful aid to daily living. Those who continued to travel after their spouse's death and those who had relatives and family who did not live locally mostly appeared comfortable using a computer. This contrasts with findings by Ward et al (2012) whose participants spoke of finding the internet overwhelming and so deliberately avoided it.

Computer usage described in the current study indicates the importance placed in keeping in touch with others by the participants in this study. Several participants whilst comfortable using a computer were distrustful of using it to make purchases and so would find what they wanted to buy and then ask a relative or friend to make the purchase for them. Reflecting findings by Ward et al (2012) several participants spoke of the unfairness of organisations who offered discounts for buying online; and how they felt discriminated against if they did not feel able, or wish, to do this. The majority of participants reported having a mobile telephone but generally described it as used only for emergencies when away from home, or to provide reassurance when out alone. Several had been given their telephone by adult children who had programmed key telephone numbers into it for them.

Of more importance to participants in the current study was opportunity to be with, and to talk to, other people. By the time of the second interviews participants who had less opportunity for social contact appeared notably more distressed and spoke more often of feeling isolated and lonely. Although mood was not measured in the current study this finding perhaps differs to results reported by Stroebe et al (2005) from a large prospective study of widowhood. This

suggested that the amount of social support is indicative of levels of depression but is not related to distress or recovery. Social contact was found by Janke et al (2008) to suggest increased capacity for coping and higher scores on well-being. Of note they identified that face-to-face contact was of importance; telephone conversations and attendance at social clubs and organisations were of less benefit to well-being. Participants in the current study although distressed did not appear depressed; although they largely did value face-to-face contact over other means. The role of social interaction in widowhood would be a topic worthy of further investigation particularly in view of the increased means of communication now available. Holtslander and Duggleby (2010) noted the importance of social support in the process of re-establishing life as a single person; it is this context which perhaps most clearly reflects the experience of participants in the current study.

Physical activity was highlighted in the current study as important to the participants. Some valued the opportunity to engage in physical activities such as gardening which was seen as productive; whilst others described the benefits of walking and getting out of the house. The latter was also described as offering opportunities for social interaction; participants described walking to their local shops taking much longer than necessary because of the opportunity to meet people on the way. Participants spoke of the pleasure gained from walking with others; reflective of the social connectedness of the occupation. The majority of interviews for the current study took place during winter months and for some of the participants the darker days and more unpredictable weather acted as a deterrent to going out unless necessary. Where walking was described in relation to fitness it was used by three of the participants, two with health difficulties, to measure how fit they were by noting how far they could walk; a fourth participant had engaged in sport as a younger woman and now in her eighties combined walking her dog with a long daily walk to maintain her fitness. Janke et al (2008) suggested that physical activity during the adaptation to widowhood may offer two benefits; firstly due to the recognised benefits for physical and mental wellbeing provided by exercise; secondly in terms of increased capacity to cope. These appear to have been borne out by findings from the current study.

A further aspect of re-engaging in occupations for the widowed participants in the current study related to taking ownership of some of the tasks and occupations previously undertaken by their deceased spouse. Some participants saw this as positive allowing them opportunity to do things in their own way and perhaps also provided a boost to self-confidence. For others needing to complete unfamiliar tasks was a cause for anxiety and worry. Participants who had previously been independent or who had managed aspects of household maintenance and finances were less concerned. For example three of the female participants had spent periods of time alone whilst their husbands worked overseas; all demonstrated a preparedness to take on those tasks

previously completed by their husbands when they returned to this country and in retirement. If they were unable to do something they would actively seek help rather than defer to one of their children or wait for someone else to notice and offer to help. Other participants were more likely to ask one of their children to complete the task, or to wait for them to notice; resonant again of Alea and Cunningham's (2003) concepts of accommodation and compensation in help seeking behaviour. Similarly Bennett et al (2010) identified that whilst some widows became independent, some did not and transferred the dependence for specific activities to other family members. It was noted that this may not always be the preferred outcome for the widows but other factors including health issues or family persuasion may be important. Reflecting the findings of the current study Bennett et al (2010) proposed that if a widow had previously been independent she would remain so unless health issues precluded ongoing participation in specific occupations.

The first three sub-themes under the theme of *taking yourself forwards – staying in touch, taking ownership and refilling the day* – appeared to lead participants to the point at which they began to re-engage with their previous occupations. In order to do this reflection on how this might be done appeared to take place and this reflects the final sub-theme *revising occupation*. For some this involved making decisions independent of their family whilst for others it involved deciding which occupations to continue with and which to relinquish. Some participants returned to familiar occupations they had shared with their spouse whilst others returned to things they had previously done independently. There was an overall sense of moving forward amongst all of the participants; a recognition that life would continue to move on and they would continue to engage in occupations. Engagement in occupations offered most participants opportunity to interact with others and to keep in touch with life outside of their immediate day-to-day existence.

The issues which appeared most likely to prevent participants being able to do the occupations they particularly wanted to do were limitations due to health and aging, and lack of practical means to do so such as transport. Although self-confidence was referred to and noted to have decreased for some participants; the recognition that "doing" was beneficial was universally identified by participants and appeared to supersede issues of confidence. Despite limitations engagement in occupation was not surrendered lightly and participants appeared to consider various strategies to re-engage in meaningful occupations. Participants spoke about the act of re-engaging as a moving forwards; such that it appeared to be a positive, and inevitable, marker to others as well as themselves.

In this final theme, *taking yourself forwards*, participants were seen to be engaging in, or striving to engage in occupations. Although for some of them their occupations were as much about

keeping busy as they were about engagement in personally meaningful occupations; there was an emphasis on “doing” and a recognition that this was important and positive. For many there was a return to engagement in their previous patterns of occupation. In this sense this aspect of engagement in occupation during the first year of widowhood was identified as an *active context*. This refers to the notion that participants actively engage with a process of decision-making, planning and preparation regarding their future patterns of occupation and participation. The two previous contexts identified – intrapersonal and adaptive – refer to a more internal process which allow for adaptation to the new situation and review of former occupations. In this final context participants had begun to re-engage with their occupations and routines with more independence and confidence.

6.5 Superordinate theme: Recovering Occupation

The superordinate theme - *recovering occupation* - links the three themes together creating an interpretation of the findings and explaining the lived experience of the participants in the current study of engaging in occupation following spousal bereavement. It is emphasised that the superordinate theme relates to occupation and engagement in occupation during the first year of widowhood and not to the whole experience of bereavement. Unlike in the previous discussion, this section will include some direct quotations from the interview transcripts to illustrate links between the experiences of the participants and the literature.

The use of the phrase “recovering occupation” refers to the deliberate actions participants took in order to revise and thereby resume former occupations. *Recovering occupation* acknowledges the irrevocable changes which have taken place but provides a means to restore and re-integrate some traces of the former life with their spouse; in this way both continuing bonds and continuity may be identified. *Recovering occupation* refers to both the resumption of former occupations and to the notion of engaging in chosen occupations per se after a period which was largely comprised of those inherent in caring for their spouse. The phrase also refers to the notion of re-engagement in ordinary, everyday occupations; rather like the idea of becoming active again after a period of inactivity. The sense is of an awakening or recommencement of life after a period which for many of the participants felt outside of normal experience. In this way recovering occupation describes how bereaved older people re-engage with life after spousal bereavement.

As has been seen in the previous discussion occupation provides a means to link with one’s past and also to create a future; thereby providing a thread of continuity through life. Initially, through the use of continuing bonds participants felt supported to engage in occupation which began their journey to recover their occupations. Practical and emotional support from others provided further encouragement in this. At this point the occupations reported by participants largely

reflected those deemed to be essential by the individual participant. They tended to be more home-based and reflective of personal and domestic care activities. Social interaction was primarily provided by close family and friends who were providing support at this time.

Over time the participants began to review their previous occupations and consider new occupations previously completed by their spouse. This review involved consideration of whether to maintain the occupation; revise it; adapt one's own capacity to undertake it; or pass it onto others to complete. In older age participants were seen to consider their physical and emotional capacity as well as practical issues such as time in deciding which occupations to pursue.

Finally participants began to engage in previous and new occupations reflecting a revised occupational repertoire which was largely reflective of their new situation and identity as a widow/er. Occupations reported by participants continued to include personal and domestic care activities but were also seen to include social and leisure occupations felt to be personally important and meaningful to the individual.

Participants described the occupations they undertook in terms resonant of Pierce's definition: "a specific individual's personally constructed, non-repeatable experience ... a subjective event in perceived temporal, spatial, and sociocultural conditions that are unique to that one-time occurrence. An occupation has a shape, a pace, a beginning and an ending, a shared or solitary aspect, a cultural meaning to the person, and an infinite number of other perceived contextual qualities" (Pierce, 2001, page 139).

Occupations are further acknowledged to reflect complex patterns of behaviour and action; to provide opportunity to develop and exercise skills; they were seen to be contextual linking to time, place and culture; to provide a sense of purpose and a means to organise behaviour and life; occupations offer choice and individually interpreted meaning whilst contributing to the development of identity (Pierce, 2001). Rarely did participants identify occupations which did not meet these criteria. When asked how they managed occupations they did not enjoy, few could identify anything specific. Where they did this was largely due to the effort involved and regret that the occupation had become troublesome due to age; nevertheless participants spoke of how they continued to try to complete such chores and indicated they had meaning in the stream of their everyday occupations. Some of the participants spoke of having adapted occupations to accommodate age-related constraints but continued to attempt them all the same.

Social and leisure occupations were favoured by all of the participants who expressed regret where they were unable to continue participation following their bereavement. For the participants these occupations frequently provided opportunity to be with a group of familiar people and to feel secure in this group; they also provided opportunity to relax and feel pleasure

in shared occupations; for some participants these occupations were linked with personally meaningful occupations such as hobbies and in this way were a means to be creative. These components reflect the work of Leighton (Tremblay, 2009) who identified eleven conditions key to the maintenance of healthy human functioning. Balk (2011) applies these to the process of adapting after bereavement; they can also be considered in relation to occupation. Six in particular appear most relevant to the experience of the participants in the current study: securing recognition; expressing creativity; being oriented in terms of your place and society; securing and maintaining membership in a human group; belonging to a moral order; genuinely laughing. Striving to achieve these reflect some of what participants appeared to describe of their experience of occupations. These are considered, with Pierce's definition of the components of occupation in Table 6.1. Extract from the interviews with participants are included to illustrate the relevance.

Table 6.1 Leighton's Human Sentiments considered in relation to Pierce's (2001) definition of occupation

Leighton's Human Sentiments	Components of an occupation	Quotations from interviews with study participants
Securing recognition	Sense of purpose; Contribution to the development of identity	<p><i>"It's a saving grace actually. You've got to have a hobby if you're, you know, if you're on your own you've got to have a hobby I think ... Satisfaction. Satisfaction, because I've got a very deep interest in all ... things aeronautical, and people say I'm an expert on the Fleet Air Arm, you know. But I don't feel an expert. There's a lot more I'd like to know. But I get all sorts of questions sent to me"</i> (Charlie, 2/25/13-24).</p> <p><i>"Well, they call me an expert – whether I am one ... I don't feel an expert because there's so much I don't know, but on my chosen subject of Fleet Air Arm, I know more than a lot of people ... they've all been in the aviation world all their life and the rest of it, and yet they still ask me. Isn't it amazing?"</i> (Charlie, 2/26/17-20).</p>
Expressing creativity	Complex patterns of behaviour and action; Opportunity to develop and exercise skills	<p><i>"I don't know, it's a fascination, it's fascinating to be able to, or not to be able to that's a bit pretentious, to try to capture something on paper that you see. It's much more satisfying than photography, that's all I can really say"</i> (Martin, 1/9/33-35).</p> <p><i>"you get so absorbed in doing it that you just, you know the rest of the world doesn't exist pretty much"</i> (Martin, 1/12/4-5).</p>
Being oriented in terms of your place and society	Contextual linking to time, place and culture; Providing a sense of purpose and a means to organise behaviour and life	<p><i>"I think once, once you've been, you always think of oneself as a soldier"; "as a professional soldier you spend your life really, basically thinking about other people"; "The Army is a way of life, it's not just a job"</i> (Oliver discussing his career and life as a soldier in 2, page 25 line 4 and page 26, lines 2 and 22).</p>

Chapter 6 Discussion of the themes and superordinate theme

Securing and maintaining membership in a human group	Complex patterns of behaviour and action	<i>"at my choir ... we do have fun because we do exercises to start with and it's quite funny watching, I'm sure I'm quite laughable ... and we do exercises with our voices, with our bodies and hissing and puffing and all that, and it's funny, and then we do laugh and we sing, and that's the best thing you can do and I do then forget. I find that very, very therapeutic which is why I go ... I think really I like it and I meet my chums there as well, so it's done a lot for me and I'm very fortunate, very fortunate ... so no, got good neighbours, good friends, acquaintances and support so it helps tremendously"</i> (Jackie, 1/17/29-40).
Belonging to a moral order	Provide a sense of purpose and a means to organise behaviour and life; Offer choice and individually interpreted meaning	<i>"I'm Catholic, yes, that's been a great comfort obviously to me"</i> (Davina, 1/7/29-36). <i>"I belong to a, they formed a widows club at the church which has been such a help to so many of us because a lot of us became widows at the same time"</i> (Davina, 2/1/30-32).
Genuinely laughing	Contextual linking to time, place and culture	<i>"I do go out, I have regular going out with other people. I have once a month Trivial Pursuits, an evening of laughter because we're all so damned ignorant, though we do have a couple of Mensa people there"</i> (Aileen, 1/1/46-49).

The quotations taken from the participants' interview transcripts reflect Peirce's definition of occupation and Leighton's components of healthy human functioning and intimate why participants appear to strive to "recover" those occupations which formed a part of their previous life prior to the spouses' deaths.

Participants identified adaptations they made in order to continue engaging in specific occupations. These included reorganising daily routines; enlisting the support of others; learning new skills and identifying strategies to address practical issues such as transportation. These reflect Hoppes and Segal's (2010) concept of occupational accommodation and facilitated the reintegration of personally meaningful occupations into the participants' lives. Challenge was experienced by participants in the current study who were limited by constraints such as health issues and transport or financial issues which prevented engagement and which they felt unable to surmount.

Participants in this study acknowledged the challenge of loneliness and boredom and described how they used occupation to manage these. Emphasis was placed on the importance of opportunities for social occupations to fill the need for companionship. Echoing research by McIntyre and Howie (2002) and Ward et al (2012) regarding the importance placed on social interaction and occupations by older people.

The movement suggested by the proposed model from the present back to the familiarity of past occupations and then forwards to a future revised occupational repertoire can be considered in light of Wilcock's (1998b) model of occupational engagement - "*doing, being and becoming.*" By "doing" or engaging in occupation, participants sought to re-craft a meaningful future self and in doing so created a revised occupational identity in widowhood; thereby "becoming" a widow/er. This development may also provide evidence of the personal growth which has been argued to occur following bereavement (Calhoun and Tedeschi, 2013). The occupations engaged in by many participants also reflected the additional fourth component of Wilcock's (1998b) model – "*belonging*" as proposed by Hammell (2004). *Belonging* relates to the interpersonal aspects of the occupations identified by participants and their recognised need for interaction, as well as the importance of being part of something beyond one's own, potentially isolated existence

6.6 Summary

The current study aimed to explore how engagement in occupation is perceived by older, bereaved spouses.

Two anticipated outcomes guided the completion of the study:

- Development of an understanding of the lived experience of engaging in occupations during the first year of widowhood in older age.
- Identification of how older people who are bereaved perceive their daily routines and activities.

The following summary of the findings aims to address these and provide evidence of the achievement of the outcomes.

The three themes and the superordinate theme explain the participants' lived experience of engagement in occupation during the first year of their widowhood; these have been considered in light of previous research and theories of grief and bereavement; and occupation. The three themes identified can be considered in relation to different contexts within which older bereaved spouses experience occupation following the death of their spouse. The first theme – *retreating to the familiar* – refers to the intrapersonal context during which participants withdraw in order to revise their relationship with their spouse. For the majority of the participants this involved the creation of continuing bonds. A novel expression of a continuing bond was identified from the participants experience; the recreation of the previously shared daily routines can be considered a means to keep things the same in a similar way to how more traditionally expressed bonds aim to maintain the relationship with the deceased; here the bond focuses on the relationship with the past life with the spouse. The intrapersonal context reflected in retreating also incorporates recognition of the importance of support being offered by others. Support offered at this time appears most often provided by family; but for those without family, by friends and religious organisations.

The second theme – *taking stock* – can be described as an adaptive context in which participants appeared to gain insight into their changed circumstances and recognise the impact of these. As this occurs participants begin to revise their view of themselves and the world and adapt how they comport themselves in what is experienced as new terrain. Adapting how life is organised on a daily basis and how patterns of interaction with others are conducted are integral to this context. For many of the participants being alone was a new phenomenon and required adaptation on both a practical, physical level and an emotional level. A change in the pace of life was also experienced and was often the result of having more to do now that there was nobody with whom to share the routine and domestic tasks of living. A change in the pace of life was

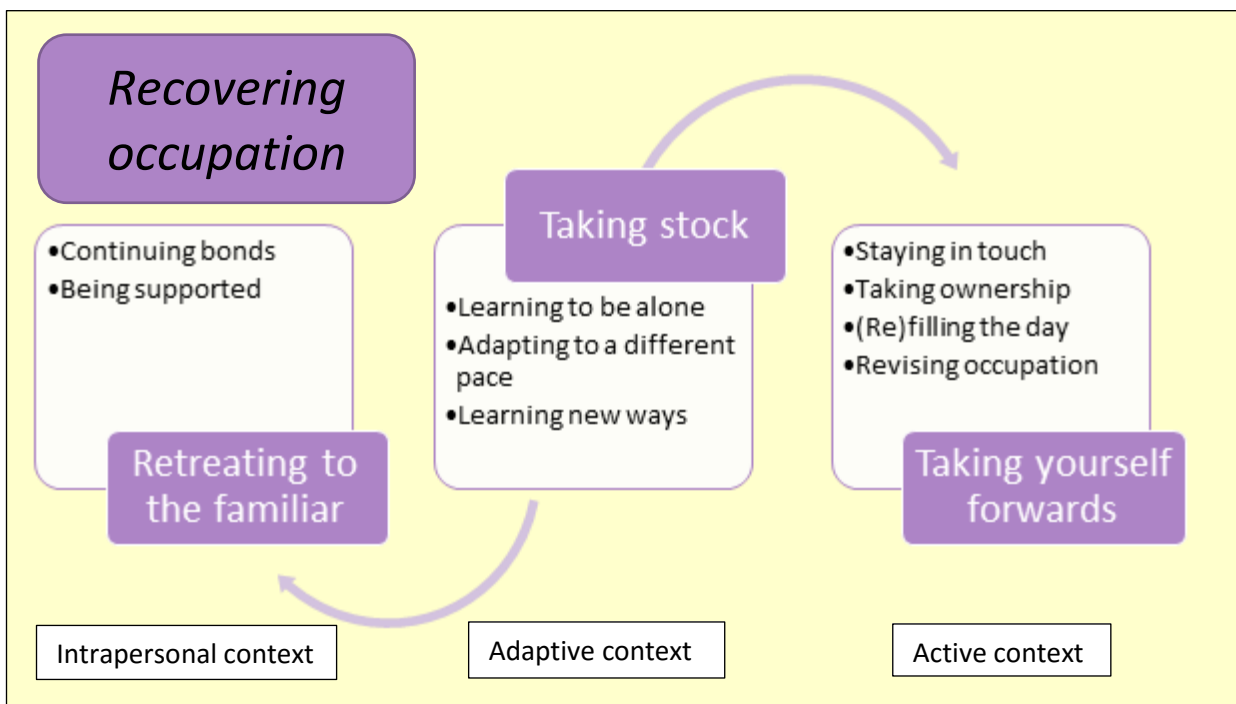
described by participants in relation to the effects of aging and increasing health issues which created limitations on energy and mobility. In order to accommodate both the impact of being alone and a change in how time is experienced, participants described the necessity of learning new ways to manage occupations and daily routines.

The third theme – *taking yourself forward* – occurs within an active context. Participants identified the importance of relationships and meaningful occupations and action is taken to enable these to happen. There is a felt need for companionship and opportunity to talk and interact with others and where able participants made efforts to satisfy this need. Further experiences which demanded an active response were where participants had to, or chose to take on those occupations and responsibilities formerly completed by their spouse. For some these actions were a means of satisfaction and pride and brought an increase in confidence in their ability to cope. For participants it was important to remain active and to find meaningful ways to structure their time. Constraints brought by aging and health limitations were experienced as frustrations and for many participants prompted the development of strategies to minimise their effects. Being busy was seen as positive and careful thought went into ways to ensure this. The occupations which participants found meaningful in widowhood were often those they had previously engaged in, or were in some way linked to these. Again health limitations proved more challenging to manage. For participants who had been long-term carers and who had not engaged in leisure occupations for an extended period of time, bereavement brought the challenge of starting again; in older age this appeared particularly demanding. In summary the theme of taking yourself forward reflects the adaptations which must occur in order to forge a revised occupational identity in widowhood and an ongoing life narrative.

The three themes and their proposed contexts provide the means by which the superordinate theme of *recovering occupation* is achieved; together these suggest a process which evolves over time. The themes and their related contexts can be understood to apply to each of the participants but the duration of time spent in each context was found to be individual. The development of the themes during analysis was completed by adopting a hermeneutic approach of moving attention between part and whole. To understand the themes and the superordinate theme it is also necessary to adopt this approach; understanding of individual themes requires an appreciation of the whole interpretation; understanding of the whole interpretation of the experience requires examination and understanding of each part / theme. The strength of a longitudinal approach was the opportunity it provided to recognise and confirm the temporal aspects of the interpretation; the notion of a stepping back, or retreating, before moving forwards.

Figure 6.1 Recovering Occupation depicts the whole experience of engagement in occupation including the three themes and their related contexts; the diagram also indicates the temporal and fluid aspect of the interpretation which was felt to occur between moving back, or *retreating*, to a sense of familiarity and security; and moving forwards towards a revised occupational identity. Together the three elements aim to provide an explanation of the lived experience of the recovery of occupation in the first year of widowhood; and thereby address the aim of the research to explore the lived experience of occupation for older widower/ers.

Figure 6.1 Recovering Occupation



In relation to the theories of grief and bereavement discussed in Chapter 2 the diagram developed to reflect the findings from the current study presents potential links to both the continuing bonds approach to grief (Klass et al, 1996) and the dual process model (Stroebe and Schut, 1999). The fact that most of the participants developed a continuing bond to their spouse suggests no support for Freud's interpretation of the purpose of mourning being emotional detachment from the deceased (Freud, 1917/1984). Freud did however describe the completion of mourning as enabling re-engagement in life through dis-engagement with the shared past (Freud 1917/1984; Granek, 2010); in this way a tentative link with the findings of the current study might be proposed as the model outlined explains how participants moved from a position of shared occupations to revised occupations and routines as a widow/er. Neither do the findings suggest links to the stages approach to grief (Bowlby, 1980); although this cannot be stated with certainty as the current study did not set out to explore this and it can be seen that participants did in fact appear to progress through three phases of adaptation. The first of which identified by

Bowlby (1980), *numbness*, could perhaps be likened to the first theme identified in the current study, *retreating to the familiar*, which might perhaps arise from a desire to defer acceptance of the reality of the death of their spouse. Subsequent to this stage, the stages approach moves towards ultimate detachment from the deceased; this was not in evidence in any form in the current study in which participants largely maintained ongoing bonds to their deceased spouse.

Strong evidence was drawn from the participants' experience with regard to the development and maintenance of ongoing bonds to the deceased. These appeared to consistently remain in existence throughout the duration of the data collection period of the study; where participants identified a continuing bond in the first interview, this was still present at the time of the second interview. The novel occupational bond identified in this study potentially extends current understanding of the continuing bonds model. This was less evident at the second data collection point but this might be explained by the idea of its purpose being to support the bereaved person to engage with everyday routines. By the time of the second interview the participants had established some form of day-to-day routine which was largely adapted to serve their needs as a widow/er rather than part of a couple.

The model portrayed in the diagram can also be linked to the restoration-focused component of the dual process model of grief (Stroebe and Schut, 1999). The diagram proposes how the participants re-engaged with occupations from the time point of their spouse's death. The current study explored participants' experience of occupational engagement as a widow/er and did not address their emotional or psychological experiences during this period. Had it done so it may have shed light on the oscillation component of the dual process model. Participants were observed to experience a range of emotions during this period which further study might serve to link with their engagement in and performance of their occupations and routines.

6.7 Conclusion

This chapter has explored the findings, providing an interpretation of the participants' experience of engagement in occupations over the course of the first year of widowhood. Discussion has considered how the findings contribute to theory and the published body of literature on occupation, older people and bereavement. The final section of the chapter reconsidered the initial research question and anticipated outcomes.

The next chapter will draw the thesis to a close with consideration of the implications of the findings of the study for policy and practice. Areas for future research and limitations of the current study will be identified and a reflection on the process of completing the study will conclude the thesis.

Chapter 7 Implications and conclusions

7.1 Introduction

Chapter five of this thesis reported the findings from the study which aimed to explore the lived experience of participation and engagement in occupations during the first year following spousal bereavement. Chapter six considered these findings in light of current literature and theory. This, the final chapter of the thesis will discuss the implications of the key findings in relation to policy, health and social care practice and the occupational therapy profession. The key findings which will be discussed are the previously unreported presence and role of occupations in relation to the continuing bonds model of bereavement; constraints to engagement in occupations following spousal bereavement in older age; and the experience and process of returning to engagement in occupations by older people.

The development of new understandings and interpretations of the participants' experience has highlighted further gaps in knowledge and understanding; this chapter will consider areas for further investigation indicated by the current study. Recognised limitations of the study will also be identified; and the chapter will conclude with comments on the reflexive approach adopted by the researcher; and reflection on the research experience.

7.2 Key findings from the study

Three findings are highlighted as key and will be considered. These are 1) the identification of occupation as a medium through which a continuing bond to the deceased spouse can be created; 2) constraints and limitations to engagement in occupation which occur uniquely following spousal bereavement and not simply as a result of the ageing process; and 3) the journey by which older people who are widowed return to occupations following bereavement.

The continuing bonds model of grief posits that death does not end a relationship but transforms it in such a way that the relationship between the bereaved person and the deceased can continue (Klass et al, 1996). Not only does this allow the interpretation of grief to be transformed from a psychological or psychiatric condition to a social construct; it also allows for individual variation of experience and expression (Valentine, 2008). Consensus regarding the potential benefits or disadvantages of maintaining bonds to the deceased remains unclear (Stroebe et al, 2012). Nevertheless literature has acknowledged varied forms of bonds which are used by bereaved people. These have included reminiscing about the deceased by looking at photographs; and talking about them and recalling memories with others. Other forms include conversing with the deceased; maintaining and using their possessions; and sensing their presence.

The participants in the current study appeared to express a novel form of continuing bond involving the recreation of the routines they had previously undertaken when their spouse was alive. They described working to recreate previous routines and ways of organising daily life; sometimes this involved working out how to do the things their spouse had done and trying to do things in the same way even when these were not occupations they had actually performed before. At the same time they spoke of the changes they had made and continued to make in how life was organised and executed. Together these actions implied a dual perspective on daily occupations where participants could project the appearance of functioning and adapting to their new situation whilst at the same time they were able to benefit from the reassurance and sense of security of the ongoing bond with their spouse. The evidence of changes being made may reassure concerned family and friends but it was perhaps the strength drawn from the continuing bond which facilitated these changes to be made.

This phenomenon was noted only in the first interviews with the participants; as by the time of the second interviews participants appeared to have established routines which fitted their new status as a widow/er. Ongoing debate in the literature on continuing bonds indicates uncertainty of the role played by continuing bonds (Stroebe et al, 2012) with some researchers proposing a role in identity adaptation (Root and Exline, 2014). The presence of the occupational continuing bond indicated here would support that purpose. Participants were able to make changes gradually and as necessary in order to reorganise daily life and reduce the overwhelming demands experienced in the period after their spouse had died. At the same time the continuing bond allowed for the belief that life was continuing as before and in this way the couple could continue to exist (Root and Exline, 2014; Connerton, 1989). This may be a form of denial as Saunders (1989) and Raphael (1984) proposed the maintenance of ongoing bonds to be; and yet the participants did not appear to be denying the death of their spouse. On this basis the bond appeared to be a means to “buy” time during which reappraisal and revision of daily routines and occupations can be made.

The participants in this study were all aged over 65 years; their ages ranged from 65 years to 84 years, indicating a potentially diverse group with differing experiences of the later stages of life. This diversity provided a range of information about the potential constraints and barriers to engagement in occupation by older people. These included health conditions which limited engagement due to reduced mobility; sensory impairment such as visual problems; financial concerns particularly in the earlier interviews when the deceased spouse’s estate was still to be settled; and a lack of transport. Of all of the constraints identified, it was the latter, difficulties with transport, which appeared to pose the most significant barrier to engagement in occupations after the initial loss of self-confidence identified immediately following bereavement.

Accommodations considered and made for health difficulties included pacing and delegating more challenging tasks to others. Financial concerns were mostly managed by seeking advice or assistance. Whilst this is unlikely to represent the experience of all older people, few of the participants in this study were completely unable to find means to pay to engage in the occupations that were particularly important to them such as membership of organisations related to a favourite hobby or going out with friends. For the most part costs were linked with transportation costs which appeared to form the biggest constraint to engagement.

Where older people continue to be able to drive, opportunities for remaining independent in daily occupations, and for having choice regarding participation in occupation are supportive of engagement. Whilst the number of older drivers in the UK continues to increase (Department for Transport, 2010), within the participant group one third did not drive; four had ceased driving for health reasons; and two had never learnt to drive. Using public transport might appear to offer an alternative, particularly where free bus travel is available, this proved often not to be a satisfactory response. To use public transport older people must be able to get to a bus stop and want to go where the bus route will take them. Additionally the need to carry shopping or other items makes use of public transport more difficult especially when there are health and mobility limitations to consider. Where public transport is used it might involve taking a taxi to a rail station; some participants expressed reluctance and anxiety initially about using taxis where this had not been an activity they had done before. The physical act of using public transport was also seen as a cause for anxiety due to the mobility required to do so. One participant described having to trust to luck when getting onto and descending from the train; an act involving throwing his suitcase out and leaping after it hoping he would be able to cover the distance between the train and the platform.

Following spousal bereavement participants described feeling a loss of confidence; possibly linked with the loss of their primary support and collaborator in life. This can result in feeling unable to ask for help with getting around and thereby a reduction in occupational opportunities. Older people without available transport, and without financial means and confidence to seek alternative means, may thereby become dependent on others even when they might otherwise remain independent. Having no, or limited access to, transportation might also lead to limited opportunities for social interaction which participants in this study, as in previous research (Ward et al, 2012), identified as important.

The third key finding to be drawn from the current study was the journey by which older people who are widowed return to occupations following bereavement. Participants appeared initially to follow a path which took them back to familiar occupations of the past when their spouse was

alive, before a period of review and adaptation which appeared to facilitate a forward movement towards a revised occupational repertoire. For the older people in this study this fluid movement back and then forwards was feasible as none were working or had responsibilities for other people. The implications for other groups of people will be considered in the professional practice implications of the findings later in this chapter.

7.3 Policy implications

The increased number of older people in the world population presages increased demand for health and social care services (Department of Health, 2001; WHO, 2002; ONS, 2015; Kings Fund, 2016) and subsequently increased costs of providing such care to this group. As the overall population continues to decline this may also result in a shortage of health professionals and people to care for the increased older population. Emphasis must therefore be on the importance of maintaining the health and wellbeing of older people for as long as possible in order to reduce demand on what may be reduced health and social care resources (Department of Health, 2001).

The situation becomes more paramount in relation to older people who are widowed. Significant health implications have been reported in the years following spousal bereavement. Stroebe et al (2007) concluded that for widows, psychological distress, changes in social and living circumstances, altered eating habits and loneliness experienced in the first two years of widowhood posed significant health risks. They further commented that widows were more likely than non-widowed women to have physical health conditions, require medication, and to be admitted to hospital (Stroebe et al, 2007). Laditka and Laditka (2003) reported that widows who experienced social isolation were at further risk of being admitted to hospital emphasising the importance of social connectedness following spousal bereavement. Social contact either face-to-face or by telephone was found to significantly reduce this risk (Laditka and Laditka, 2003). In the early days of widowhood social support is commonly associated with support with instrumental activities of daily living such as help with household chores (Scott et al, 2007) which perhaps provides encouragement to engage in these activities. Nihtila and Martikainen (2008) propose both social and instrumental support to be implicated in the wellbeing and avoidance of hospitalisation in the years following spousal bereavement. However Guiaux et al (2007) propose this effect to offer temporary protection only as social and instrumental support was found to decrease after 2.5 years.

Scott et al (2007) reported that whilst social support offered some health protection in widowhood; additional benefit was experienced where support was seen as reciprocal. This lends support to activities such as the widows group described by one of the participants in the current

study. Scott et al (2007) proposed that the reciprocity involved in such groups served to enhance feelings of empowerment and self-esteem. However important factors to recognise in such ventures include the availability and accessibility of opportunities and that the widow is healthy enough to participate. Cattani et al (2005) and DiGiacomo et al (2013) both argue however that social support is more effective for the majority of older people who experience bereavement than formal bereavement interventions; and Stroebe (2009) concludes that the majority of widowed people cope with and adapt to their grief without the need for intervention. These arguments are borne out in conclusions by Lund et al (2010) and Caserta et al (2004) who posit that opportunities for educational and social support offered enhanced benefits over bereavement-focused interventions.

Whilst older women feature more often in bereavement research this should not imply that older men do not grieve. Stroebe (2009) proposes that much bereavement research carried out in Western cultures intimates that men are more likely to demonstrate resilience following bereavement, including spousal bereavement. She argues however that the adoption of a “stiff upper lip” to grief may result in grief being directed towards less helpful management strategies such as increased use of alcohol and somatisation. Both of which have implications for health and wellbeing for older widowers. Studies which focus on health risks in the early period following spousal bereavement; generally considered to be the first six months; suggest that widowers are at higher risk of mortality than widows (Stroebe et al, 2009). Although statistics indicate this still to be an infrequent event associated with bereavement (Stroebe, 2009); the risk remains for older people who are bereaved.

Prigerson et al (2009) warn of a significant risk that older people underreport intense grief and so it is likely that evidence for the physical health related consequences of bereavement is inaccurate. A similar situation is also thought to occur in relation to depression among widowed people. Hansson and Stroebe (2007) suggests the risk of depression is lower in older people; however Graham et al (2011) report that approximately 25% of older people in the United Kingdom have symptoms of depression requiring treatment, with less than one in six reporting these to their General Practitioner; and only half of these receive adequate treatment. It might be concluded therefore that older widow/ers are at a significant risk of experiencing depression.

Inactivity is recognised as being detrimental to physical and mental health and wellbeing (Tancock and Roberts, 2015). Strategies to support people to remain as active and engaged in meaningful occupations throughout the lifespan must therefore be given priority in order to ensure the beneficial effects are experienced by as many people as possible including those bereaved by the death of their spouse.

Despite evidence supporting the importance of social connectedness in the maintenance of health and wellbeing in widowhood; of key importance is opportunity to access such support (DiGiacomo et al, 2013). In the current study it was noted that a lack of transport or inability to access available transport was noted to be a key factor in whether the participants re-engaged in occupations following bereavement. Whilst some of those participants without means of independent transport had relatives who would drive them to places they needed to go, such as shopping; this rarely included social and leisure occupations. This part of their lives could thus become effectively unavailable to them and potentially place them at risk of health consequences. In order to minimise health risks faced by older widow/ers it is important that consideration is given to accessibility to opportunities which offer support.

Whilst transportation and mobility issues are key issues for consideration it must also be acknowledged that the desire to be seen to be independent may pose further constraints on engagement (Goll et al, 2015). Reaching out to older people to encourage engagement may therefore need to be a deliberate and persuasive act. Although it is recognised that General Practices are understaffed they hold a key position in relation to access to older people. After the age of 65 years older people are invited to participate in various health checks; whilst many may already attend their surgery on a regular basis. Recognising the risks that social isolation and loneliness pose, the responsibility of identifying those at risk and directing and encouraging them to engage in support to ameliorate the risks should lie with all health and social care professionals and associated staff. Windle et al (2011) refer to the role that primary care and other health and social care services can play in what they refer to as “primary prevention” for older people who whilst healthy, may not be engaging in strategies to maintain their health and wellbeing.

Encouragement and opportunity to access social support opportunities is important in relation to reducing the risk of loneliness and social isolation (Windle et al, 2011) and the subsequent secondary health risks associated with these. It should also be acknowledged that actual engagement with support services may depend on other factors. Goll et al (2015) identified factors which prevent engagement including fears of social rejection by peers and concern of potential threats to self-identity. The latter issue was associated with concerns about being linked with a negative impression of old age and a reluctance to be seen in this way. Strategies to challenge this impression and emphasise positive and supportive aspects of social networks and groups should be adopted. SCIE and Contact the Elderly (2012) and Goll et al (2015) identified that befriending networks and social groups which focus on creative or therapeutic activities and group discussions have been particularly successful. Assertive approaches to encouraging the engagement of older people were recommended by SCIE and Contact the Elderly (2012). However in relation to newly widowed people this should be done with sensitivity and recognition that

introducing new environments and situations early on following a bereavement may cause anxiety for widow/ers who are still coming to terms with the impact of their loss.

Whilst strategies to support older widow/ers continued engagement in occupations must be addressed so too should efforts be placed on enabling younger people to develop and maintain skills to support them during widowhood and older age. Opportunities for children and adults to develop strong occupational identities (Christiansen et al, 2015) should therefore be emphasised and supported. Whilst educational achievement is often portrayed as a primary goal for younger people; studies which consider the health benefits of engagement in occupations present evidence for a broader understanding of achievement. Concerns have been expressed about the increase in risk-averse behaviour by younger people; whilst such an approach may offer some protection against injury it offers little benefit in terms of ability to cope with the challenges of later life.

Support to develop resources and life skills such as confidence in financial management; and maintenance of healthy lifestyles supportive of continued wellbeing and independence should also be given attention. Developing positive lifestyle habits early in life facilitates increased coping and longer independence in later life through better physical and psychological health and increased practical resources. By successfully managing difficulties in life and achieving goals, individuals build resilience which further supports successful negotiation of life crisis and challenges (Erlandsson and Christiansen, 2015). Such strategies are in keeping with current approaches to negative health issues such as obesity and smoking. Adoption of healthy habits early in life will not only support healthier later years but also more positive experiences. Whilst attaching messages about preparing for healthy old age to such ventures is unlikely to enhance their appeal to younger people; focusing on positive experiences and opportunities for positive personal development may be more appealing. Development of problem-solving skills, ability to assess and take reasoned risks, and awareness of strategies to maintain self-esteem during challenging times are valuable for everyone. Adopting an approach which emphasises preparing from the beginning for the whole of life might offer opportunities to develop the skills and experiences necessary to live as much of life as positively as possible.

7.4 Implications for health care professionals practice

In the United Kingdom older people represent the greatest users of health care provision (Department of Health, 2001). It follows therefore that all health and social care professionals should have an understanding of, and the skills to address, the challenges that this group of the population may experience. This includes an awareness of the potential impact of bereavement and widowhood. Investigation of the grief education content of pre-registration educational

programmes for health professionals by Breen et al (2013) suggested a narrow focus in each of the programmes examined; with attention given to either the stages approach to grief or grief as a social construction. Whilst both aspects are relevant to the future work of health professionals; the current study has demonstrated that the experience of grief has implications wider than these approaches might indicate. Understanding of signs and expressions of grief are pertinent if accompanied by an appreciation of the implications these might have for how life is lived following bereavement. Similarly an appreciation of social and cultural interpretations of grief are relevant if accompanied by an appreciation of the potential psychological and physical implications. A broad appreciation of the experience of bereavement and grief is proposed to be essential for health and social care professionals; a partial awareness may in fact pose a risk to the bereaved if issues linked to health and wellbeing are neglected.

Whilst preparation of qualified health and social care professionals for practice is of importance; the role of support staff in these fields is also significant. Support workers are likely to work with older people in the course of their work, and may spend more time with them than qualified health professionals allowing greater opportunities to build supportive, trusting relationships. An appreciation of the experience of bereavement and grief is therefore an important aspect of training and preparation for these roles. Currently training if provided is likely to focus on practical techniques relevant to their role, and health and safety issues such as moving and handling techniques. Attention to issues such as bereavement could also be given in order to prepare support staff for their interactions with people who have been bereaved.

Alongside an appreciation of the impact of bereavement is a need for health and social care staff to feel confident to address these issues with their patients and clients (Department of Health, 2001). For health care workers who have not experienced significant bereavement, knowing what to say and how to broach the subject can also be a cause of concern. A lack of experience or confidence in this area might lead to important issues being neglected or avoided completely to the detriment of the bereaved person with bereavement becoming the “elephant in the room” which everyone tries to ignore. Opportunity to talk about their feelings and how they are coping are important to people after bereavement and, as was identified by participants in the current study, they may fear broaching the topic themselves for fear of causing discomfort to others or risking becoming upset themselves.

An awareness of grief and its implications can help health and social care staff to better support those they work with who have been bereaved and facilitate access to more specialist support services if necessary. Moreover they would be equipped to maintain a watchful eye for signs of isolation or subsequent health issues; and provide encouragement to take steps to address these. Those who work with patients and clients in their homes may also be privy to, and with enhanced awareness, recognise signs indicating a lack of social contact and engagement with everyday

occupations. Similarly with an informed approach health and social care workers could provide reassurance that behaviours adopted subsequent to bereavement, such as continuing bonds with the deceased, are appropriate and not cause for concern (Worden, 2009).

7.5 Implications for professional practice of occupational therapists

As indicated in the first chapter of this thesis, occupational therapists rarely work specifically in bereavement support or intervention roles. Most will though at some point in their careers work with patients and clients who have experienced a bereavement or other significant loss.

The underpinning principle upon which the profession is based is the understanding that engagement in meaningful and purposeful occupations contributes to health and wellbeing (Christiansen et al, 2015). Findings from the current study suggest that the motivation to engage in occupations remains despite the loss of the spouse; but that challenges and constraints may preclude engagement. Occupational therapists are ideally skilled and equipped to support the development of strategies to facilitate re-engagement.

The Lifestyle Redesign® programme, the value of which was demonstrated by two randomised controlled trials, the Well Elderly study 1 and 2 (Jackson et al, 1998; Clark et al, 1997; Clark et al, 2012), is an intervention designed to support older people to develop skills and confidence to engage with personally meaningful occupations. Whilst the programmes reported do not focus specifically on widow/ers, the skills included in the programme would appear to reflect issues identified by participants in the current study. It is proposed that a similar programme adapted to specifically focus on issues identified by bereaved people would be of benefit and could be delivered within the remit of current occupational therapy services. It is acknowledged however that current health and social care services may not be appropriate organisations from which such services are offered. With the increasing recognition within the occupational therapy profession of the importance of developing emerging areas of practice in order to reach those who would benefit from occupational therapy (Cooper and Raine, 2009); interventions such as an adapted Lifestyle Redesign® programme could be offered through the voluntary sector by charities such as Age UK and CRUSE. The intervention delivered educational and practical skills training elements in a group format to older people. Broad topics covered in the programme, which was found to offer long-term benefits to the participants, included the importance of occupation; occupation and health in older age; personal safety; mobility and transportation; social relationships; managing finances; time use and energy conservation. These reflect issues identified by participants in the current study. The fact that the intervention is delivered in a group format serves to address the need for social support and connectedness for older people who are bereaved (Windle et al, 2011; Goll et al, 2015).

Caserta et al (2004) reported on a bereavement intervention programme for older widows and widowers. This involved the provision of information about a range of activities of daily living and community resources. The key difference between this and the Lifestyle Redesign programme was that the latter involved support to practice applying the skills discussed; whilst Caserta and colleagues provided information about the different topics and participants were required to implement them independently. Whilst this approach may be applicable to some; the loss of self-confidence identified by participants in the current study would suggest that a more involved approach to the delivery of such a programme might be more successful. Participants in the Caserta et al (2004) study were younger than those in the current study and in the Well Elderly studies; age too may play a part in the appropriateness of the two interventions; possibly younger people feel more able to independently research or implement adaptive strategies.

Participants in the current study were recruited with the help of two hospices and were all contacted by the bereavement service at the hospices three months after the death of their spouse. Although occupational therapists are employed by hospices to work with the palliative care teams to support patients cared for by the hospice; support to those bereaved does not generally feature in the remit of the occupational therapists role. This may be due to financial reasons with focus being on the patients cared for by the hospice. Nevertheless the skills of the hospice occupational therapist mean they are well placed to facilitate an extension of their remit in order to work with the spouses and next-of-kin of the deceased. The provision of individual or group interventions to address the challenges to engagement in occupations could be appropriately offered through the bereavement services provided by hospices. Occupational therapists accepted role of working with their clients in the community and in their own homes would also ensure access to support for those without the means to travel.

The potential development of the current role of occupational therapy to include working with bereaved people emphasises the need to review educational provision on grief and bereavement. As identified by Breen et al (2013) current provision tends to focus on palliative care and acknowledgement of the stages approach to grief. Some attention to broader issues of loss is also likely; this might include loss of role and loss of identity. As the findings from the current study indicate engagement in occupations following bereavement and loss have significant relevance to the role of occupational therapists. As such educational programmes must recognise this and prepare their graduates for these aspects of practice. Personal experience within an educational setting suggests that student occupational therapists embrace this understanding. They subsequently seek further support to develop their communication skills to enable them to translate this into practice, whether that be with bereaved clients and relatives, or in their work in other settings where clients have experienced loss. To ensure their work is evidence-based the recommendations in the following section for research into other forms of loss would be of value.

The current study identified a journey which participants made in their recovery of occupation. This involved a movement back to their previous occupations; and a period of taking stock of the changes which had occurred; before adaptation to occupations and routines enabled a revision of occupations and facilitated moving forwards. This understanding bears consideration by occupational therapists in their work with clients; and emphasises the need for further research into whether this journey is experienced following other forms of loss. Anecdotal evidence indicates a return to occupation following loss might follow a similar pathway. The Paralympian Martine Wright spoke of how after losing her lower limbs during the 7/7 London bombings she returned to her previous employment but realised that her loss had prompted changes that meant she needed to review her situation, and employment, and ultimately led to her engaging in sitting volleyball and captaining the British Paralympic team (White, 2013).

7.6 Implications for future research

This section will consider issues for further investigation and research which have been indicated by this study and the findings. These have been organised under three areas of focus – occupation and continuing bonds; the model of *recovering occupation* following spousal bereavement; other forms of loss and bereavement.

7.6.1 Occupation and continuing bonds

This study identified the use of occupation as a form of continuing bond by participants. This appeared to provide a form of symbolic support which enabled the participants to engage with daily routines and complete necessary activities of daily living. Adoption of this form of ongoing bond perhaps deferred the necessity to make decisions about changes to routines during the initial period of time after bereavement; these appeared to follow and be undertaken on a gradual basis. The use of occupations as continuing bonds with the deceased is proposed as an area worthy of further investigation. Exploration of the role that such bonds may have in relation to adaptation following bereavement and potential involvement in revision of identity, and more specifically occupational identity would also be of relevance.

7.6.2 Model of recovering occupation

The findings drawn from the current study suggest a fluid process of recovering occupation involving first a movement back, or *retreat* to, the security offered by the routines and occupations from the past before bereavement occurred. This appears to be followed by a period of taking stock of the new situation, during which the older widow/er spends time reviewing the changes which have occurred and the impact of these on everyday life and the occupations which comprise daily life. This is the first time this process has been documented in this way and warrants further investigation. Aspects such as the decision making process which leads to

changes being made would benefit from further investigation. Study of the process of revision of occupational identity which occurs following bereavement and loss may help to further understanding of the role that occupation may play in adaptation.

7.6.3 Alternative forms of loss and bereavement

The model of recovering occupation was constructed from the data provided by participants aged 65 years and over who had been recently spousally bereaved. Further study to assist in the development of the model; and indicate its relevance and application to experiences following other kinds of loss would be appropriate. Application of the model to children and younger adults who experience bereavement would therefore be of interest and value in relation to understanding their experience; the role that occupation might play at different points in human development; and support the development of appropriate interventions to address difficulties associated with grief such as prolonged grief disorder (Prigerson et al, 2009; Jordan and Litz, 2014). Similarly investigation of loss in different kinds of relationships such as sibling and parental bereavement would also reap benefits for those who experience such losses. The role and experience of occupation in other forms of loss; including health-related loss such as amputation (Zarnegar, 2015) and severe mental illness (Wittman and Keshavan, 2007); and social losses such as loss of employment (Vickers, 2009) would also be of value for occupational therapists and other health and social care professionals who work with and support people who have these experiences.

7.7 Limitations of the study

The study adopted a phenomenological approach appropriate to the intention to explore the lived experience of engagement in occupations during the first year of widowhood. This has been discussed in detail in chapter three (Methodology) and chapter 4 (Study design and data analysis). The adoption of a longitudinal approach provided a unique opportunity to gain an understanding of participants' interpretations of their experiences and how these evolved across the year of the data collection period. It is claimed therefore that utilisation of a phenomenological methodology and a longitudinal approach provided an appropriate means to address the identified research question. Two issues have however been identified as potential limitations to the study. The first being the length of time to completion of the project; the second relating to the specificity of the participant group.

7.7.1 Duration of the project

This study collected data across two time points for the participants; the first being 3-4 months and the second at thirteen months after their spouse died. Recruitment involved a rolling schedule of posting the study information to potential participants at four time points over a 3.5

month period; this was designed to stagger the timing of the first interviews. This resulted in data collection taking approximately fifteen months due to the avoidance of the Christmas period in order to avoid causing distress to applicants. Even so as a part time student who works full time in Education this did not provide sufficient time to transcribe and analyse all of the data collected before commencing the second interviews. Later constraints on time available deferred the completion date further. Nevertheless it is argued that these unavoidable delays did not detract from the findings and in fact allowed for additional time for consideration and development of these with further returns to the data. The study presented remains an original investigation; and the findings presented indicate novel understandings of the participants' experiences of occupation during the first year of widowhood which remain relevant.

7.7.2 Participant group

A purposive sampling approach (Cresswell, 2007; Flick, 2014) was taken to recruitment with the aim to recruit older people who had experienced spousal bereavement. In order to ensure participants had a similar experience recruitment was made from two hospices and specific inclusion and exclusion criteria applied. No claims have been made that the findings presented reflect the experience of all older people who are spousally bereaved or for people bereaved by other means. Whilst this may make application of the findings very specific; the findings do provide interesting phenomena for further investigation with other groups. In this way the study can be claimed to have achieved one of the aims of qualitative research; through the use of inductive methods novel experiences can be constructed which provide avenues for further exploration and verification to ascertain potential transferability (Patton, 2002).

7.8 Reflexivity and reflection on the research experience

The final section of this chapter considers the concepts of reflection and reflexivity and the impact of engaging both practices in the completion of this research project. Finlay and Gough (2003) describe reflexivity as a critical, on-going self-awareness that the researcher brings to the research allowing them to recognise and understand the impact of their personal experiences and identity. Reflexivity differs from reflection, which requires retrospective consideration of events, demanding a more immediate and dynamic attention to the research process. Various forms have been described including reflexivity as a form of self-critique to facilitate the researcher in recognising their part in the construction of the data (Finlay and Gough, 2003). Finlay (2003) proposes that as well as those experiences and understandings of the researcher which contribute to the research; reflexivity also relates to how the understandings and beliefs of the researcher are changed by the research process. In this way reflexivity relates to epistemology; how the researcher positions themselves within the research situation; and how they understand

the experiences which have influenced their individual understanding of the world (Finlay and Gough, 2003). These issues bear particular importance in interpretive research endeavours where the researcher has a responsibility to construct an interpretation of their participants' actions and behaviours.

It is argued that no research can remain completely objective. Every researcher brings personal and individual influences and experiences to their work and these will have influence on all aspects of the study from early motivations, to design, data collection and analysis (Finlay, 2002). Mulhall (1996, page 31) in his critique of Heidegger's philosophy of scientific enquiry argued it "is not that beginning an enquiry is impossible, but that it cannot be presuppositionless; accordingly, presuppositions ought not to be eschewed, but rather acknowledged and used to best effect". Whilst Heideggerian approaches to research do not promote the use of bracketing; recognition of the relevance and impact of personal experiences and views is understood to be integral to the research process. These have been integrated into the thesis; in the introductory chapter where my professional practice experience is explained; and later in chapter three regarding the selection and justification for the methodological approach adopted.

McKay et al (2003) describe reflection and reflexivity as different but closely related and argue that it is depth of analysis which differentiates between the two. Whilst reflection on an experience can provide understanding; it is a deeper more analytic and reflexive approach which provokes the development of insights. These in turn lead to greater understanding of the individual and their personal understandings, values and beliefs. A research journal was maintained throughout the research process as a means to capture and explore issues which arose (Finlay and Gough, 2003). The act of maintaining a journal could be argued to be a demonstration of the links between reflection and reflexivity. The act of identifying and writing about an experience undertaken retrospectively provoked illumination and analysis of underlying pre-understandings which had led to their development. The insights drawn from this process would in turn influence subsequent interactions with participants. This process reflects the iterative nature of the hermeneutic circle where pre-understandings are supplanted by new understandings which contribute to the interpretation of new experiences. The following sections provide illustration of some of the experiences examined in this way; these relate to epistemological and methodological perspectives; and the experience of the researcher role.

7.8.1 Epistemological and methodological considerations

As a novice researcher I commenced doctoral study after 17 years' experience working as an occupational therapist in mental health and learning disability settings; and 3 years working in Education. In my professional practice I had always attempted to maintain a client-centred

approach to my work (Rogers, 1995). I had developed an open, non-structured style of interacting with clients in order to ensure those I worked with were able to disclose, and focus on what felt important to them rather than imposing my own expectations and assumptions regarding what difficulties they may be experiencing. I was concerned that this approach to interviewing in a research context might result in the collection of an assortment of unrelated data. To try to ensure relevant data I developed a detailed interview schedule with prompts designed to ensure what I deemed to be important and relevant issues were covered. I held this conception alongside an intellectual understanding that direct questions and prompts could be construed as over-directing the data collection and imposing my own understandings and interpretations.

During the interviews however I did not refer to the schedule; reverting instead to a more familiar, open and conversational style of interviewing; for the two-fold reason of putting the participants at ease and to attempt to share control of the interview and the material discussed (Brinkmann and Kvale, 2015; Wolgemuth et al, 2015). During the first interview with each participant they chose to tell me about their spouse's death; often recounting the last days and hours leading to the moment of death. Although I had some concern that this was not what I was seeking to learn; during the first interviews I came to rationalise that it was important for the participant to tell me this information. Whatever strategy I attempted to not lead to this information being shared, the information was still prioritised and I came to realise that from the participant's perspective they needed to tell this information because it was the beginning of their story and the point from which their life as a widow or widower began. As Janesick (2011) claims it is necessary for the researcher to enter and engage with the participants' world. For some too it was a cathartic act (Wolgemuth et al, 2015); I was the first person with whom they had shared their experience. My expectations had been based on my previous experiences as a therapist and I anticipated the research experience to be different and have a more specific focus. I had expected their story to be about participating in occupations in widowhood; whilst their stories were about becoming a widow or widower. Being able to allow the stories to unfold in their own way has hopefully provided a far greater insight into the impact of widowhood on occupation than a more structured approach might have done.

With this insight I felt I gained an experiential understanding of qualitative research; and the relevance and nature of an interpretivist paradigm involving such a challenging experience as spousal bereavement. With this came a renewed sense of responsibility towards the participants' vulnerability at that time; and self-awareness of my previous understandings during the construction of interpretations of the data during later analysis. It might be argued that this circuitous process reflects the hermeneutic circle whereby as new insights were developed I was able to consider these in light of my previous experiences.

7.8.2 Researcher considerations

In positioning myself within the research it became apparent early on that my background as an occupational therapist has equipped me with some understanding of the concept and role of occupation for individuals. Alongside this I maintain a fascination with how individuals organise their lives and the meanings these hold for them. I view the concept of occupation as a potentially positive one, offering psychological and physical benefits whilst acknowledging that this is not always true, particularly in situations where people are denied choice and opportunity. These understandings were challenged during the first interviews when it became apparent that some participants did not understand or share this view; and consequently why it should be of interest to others. Although several spontaneously acknowledged that they believed it to be important to remain active and busy, and felt time spent with nothing constructive to do was wasted time; several expressed concern that what they were telling me was not really what I wanted to hear or that they did not really understand what I wanted to hear. Recognition of their confusion and the impact of my own views allowed me to enhance the explanations I gave to subsequent participants prior to commencing each interview. At the same time I grew more conscious of the importance of the language I used so as to avoid influencing their interpretations. Again this iterative approach reflects the hermeneutic circle; by developing an interpretation of what was occurring during the interviews I had cause to return to my earlier professional understandings and to reinterpret these before returning to the participants and the interview experience.

Similarly I grappled with the issue of how to explain my role and interest in this topic to the participants. I reasoned that they may have had experience of occupational therapy themselves or during their spouse's illness and I did not want these to influence their responses during interview. Ultimately most gave no indication that they considered these of any relevance and I concluded that I remained simply "a researcher" to them. For those who asked me, I had decided to be honest and to explain my background as a health professional, and more specifically an occupational therapist. I reasoned that this was an appropriate response in order to try to maintain a balance of control and power in our relationship; if I wished the participants to disclose personal information to me I should be prepared to reciprocate if asked.

At times during the interviews with participants I experienced role conflict between my current role as a researcher and my previous role as a therapist. I was prepared for participants to become distressed during the interviews but had not so clearly anticipated my reaction to this. I became aware of the urge to step into the therapist role at times both when participants were distressed and when they asked questions regarding their experience. The effort to resist it was frustrating but to change roles would have created further role conflict and potentially created changes in the balance of power I worked to create (Brinkmann and Kvale, 2015). Whilst

Brinkmann and Kvale (2015) propose that the researcher maintains a position of power and a research interview can rarely be seen as reflecting an equal balance; I aspired to the aim of situating the participants in the position of expert; and aimed to create an impression of myself as an interested but inexperienced witness. Had I stepped into the therapist role to offer support or respond to their requests for information or advice these roles may have reversed. Instead it was important to sit with the frustration; a position in which I came to see myself as a “handcuffed therapist”. Reflection on this image and questioning why “handcuffed” and not “gagged” led to acknowledgement that the therapist role encompasses more than words and reflects the whole therapeutic relationship; a relationship which differs significantly to that between the researcher and participant.

My presumption that experience of occupational therapy might influence participants’ responses to the interview was proved inaccurate on one occasion. One participant, who had not asked me about my background, made a spontaneous comment during the interview about an occupational therapist who had visited his wife when she was discharged from hospital. The encounter had not been positive and he expressed his frustration about it. As he related this story I found myself feeling conflicted between appreciating his reaction to the episode and feeling frustrated that a “colleague” might have unwittingly been insensitive to this gentleman and his wife; whilst at the same time recognising her clinical reasoning. This experience illustrates the relationship between reflexivity and reflection. My immediate reaction to the story caused an almost physical response of frustration at both the occupational therapist for causing the participant distress; and embarrassment on her behalf that she had unthinkingly caused him to feel this way. My reflexive response required that I processed this as an occupational therapist and “returned” to the interview as a researcher. My reflection on this event was retrospective after the conclusion of the interview. Together these two responses enabled me to better understand both the distinctions between roles of practitioner and researcher; and the importance of attending to the balance of power within the research process.

7.9 Overall summary of the thesis

This thesis has presented the process undertaken to complete this study which aimed to explore the lived experience of engaging in occupations by older people during the first year of widowhood. Recruitment was completed with the help of two hospices which had cared for the participants’ spouses. The study adopted a Heideggerian interpretive phenomenological methodology. A longitudinal approach provided opportunity to collect data across the first 13 months after the death of the participants’ spouses; participants were interviewed for the first time approximately three months after their spouse died; and again thirteen months after their

bereavement. This allowed a unique opportunity to develop an understanding of the participants' experiences as they re-engaged with a range of occupations across the year. These included routine occupations necessary to maintain the self and the home; social and leisure occupations.

The thesis is presented in sequential order to reflect the research process and how it was undertaken in the completion of this study. Chapter one introduced the background to the study; the justification and rationale for the need to investigate this topic and the research question, aim and anticipated outcomes which underpinned the study. This chapter also provided contextual background information about the researcher's previous professional experience. Chapter two provided further contextual information regarding explanation and discussion of the concept of occupation; and of the evolution of bereavement theory. The chapter concluded with a scoping review of the small body of published research relating to occupation and bereavement. Chapter three explained the epistemology, ontology, methodology and method which together formed the structure and philosophical approach to the study. This chapter also included discussion of specific strategies adopted to provide a measure of the quality of the study. Chapter four explained the study design and how it was executed including the preparations undertaken prior to data collection; the data collection process; and data analysis. Data analysis followed the hermeneutic circle and this was illustrated using illustrations of the processes undertaken.

Chapter five presented and explained the findings developed from data analysis. Quotations taken from both sets of interviews with the participants were included to illustrate the three themes and the superordinate theme identified. These were discussed in relation to current research and theory in chapter six. The final chapter, seven, has identified the potential implications of the findings from the study in relation to policy, health and social care practice and the profession and practice of occupational therapy. Areas identified for further investigation have been identified and limitations of the current study identified. The chapter concludes with a discussion of reflexivity and reflection and how these activities were integral to the research process.

A model of recovering occupation following spousal bereavement in older age has been developed. This reflects the journey which the participants appeared to undertake as they resumed participation in the occupations which provided meaning to their day-to-day lives during the first year as a widow or widower. The journey involves a return, or retreat, to familiar occupations which are undertaken with intrapersonal and interpersonal support. The former provided symbolically through continuing bonds with the deceased spouse; the latter offered by close family and friends. A unique form of continuing bond involving the previous occupations and routines shared with the spouse was identified. Over time as confidence returns adaptation of

occupations and a revision of the occupational repertoire and occupational identity occurs which facilitate re-engagement. A consequence of ageing was seen in the potential constraints to re-engagement and these are considered.

The study was undertaken on the basis of the understanding of the intrinsic link between occupation and health and wellbeing. In considering the findings from the study and their potential implications; attention to the role that continued engagement in occupations in later years might play in alleviating the likely social and financial impact of the growth in the older population is proposed.

Appendices

Appendix A Scoping review of literature on occupation and bereavement

Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Breen L, Fernandez M, O'Connor M, Pember A	2013	Australia	Document review; face-to-face & telephone interviews	n/a	Staff (9) & students (20) from 6 health professions programmes at 5 universities	To investigate how and where bereavement, grief & loss are covered in health professions programmes.	Qualitative; multiple case study	n/a	For OT: curricula primarily covered end-of-life care. Focus on psychological and psychiatric impact of bereavement, not on sociological aspects. Stages approach to grief covered.
Brewer J, Sparkes A,	2011	UK	Participant observation, interviews, critical friend, reflexive research journal	1 year, including 3 specialist weekends and key social events e.g. Christmas	13 participants; 4 recently bereaved; 9 bereaved 10yrs after attendance at camp	To give voice to bereaved young people to allow them to explain the meanings they attributed to outdoor physical activity	Qualitative, ethnography	n/a	Four sub-themes identified: sense of freedom; distraction/escapism; retaining memories; and family cohesion

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Caserta M, Lund D, O Bray S	2004	USA	Programmes covered: managing personal health; stress management; managing finances; understanding grief; medication management; exercise & physical activity; accessing community services; nutrition; home management; social functioning; personal growth.	11 weekly 2 hour sessions for widowed participants. Five programme ran for the study. 82% attendance rate.	84 older widow/ers (age >50 yrs); median length of time since death of spouse – 12/12 (17% >2 yrs; 79% <18/12). Average 17 participants per programme.	To describe changes in self-care & daily living abilities to meet the challenges of widowed life as a result of the programme.	Quantitative; statistical analysis	Evaluation (self-administered questionnaire): pre; post; 2 and 4 month follow-up	Improvements identified in active coping, household management and home safety. Increased sense of self-efficacy identified. Increased social interaction & engagement with community resources

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Creed J, Ruffin J, Ward M	2001	South Carolina USA	Evaluation of a camp for bereaved siblings	Weekend camp; postal survey follow-up with parents and staff	19 children aged 6-15 years; 12 (of 17) parents & 7 (of 10) staff completed evaluation	To review the impact of a weekend camp for bereaved siblings	Mixed methods evaluation – descriptive statistics from survey & qualitative review	Written evaluation of camp experience (children, parents and staff)	Campers - creative (art) activities were rated most highly; social activities least effective. Recognition that support from others can be beneficial was rated highly. Parents rated that opportunity to acknowledge grief; and recognition of not being alone were rated highest. Staff rated art activities, memory books; focus on feelings and interaction with others as most beneficial

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Fitzpatrick T, Spiro A, Kressin N, Greene E, Bossé R	2001	Massachusetts, USA	Part of a longitudinal study of aging men. Participants completed the SF-36 (perceived physical & mental health); HSB (leisure activities); ELSI (stress) + 2 control variables (age & employment status)	n/a	799 older men: 373 bereaved; 426 non-bereaved	Do leisure activities buffer the effect of stress (other than bereavement) on health among a group of bereaved men & a group of non-bereaved elderly men? Does this buffering effect differ between the bereaved & non-bereaved?	Quantitative, inferential statistics	n/a	Leisure activities moderate stress (non-bereavement stress) on physical health; moderating effect of leisure activities on mental health was not demonstrated. Social activities exerted a significant moderating negative effect on stress predicting physical health for bereaved men.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Fluegeman J, Schrauben A, Cleghorn S	2013	Midwest, USA	2 focus groups with children (10) & interviews with camp staff (4); demographic questionnaire	ns	10 bereaved children aged 6-17 years	How do camp activities & relationships formed at camp impact on bereavement? Is there a role for OT in community based bereavement programmes?	Mixed methods	n/a	3 themes: environment; flexibility; personal realisation. Reduction in children's sense of isolation. Development of coping mechanisms. Recognition by children that seeking support was beneficial. Activities facilitated emotional expression.
Forhan M	2010	Canada	Diary entries recorded from 1 day – 1 year after birth of still born son	1 year	1 female (author)	To describe the meanings attached to the experience of grief in the context of participation in occupations.	Qualitative, auto-ethnography	n/a	Describes 4 transitions: The journey begins; The reality of the loss; Moving forward; Resumption.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Hasselkus B	1993	USA	Exploration & discussion of occupations during the last days of author's mothers life	1 week	1 female (author)	To describe a personal experience of caregiving and occupation during the final days of life.	Qualitative, auto-ethnography	n/a	Discussion of concept of presencing; connecting
Hoppes S	2005a	USA	Narrative account	n/a	1 male (author)	To develop a narrative to examine engagement in familial social participation & caring.	Qualitative, auto-ethnography	n/a	Discusses meaning and purposes of family social participation & caregiving during the period when a relative is dying.
Hoppes S	2005b	USA	Narrative account on role of occupations when a relative dies.	n/s	1 male (author)	To explore the role and course of occupation during a period in which a relative was taken ill and died.	Qualitative, auto-ethnography	n/a	Identified 4 stages: occupational maintenance/dissolution/ambivalence/restoration & adaptation.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Hoppes S, Segal R	2010	USA	Semi-structured interviews; approx. duration 1 hr	n/a	17 women; 14 men; 25-69 years; range of losses	To identify, describe & illustrate 3 occupational responses to bereavement	Qualitative	n/a	Descriptions of occupational accommodation / assimilation & continuing bonds in relation to occupation
Hurst J	1998	UK	Opinion piece	n/a	n/a	Review of the loss & bereavement experience of people with learning disabilities	n/a	n/a	Discusses experiences and expressions of grief in LD; approaches to support.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Ilott I	1996	UK	Report on evaluation of a module on loss in an OT educational programme	6-week educational module	25 in-service OT students	Why is loss afforded scant attention in OT / OT literature? Is this due to denial; consideration that it is of peripheral relevance or because it is seen as so implicit it is taken for granted?	Module evaluation – small number of descriptive statistics reported.	Module discussion & evaluation; follow-up postal survey after graduation. Students also completed a critical diary of their experience of the module but this was not used in the evaluation.	Module evaluation indicated both recognition that the content was difficult and challenging but also that it was necessary. Follow-up survey indicated the relevance of loss to professional practice.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Ilott I	2006	UK	Critical reflection on personal experience	n/a	1 female (author)	To explore the relevance of objects and to review their role in coping with the loss of a parent	Qualitative; reflective narrative	n/a	Describes personal experience of commissioning the transformation of possessions into "living legacies." Process and outcome is reported to provide a coping strategy for loss.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Kang H, Yoo Y	2007	Korea	Intervention study to explore benefits of dan-jeon breathing technique; self-help group aimed at increasing awareness and management of grief; a health assessment.	10 weekly sessions of 2 hours – 60 mins dan-jeon; 60 mins self-help group.	17 women in the experimental group; 10 participants in the control group. Participants chose which group they wished to join. All were aged 35-64 years and spousally-bereaved.	To develop an intervention to reduce grief levels, stress and immune responses of bereaved middle-aged women.	Quantitative; inferential statistical analysis.	All participants were assessed for levels of grief, symptoms of stress and immune response pre- and post-intervention.	Reductions in levels of grief and stress symptoms were identified in the experimental group.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
McClatchey I, Wimmer S	2012	USA	Semi-structured interviews 3-9 months after participation in a weekend bereavement camp; or a workshop for parents/guardians.	Weekend camp / 1-day workshop. Interviews took place 3 or 9/12 after participation.	32 interviews involving 13 families: 19 bereaved children aged 8-18 yrs; 13 parents/guardians	To examine what elements of the bereavement camp were most helpful to participants.	Qualitative, phenomenological study; follow-up to a quantitative, controlled study	n/a	Two themes identified based on therapeutic interventions (counselling sessions, seen as most healing part of camp; memorial service; balloon release & journaling) and traditional camp activities (most healing being connecting with others; canoeing; talent show).
McIntyre G, Howie L	2002	Sweden	3 x interviews	n/a	1 elderly widow	To explore & interpret adaptation to widowhood through engagement in occupation	Qualitative, case study	n/a	3 themes: doing in widowhood; social relationships in widowhood; occupational adaptation to widowhood.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Mattock S, McIntyre A	2016	UK	Semi-structured interviews	1 interview per participant	9 older people widowed 15 years	To explore role of spouse-carers experience of caring and transition to “post-care” & occupations during this period	Qualitative; IPA	n/a	4 themes identified: Continuity; Roles & occupations; Support; Change & transition
Miliken B, Goodman G, Bazyk S, Flinn S	2007	Ohio, USA	Postal survey	n/a	56 school-based OTs	To identify the incidence of children with grief issues seen by school-based OTs, and how these are addressed by OTs in schools (grief was understood broadly to encompass all potential “loss” issues).	Quantitative, descriptive statistics and thematic analysis of survey data	n/a	Majority of school based OTs worked with children with grief issues which impacted on their ability to study and to engage in study. Majority felt grief was better managed by team members more readily available. OTs lack confidence to address these issues.

Appendix A Scoping review of literature on occupation and bereavement

Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Nyman A, Josephsson S, Isaksson G	2014	Sweden	Interviews, participant observation	2 phases – 6/12 in 2009-2010; 2 further contacts in 2012	1 older widow	To explore how agency is enacted in occupations with others and evolves over time	Qualitative, narrative & transactional approach & analysis	n/a	Agency identified to be negotiated and socially constructed
Oakley F, Khin N, Parks R, Bauer L, Sunderland T	2002	Maryland, USA	Pilot study, small RCT; part of a longer, 13/12 study	8/52	10 older, depressed, bereaved people (<3/12)	To test ADL function & to evaluate the effect of anti-depressant medication on ADL performance	Quantitative	Assessment of Motor & Process Skills	All 10 participants responded to anti-depressant medication; ADL performance was reported to have improved.
Okoneski D	1991	USA	Discussion paper	n/a	n/a	Overview of experiences of grief for gay people	n/a	n/a	Considers gay grief; implications of HIV / AIDS deaths (paper was published during early days of understanding of HIV; includes a personal account.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Pickens N, O'Reilly K, Sharp K	2010	USA	Participant observations; semi-structured interviews; group interview with staff members; document & artefact review	3 months	5 hospice patients & their family caregivers ; 25 staff members	What are the occupations of family caregivers in end-of-life care?	Qualitative, ethnography	n/a	Two themes: Holding onto normalcy; Overshadowed needs of caregivers. Also identified the uncertainty for caregivers associated with dying.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Scaletti R, Hocking C	2010	New Zealand	Use of narrative, storied approach to support children's bereavement – creative occupation, group work & story telling	ns	NA – paper is a descriptive account of working with traumatised children; case study child based on author's professional practice experience	To provide a descriptive account of the use of a storied approach to working with children	Descriptive case study (not empirical paper)	Proposed measurement of behaviours	Storytelling is a valid intervention with bereaved children. Repeated telling of their story helps children to make sense of and integrate their experience & feelings.
Stewart S	1997	UK	Opinion piece	n/a	n/a	Review of loneliness, loss and grief in old age	n/a	n/a	Discusses loss; loneliness, grief & depression; recognition of the role of autonomy in coping.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Thibeault R	1997	Canada	Critical reflection on personal grief	n/s	1 female (author)	What is different, if anything, in a bereaved counsellor? How does the experience of being a therapist affect the adaptive responses to loss?	n/a	n/a	Reflection on how the professional principles of practice are adapted to meet individual (client) need rather than applied like a template.

Appendix A Scoping review of literature on occupation and bereavement

Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Utz R, Carr D, Nesse R, Wortman C	2002	Detroit, USA	Analysis of longitudinal data collected for the CLOC (Changing Lives of Older Couples) study. Measures of formal & informal social participation completed. Demographic data collected re income, children, transportation , income, race, education.	Data collected pre-widowhood; participants completed a baseline interview and then further data collected 6, 18 and 48/12 after the death of their spouse. Participants were matched with non-widowed controlled participants.	297 older adults (217 women; 80 men); (210 widowed people; 87 non-widowed)	To explore how older adults alter everyday social participation following widowhood & whether theoretical explanations from social gerontology are useful in explaining changes.	Quantitative, statistical analysis of longitudinal data collected as part of a larger study	n/a	Widows showed an increase in informal social participation; formal social participation remained constant before & after widowhood. Social participation identified as a coping strategy. Desire for continuity in participation recognised. Widowhood is a process not an event. Widowhood status involves more than 1 person (in terms of providing support). Participation in widowhood can be dependent on economic, intellectual and interpersonal resources.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Utz R, Reidy E, Carr D, Nesse R, Wortman C	2004	Detroit, USA	Used data from the Changing lives of Older Couples study. Participants were interviewed before the death of spouse & 6/12 after death of spouse.	In total 9-76/12 (dependent on when spouse died); 06/87 – 04/88	288 participants, 65 yrs+. 202 widowed people (145 women); 86 matched controls (65 women).	3 hypotheses: 1. Late-life widowhood will increase hrs of housework for men & decrease for women. 2. Dependence on children for housework will reduce hrs spent on housework for men & women. 3. Dependence on children will partially explain hypothesised gender differences in how much housework is performed	Quantitative, inferential statistics	n/a	Hypothesis 1 was partially supported – men do more housework; effect for women was not supported. Widow/ers who receive support from adult children do less housework. Widowed mothers receive more support from adult children; children appear to provide more support to mothers than fathers.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Utz R, Lund D, Caserta M, Devries B	2011	USA	Part of “Living After Loss” project which explored the efficacy of a group intervention that derived from the Dual Process Model of Coping. This paper used results from the pre-test, baseline assessments. P’s completed the Perceived Self-Care & Daily Living Competencies Scale.	Intervention was 14/52. Recruitment took place: 02/05-04/08.	328 recently bereaved people (2-6 months), aged 50+	To what extent do recently bereaved persons report self-competency in routine activities; what factors were associated with higher and lower perceptions of competency? Do perceived competency levels differ among widow/ers? Was perceived self-competency associated with higher or lower bereavement-related outcomes?	Quantitative, inferential statistics	n/a	Participants with more personal resources (income, good health, higher education levels) were most competent in daily life tasks. Higher competency was associated with better mental health. Gender differences in perceived competence were evident in types of activities.

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Author	Year of publication	Study location	Intervention / data collection method	Duration of intervention /study	Population	Study aims / aims of paper	Methodology	Outcome measures	Key results
Vale-Taylor P	2009	UK	Study explored post-funeral remembrance activities & rituals. Participants given option to complete a questionnaire or take part in an interview. Bereavement counsellors participated in a focus group.	Questionnaire contained 24 rituals & asked which the participant had carried out; & ratings of importance & significance; semi-structured interviews explored why they had chosen their rituals and how helpful they had been. Focus group about clients' experience remembrance rituals.	43 participants bereaved 12-24/12 – 25 completed questionnaire; 18 were interviewed; 6 bereavement counsellors took part in a focus group.	To explore which post-funeral remembrance activities are most significant and important to the bereaved and why.	Mixed method study – self-report questionnaire (descriptive statistics); semi-structured interviews thematic analysis); focus group (n/s).	n/a	4 categories of ritual identified: rituals for the deceased; rituals with a direct link to the deceased; rituals & community; rituals undertaken as an Act of Remembrance. Befriending identified as preferable to counselling in bereavement. Informal rituals are preferable as they reflect everyday life.

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

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Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Was there a clear statement of the aims of the research?	Yes, to explore bereaved young people's personal meanings of outdoor physical activity.	Yes, to investigate how and where bereavement , grief & loss are covered in health professions programmes. "To what extent does current education & training of health professionals prepare them to work with bereaved clients/patients?"	Yes, three questions identified: How do the camp activities impact the bereavement process among campers? How do relationships formed at camp impact the bereavement process? Is there a role for OT in community based bereavement programmes such as camp?	Yes, not structured as an aim or research question but purpose of the paper and the "study" is explained	Yes, to describe the author's personal experience of occupation whilst caring for her dying mother	Yes, not structured as an aim or research question but purpose of the paper and the "study" is explained	No	Yes, to identify, describe & illustrate 3 occupational responses after a family bereavement : occupational accommodation/assimilation & continuing bonds	Yes, to explore the relevance of objects and to review their role in coping with the loss of a parent

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Is a qualitative methodology appropriate?	Yes, ethnography	Yes, diverse programme examined; student & tutors experiences incorporated	Paper describes it as a mixed methods study; quantitative component involved a demographic questionnaire	Yes, auto-ethnography	Yes, auto-ethnography	Yes, auto-ethnography	Yes, auto-ethnography	Yes, the study aimed to explore participants' experiences	Not a research study, is presented as a critical reflection on experience
Was the research design appropriate to address the aims of the research?	Participant observation over a 2 year period	Yes, semi-structured interviews & document review	Yes, semi-structured interviews & focus groups + demographic questionnaire	Yes, self-narrative, review of artefacts, discussions & reflection	Yes, reflective, narrative account	Yes, explains auto-ethnography . Refers to diary notes, reflection, discussion with others involved in the situation explored	Yes, explains auto-ethnography . Refers to diary notes, reflection, discussion with others involved in the situation explored	Yes, semi-structured interviews	Yes, reflective, narrative account

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Was the recruitment strategy appropriate to the aims of the research?	Purposeful sampling used to recruit young people aged 9-15 (2 male; 2 female) recently bereaved and those who had been bereaved 10 years earlier aged 15-25 (5 females; 4 males). Ages at bereavement : 3-12 yrs.	Recruitment of staff and students sent via course coordinator, was explained & appropriate. Decision regarding which University to study was not explained but was the workplace of three of the authors	Yes, participants for focus groups (children) were randomly selected on the 1 st day of camp from completed parental consent forms. Staff were invited to participate in interviews; random selection was made from consent forms	n/a	n/a	n/a	n/a	Initial participants were known to the first author; snowballing used to recruit further participants. All had experienced a family bereavement (brief details of these are explained)	n/a

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Were the data collected in a way that addressed the research issue?	Participant observations were supplemented with informal interviews during activity, semi-structured interviews and photographic and video footage of key events	Yes, although for students relied on recall as only final year students were included.	Yes, semi structured interview schedule was developed by the researchers with relevant professional support and quality measures undertaken	Yes; diary notes & reflections	Yes, reflection on personal experience	Yes, "data" were collected in ways pertinent to auto-ethnography	"Data" collection based on recall	Yes, semi-structured interviews; interview schedule explained	Yes, reflection on personal experience

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Has the relationship between researcher and participants been adequately considered?	Researcher was involved in the organisation where data was collected but not known to participants before the study	Not discussed	Not discussed – not made clear whether the researchers were part of camp staff	n/a	n/a	n/a	n/a	Some participants were known to the first author who also carried out the interviews. ²ⁿ ^d author was not involved until after the initial analysis	n/a
Have ethical issues been taken into consideration?	University ethical approval gained prior to data collection	Description of ethical approval included (University ethics committee)	Description of ethical approval included (University ethics committee)	Not discussed – as an auto-ethnography y the author “controls” what is written	Not discussed – as an auto-ethnography the author “controls” what is written	Not discussed – as an auto-ethnography the author “controls” what is written	Not discussed – as an auto-ethnography the author “controls” what is written	Not discussed	Not discussed; as a personal reflection the author “controls” what is written

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Was the data analysis sufficiently rigorous?	Thematic analysis described	Very clearly described. Prog. data recorded on a matrix table. Interview data was transcribed and analysed thematically. Clear description of how this was done and team members roles	Yes, description of thematic analysis undertaken was included in the paper	Not clearly explained how key stages identified emerged; refers to reflection	Not clearly explained but refers to reflection on experience	Not clearly explained how findings were identified other than by reflection on experience	Analysis involved narrative writing, discussion with others involved & colleagues. Not clearly explained how issues were identified as key to the experience	Process of data analysis was explained' second author verified and refined initial analysis. This role was swapped between both authors. Member checking was employed	Not discussed - n/a

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
Is there a clear statement of findings?	Yes, 5 themes identified and explained using lengthy extracts from the data: physical activity, sense of freedom; distraction / escapism; retaining memories; family cohesion	Yes, each programme is discussed separately and then in relation to policy, practice & research	Yes, each research question is considered separately and supported by the findings	Yes, discusses four transitions identified and links these with literature	Yes, discusses personal experience in relation to professional practice & being an OT. Discussion of “presencing”	Yes, focus on 2 aspects (caregiving & family social participation) are explored; relates experience to occupation	Yes, 4 phases identified: occupational maintenance /dissolution/ ambivalence /restoration & adaptation	Yes, these are discussed using extracts from the data	Yes, discusses personal experience of commissioning the transformation of possessions into “living legacies.” Process and outcome is reported to provide a coping strategy for loss.

Appendix B Critical Appraisal of Selected Qualitative Papers 1 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	Brewer & Sparkes, 2011	Breen et al, 2013	Fluegeman et al, 2013	Forhan, 2010	Hasselkus, 1993	Hoppes, 2005a	Hoppes, 2005b	Hoppes & Segal, 2010	Ilott, 2006
How valuable is the research?	Provides a compelling account of the role of physical activity as experienced by bereaved young people	Identifies relevant issues regarding the need for reappraisal of how grief education is delivered	Acknowledgement of small scale of study but findings are comprehensively discussed and applied to OT practice and aspects of child development	Provides a unique account of the authors experience and links these to occupation and research on bereavement	Unique account of the authors experience of caring for a dying person	Unique account of the authors experience; links to occupational engagement made.	Unique account of the authors experience and links these to occupation and bereavement theory	Provides a useful explanation of re-engagement with occupations after a bereavement ; an area not significantly explored previously or since	Unique account of the authors experience

Appendix C Critical Appraisal of Selected Qualitative Papers 2 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	McClatchey & Wimmer, 2012	McIntyre & Howie, 2002	Mattock & McIntyre, 2016	Nyman et al, 2014	Pickens et al, 2010	Thibeault, 1997	Vale-Taylor, 2009
Was there a clear statement of the aims of the research?	Yes – to understand the healing phenomena of the grief camp experience	Yes, to explore & interpret adaptation to widowhood through engagement in occupation	Yes, aimed to explore whether the occupations of spouse caregivers of people with dementia contribute to post-care period	Yes, to explore how agency is enacted in occupations with others & evolves over time	Yes, identified research question: What are the occupations of family caregivers in end-of-life care in a hospice setting?	Yes, identified research questions: What is different, if anything, in a bereaved counsellor? How does the experience of being a therapist affect the adaptive responses to loss?	Yes (in abstract) to explore which post-funeral remembrance activities are most significant and important to the bereaved
Is a qualitative methodology appropriate?	Yes, exploratory study focusing on children's experiences of grief camp	Yes, study aimed to explore subjective understandings	Yes, aimed to explore participants' experiences. IPA approach used	Yes, exploratory study using narrative analysis	Yes, exploratory study using ethnography	Yes, exploratory study using auto-ethnography	Yes, mixed methods study with exploratory approach

Appendix C Critical Appraisal of Selected Qualitative Papers 2 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	McClatchey & Wimmer, 2012	McIntyre & Howie, 2002	Mattock & McIntyre, 2016	Nyman et al, 2014	Pickens et al, 2010	Thibeault, 1997	Vale-Taylor, 2009
Was the research design appropriate to address the aims of the research?	Yes, semi-structured interviews with children and parents	Yes, 3 in-depth interviews focusing on different aspects of widowhood	Yes, semi-structured interviews	Yes, 6 interviews and participant observation over a 3 year period	Yes, ethnographic methodology undertaken over a 6/12 period using participant observation within the hospice + interviews & focus group with staff + document review	Yes, personal narrative account	Yes, semi-structured interviews used to follow-up on a self-report questionnaire. Focus group of hospice bereavement counsellors
Was the recruitment strategy appropriate to the aims of the research?	Yes, participants were invited to participate; consent was sought from parents and children	Inclusion criteria explained but does not explain how the participant was recruited	Yes, participants recruited via Alzheimer's Society although this neglected to include those who were not supported by AS. Inclusion criteria explained	Criteria for recruitment explained; purposeful recruitment. Does not specify how the participant was identified	Yes; patients, relatives informed of the study during admission process & invited to participate. Staff & volunteers invited to participate. Informed consent gained	n/a	Yes, purposeful recruitment of next-of-kin of hospice patients bereaved 12-24 months

Appendix C Critical Appraisal of Selected Qualitative Papers 2 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	McClatchey & Wimmer, 2012	McIntyre & Howie, 2002	Mattock & McIntyre, 2016	Nyman et al, 2014	Pickens et al, 2010	Thibeault, 1997	Vale-Taylor, 2009
Were the data collected in a way that addressed the research issue?	Yes, semi-structured interviews. Demographic and contextual details were also considered	Yes	Yes, semi-structured interview schedule informed by the literature	Yes, unstructured interviews allowed participant to structure her story. Participant observation took place in her home or neighbourhood	Yes; participant observation in hospice over 6/12. Interviews & focus groups with staff. Document review; researcher diaries	Yes, personal reflections and narratives	Participants chose whether to take part in an interview or complete the questionnaire; this addressed the research issue but was limited because the data sets could not be compared
Has the relationship between researcher and participants been adequately considered?	First author was founder & director of the camp so bias could be expected; any relationship with the participants was not discussed	Not discussed	Participants known to the researcher were excluded	Not discussed	Not discussed	n/a	Not discussed but author is a hospice chaplain
Have ethical issues been taken into consideration?	Description of ethical approval included	Ethics and consent not discussed. Consent was gained to record the interviews	Participants completed a consent form. Ethical approval gained (University Ethics Committee)	Ethical approval gained from Regional Ethics Committee	University & hospice ethics committee approval gained	Not discussed – as an auto-ethnography the author “controls” what is written	Regional Ethical approval gained

Appendix C Critical Appraisal of Selected Qualitative Papers 2 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	McClatchey & Wimmer, 2012	McIntyre & Howie, 2002	Mattock & McIntyre, 2016	Nyman et al, 2014	Pickens et al, 2010	Thibeault, 1997	Vale-Taylor, 2009
Was the data analysis sufficiently rigorous?	Yes, paper describes use of computer qualitative data analysis software and how the 2 researchers worked together in a way that enhanced their understanding of the material	Very clearly described. Analytic steps detailed in a table	Used IPA & template analysis; explains stages of analytic process	Explains process of narrative analysis and use of hermeneutic interpretation	Thematic analysis undertaken; member checking used; analytical logs maintained	Not clearly explained how findings were identified other than by reflection on experience	Questionnaires – descriptive statistics; interview data –thematic analysis described
Is there a clear statement of findings?	Yes, 2 themes identified: therapeutic interventions & traditional camp activities. These are discussed using extracts from the data	Yes, 3 themes identified: doing in widowhood; social relationships in widowhood; occupational adaptation to widowhood. These are discussed using extracts from the interviews	Yes; identified 4 themes which are explained using extracts from interview data: continuity; roles & occupations; support; change & transition	Yes, findings are presented as a “storied” narrative integrating data and theory	Yes, 2 themes identified: Holding onto normalcy & Overshadowed needs of caregivers. These are discussed in relation to Wilcock’s “Doing, being & becoming”	Relates personal experience to 5 aspects of professional OT practice: theoretical understanding of grief; knowledge of pathologies; use of client-centred guidelines; access to professional networks; professional values	Yes, data is explained & related to literature

Appendix C Critical Appraisal of Selected Qualitative Papers 2 (Using CASP Qualitative checklist) (CASP, 2014)

Study/ Review question	McClatchey & Wimmer, 2012	McIntyre & Howie, 2002	Mattock & McIntyre, 2016	Nyman et al, 2014	Pickens et al, 2010	Thibeault, 1997	Vale-Taylor, 2009
How valuable is the research?	Links are made between the findings and related research. Confirms role of therapeutic and traditional activity in children's grief	Findings offer a unique contribution to understanding of occupation in widowhood. Identifies limitations and areas for future research.	Makes links with relevant research. Discusses how the findings could be translated to OT practice	Findings provide an interesting interpretation of the role of agency in relation to occupation and identity	Unique contribution which clearly links findings to OT & occupation	Interesting contribution to professional practice	Identifies activities deemed meaningful and discusses why. Identifies limitations and areas for future research

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Did the trial address a clearly focused issue?	Yes; the project aimed to describe changes in self-care & daily living abilities in participants after attendance at a programme which provided information on these	Description and evaluation of a weekend camp for bereaved children	Yes, research questions: do leisure activities buffer the effects of stress (other than bereavement) on health among bereaved & non- bereaved older men? Does this buffering effect differ between bereaved & non- bereaved?	Yes, to develop a “practical system” with positive effects e.g. reducing grief, stress and immune response in bereaved middle-aged women	Yes, research questions: what is the incidence of children who present with grief issues to a sample of school- based OTs in Ohio? What is being done to address grief issues within OT practice in the school setting?	Yes, to determine if bereaved older people experience d difficulties with ADL and if these improved with anti- depressant medication	Study explored how older adults alter their social participation following widowhood & compares results to predictions derived from activity continuity & disengagemen t theories	3 hypotheses: late-life widowhood will increase housework hrs for men & decrease for women; dependence on adult children for housework will reduce hours for men & women; dependence on children will partially explain gender difference	Yes; 3 research questions: To what extent do recently bereaved people report self- competency in routine activities; & what factors were associated with differences in perceptions? Do these differ between men & women? Is perceived self- competency associated with bereavement

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
									outcomes (grief etc)?
Was the assignment of patients to treatments randomised ?	No, not an RCT. All Ps who requested to participate and who met entry criteria were eligible to join the study	No, not an RCT; evaluation was given to all attendees, parents and staff	No, not an RCT. Sample groups were composed of bereaved or non-bereaved men	No – participants were given the choice whether to participate in the experimental or control group	No – survey research; selection of sample was made randomly from a list of state registered OTs	No, 10 patients who were diagnosed with major depression following assessment with HDRS were entered into the study	No – not an RCT. Data derived from that collected as part of the CLOC study	No – not an RCT. Part of a prospective longitudinal study.	Yes; experimental group assigned to an intervention that combined restoration & loss-oriented coping; control group focused only on loss-oriented
Were patients, health workers and study personnel blinded?	n/a	n/a	No – n/a. All participants completed the same surveys	No – n/a	n/a	Yes, participants entered a double-blind parallel trial of 2 antidepressant medications	n/a	n/a	Not discussed

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Were the groups similar at the start of the trial?	n/a	n/a	Yes, demographic data indicate similarities between groups	No significant differences in grief levels, stress symptoms or immune responses; age and sex of Ps similar	All were OTs but demographic details reported represented a wide range	Paper does not discuss each participant group.	n/a	n/a	Not discussed; paper only reports on baseline assessment results

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Aside from the experimental intervention, were the groups treated equally?	n/a in relation to study design but each programme (5) ran in the same way	n/a	Yes	Yes	Yes	Yes, all participants completed the study; those who did not demonstrate any recovery after 8/52 were changed to the other anti-depressant. All responded to medication	All participants had completed the same baseline and follow-up interview and measurement scales. Controls were available for only some of the bereaved spouses due to funding cuts	Control participants were re-interviewed at similar times to the widowed sample	n/a

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Were all of the patients who entered the trial properly accounted for at its conclusion?	Not discussed; but reports that attendance was not 100%	Does not report on children's response rate; reports parents and staff response	Not discussed	Attrition was identified but not explained	n/a – sample were sent a postal survey; consent to participate was based on return of survey	Yes	n/a- used existing data	Yes, explanation of attrition provided	n/a

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
How large was the treatment effect?	Outcome measurements indicated statistically significant improvements in each self-care area. Improvements noted up to the 2/12 follow-up and then decline noted in some areas whilst others were maintained. All outcomes reported	n/a	Outcomes related to 3 different models of coping. Significant outcomes reported with discussion of these	Experimental group had significantly greater reductions in grief and stress levels than the control group. No difference between groups for immune response. All outcomes reported	37% response rate. Study was not a treatment study	Small sample size (10); this was a small study part of a larger project but measurement indicated significant improvement in depression scores (HDRS) and ADL performance. All outcomes reported	Sufficient no. participants to allow statistical analysis.	All hypotheses were borne out. Results also indicate differences between those with children & those without.	Paper does not report information about intervention. Measures of perceived self-competency & mental health were completed and correlated with gender

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
How precise was the estimate of the treatment effect?	Significant effects identified with P values of 0.001-0.05. Difference between male & female outcomes reported. Attendance was optional. Possible bias as participants volunteered	Descriptive data drawn from evaluation	Results support the hypotheses that leisure activities moderate stress (non- bereavement) on physical health; significant differences between bereaved & non- bereaved for social activities. Hypothesis re moderating effect of leisure activities on stress (mental health) was not supported.	For levels of grief and stress symptoms results were significantly better than the control group; P<0.001.	Descriptive data reported if & how OTs addressed grief in schools; barriers to addressing grief and OTs views on this	Significant improvement shown in ADL scores using AMPS pre- and post- intervention for 8 people. HDRS scores improved significantly (P<0.001). No significant difference between bereaved group and the well comparison group at treatment response phase.	Significant results reported with P values ranging P<0.001-0.0. Widowed participants had higher levels of informal social participation than non- widowed; formal social participation was comparable. Social participation decreased before widowhood & increased after	P values of 0.05 reported. Females report doing more hours of housework than men (despite accounting for health & functional difficulties). Dependence on children develops over time	P values of 0.05 reported. Baseline assessments indicated sample reported high self- competency in traditional gender related activities. Death expectancy was insignificant. Higher levels of self- competency were linked with lower grief, depression & loneliness

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Can the results be applied in your context? (or to the local population?)	Sufficient demographic and programme information provided	Camp activities described. Survey only briefly described	Sufficient detail is provided of the measurements used	Sufficient detail about the intervention is provided. Population may differ due to attitudes to intervention across cultures; age may also be relevant	Survey tool was included in the paper as an appendix. Description of study method is explained	Study acknowledges limitations but results are described in detail & address aspects measured.	Interview & survey measures only briefly described	Interview & survey measures only briefly described (part of CLOC study)	Demographic data reported; measures described

Appendix D Critical Appraisal of Selected Quantitative Papers (Using CASP Randomised Control Trial checklist) (CASP, 2014)

Study/ Review question	Caserta et al, 2004	Creed et al, 2001	Fitzpatrick et al, 2001	Kang & Yoo, 2007	Miliken et al, 2007	Oakley et al, 2002	Utz et al, 2002	Utz et al, 2004	Utz et al, 2011
Were all clinically important outcomes considered ?	Yes, results addressed all aims and outcomes & were discussed	n/a	Study aims were all addressed by the results reported	Yes. Results addressed all study aims	Yes. Results addressed all study aims	Study addressed issues raised in research questions. Recognition that bereaved may remit without treatment – authors had begun to work on identifying this in a further study	Study addressed issues raised in research questions	Study addressed hypotheses. Limitations acknowledged , and areas for future investigation. Justification for study explained	Study addressed issues raised in research questions
Are the benefits worth the harms and costs?	Yes, attendance was optional	n/a evaluation survey response.	Yes, participation was optional via completion of the surveys	Yes, sample were offered choice throughout study	Yes, participation was optional	Yes, sample benefitted from intervention	Participants entered study voluntarily	Participants entered study voluntarily	Participants entered study voluntarily

Appendix E Interview Schedule - phase 1 interviews (Version 2)

Introduction: *Thank you for agreeing to meet with me, if any of the things we talk about make you feel distressed and you would prefer not to continue that is fine. As I explained before, we can turn off the tape recorder, and either take a break or stop the interview at that point. If you're ready perhaps I can start by asking you ...*

Prompts / topics to be covered in participant interviews:

Routines

- Can you talk me through your day yesterday? (Or a typical day at the moment?)
- How would you describe yesterday in relation to other days? (Much the same / very different etc.).
- What does it take for you to get all that done / organised?
- How do you prefer to spend your time nowadays?
- How do you feel when you have got things which need doing?
- Are there some things you really don't like to do but have to do? What are the things you do enjoy / get a sense of achievement from doing?
- How do you get the things done which you don't really enjoy / want to do? How do you motivate yourself, summon up the energy / interest?
- How would you describe yesterday in relation to how your days were when *spouse* was alive?
- Does the routine of life feel the same or different since *spouse* died?

Activities

- Can you tell me a bit more about X (part of yesterday / current routine)?
- How does it feel to do X?
- Is X something you have always done?
- Would you do X now that *spouse* isn't here if you didn't have to? Can you tell me more about why?
- Why do you keep doing X?
- If X was something participant previously did before *spouse* died, how does it feel to do it now?
- When you think about *spouse*, when you're doing X (or things you did with *spouse*), how does it make you feel?

Appendix E Interview Schedule - phase 1 interviews (Version 2)

- Can you tell me about anything you do now which you didn't do before *spouse* died? Is there any reason you can think of why you do this now when you didn't do it (regularly) before?

Shared Activities

- Are there some things you have to do now that you used to do with *spouse*?
- How do you set about these activities now – same differently to before *spouse* died?
- Can you tell me a little bit about why you do those things in the same way / differently?
- What do you think *spouse* might say?
- Do you (ever) think about *spouse* when you do these activities? In what way?
- How does it feel to remember *spouse* when you're doing this activity / ies? Can you tell me more about that?
- When you've done this activity / ies that you used to do with *spouse*, how do you feel?
- Does how you feel change? (From before you have done the activity to during / immediately after / later on?).
- Is there anything you do that particularly reminds you of *spouse*?

Coping

- Is anyone else aware how it is / how much it takes for you to do these activities now?
- How does it affect the rest of your day?
- Is there anyone else you do these activities with now that *spouse* isn't here to do it with you?
- How does it feel doing these activities with someone else

Appendix F Ethics Approval



National Research Ethics Service **SOUTHAMPTON & SOUTH WEST HAMPSHIRE** **RESEARCH ETHICS COMMITTEE (A)**

EJC/STA/hph

23 December 2008

Mrs Corinne Hutt Greenyer
Lecturer in Occupational Therapy
University of Southampton
School of Health Sciences
Highfield
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Dear Mrs Hutt Greenyer

Full title of study: An exploratory study into the impact of bereavement on how people organise and go about their daily routines
REC reference number: 08/H0502/137

Thank you for your letter of 19 December 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix F Ethics Approval

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Participant Consent Form: Phase 1	3	25 April 2008
Covering Letter		20 September 2008
Application		17 September 2008
Participant Consent Form: Phase 2	1	23 May 2008
Investigator CV: Dr J Hopkinson		
Investigator CV: Professor J Addington-Hall		01 July 2008
Interview Schedules/Topic Guides	2	23 August 2008
Compensation Arrangements		01 August 2008
Peer Review		16 July 2008
Letter from Sponsor		17 September 2008
Investigator CV: Mrs C Hutt Greenyer		17 August 2008
Protocol	5	14 November 2008
Participant Consent Form: Pilot Study	1	14 November 2008
Participant Information Sheet: Phase 1	5	14 November 2008
Participant Information Sheet: Phase 2	5	14 November 2008
Participant Information Sheet: Phase 2 (new participant)	5	14 November 2008
Letter of invitation to participant: Phase 2 (new participant Bereavement Services)	4	15 December 2008
Letter of invitation to participant: Phase 1	4	14 November 2008
Letter of invitation to participant: Phase 2 (new participant, Social Worker)	2	14 November 2008
Response to Request for Further Information		19 December 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

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We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0502/137

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Mr Edward Carter
Chair

Email: scsha.SWHRECA@nhs.net

Enclosures: "After ethical review – guidance for researchers" SL- AR2 for other studies

Copy to: Mrs Christine McGrath
Southampton University Hospital NHS Trust

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix G University of Southampton Research Governance Confirmation



Ms Corinne Hutt-Greenyer
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

23 December 2008

Dear Ms Hutt-Greenyer

RGO Ref: 5990

Project Title An Exploratory Study into the Impact of Bereavement on How People Organise and Go About Their Daily Routines.

I am writing to confirm that the University of Southampton is prepared to act as sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care (2nd edition 2005).

The University of Southampton fulfils the role of Research Sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the Principal Investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Research Governance Office on this basis.

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework, and the EU Clinical Trials Directive (Medicines for Human Use Act) if conducting a clinical trial. We encourage you to become fully conversant with the terms of the Research Governance Framework by referring to the Department of Health document which can be accessed at:

<http://www.dh.gov.uk/assetRoot/04/12/24/27/041224>


In this regard if your project involves NHS patients or resources please send us a copy of your NHS REC and Trust approval letters when available.

Please do not hesitate to contact me should you require any additional information or support. May I also take this opportunity to wish you every success with your research.

Yours sincerely

Dr Martina Prude
Head of Research Governance
Tel: 023 8059 5058
email: rgoinfo@soton.ac.uk

Appendix H SUHT Research Governance Confirmation

Southampton University Hospitals NHS Trust 

Please reply to: Research & Development
Duthie Building (Trust) MP138
Southampton General Hospital
Tremona Road, Southampton SO16 6YD
Telephone: 023 8079 8591
Fax: 023 8079 8678
E-mail: claudia.fellmer@suht.swest.nhs.uk

Ms Corinne Hutt-Greenyer
School of Health Sciences,
University of Southampton
Highfield
Southampton
SO17 1BJ

17 September 2008

Dear Ms Hutt-Greenyer

ID: RHM MED0838 An exploratory study into the impact of bereavement on how people organise and go about their daily routines.

Re: NHS Research Governance and Identification of Nominated Research Sponsor

I am writing to confirm that Southampton University Hospitals NHS Trust is prepared to act, in principle, as sponsor for this study under the terms of the Department of Health Research Governance Framework for Health and Social Care.

SUHT's final acceptance of sponsorship responsibilities is dependent on full R&D approval, which will incorporate evidence of adequate funding to conduct your study.

SUHT fulfills the role of research sponsor in ensuring management, monitoring and reporting arrangements for research. I understand that you will be acting as the principal investigator responsible for the daily management for this study, and that you will be providing regular reports on the progress of the study to the Trust on this basis.

I would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework for researchers, principal investigators and research sponsors, that it is a requirement of the terms and conditions of approval that you become fully conversant with the Research Governance Framework on Health and Social Care document which is available from : <http://www.dh.gov.uk/en/Policyandguidance/Researchanddevelopment/index.htm>

Please do not hesitate to contact us should you require any additional information or support.

May I also take this opportunity to wish you every success with your research.

Yours sincerely

Claudia Fellmer

Research Governance & Quality Assurance Manager

Appendix I University of Southampton Insurance Confirmation

Southampton

Ms Corinne Hutt-Greenyer
School of Health Sciences
University of Southampton
University Road
Highfield
Southampton
SO17 1BJ

RG0 REF - 5990

23 December 2008

Dear Ms Hutt-Greenyer

Professional Indemnity and Clinical Trials Insurance

Project Title An Exploratory Study into the Impact of Bereavement on How People Organise and Go About Their Daily Routines.

Participant Type:	No Of Participants:	Participant Age Group:	Notes:
Healthy volunteers	30	Adults	

Thank you for forwarding the completed questionnaire and attached papers.

Having taken note of the information provided, I can confirm that this project will be covered under the terms and conditions of the above policy, subject to written informed consent being obtained from the participating volunteers.

Insurance will only be activated when we have received a copy of the Ethics Committee approval and you must not begin your project prior to this. Please forward a copy of the Ethics Committee approval letter as soon as it is to hand to complete the insurance placement.

If there are any changes to the above details, please advise us as failure to do so may invalidate the insurance.

Yours sincerely

Mrs Ruth McFadyen
Insurance Services Manager

Tel: 023 8059 2417
email: hrm@soton.ac.uk

cc: File

Appendix J SUHT Honorary Contract

Southampton 
University Hospitals NHS Trust

23 January 2009
PRIVATE AND CONFIDENTIAL

Human Resources Directorate
Corporate HR
C Level, Centre Block, Mailpoint 36
Southampton General Hospital
Tremona Road
Southampton SO16 6YD

Mrs C Hutt Greenyer
9 Oakwood Drive
Angmering
West Sussex
BN16 4GB

Tel: 023 8079 4246
Fax: 023 8079 6969

Dear Corinne

DEPT: Bereavement Care

1. You are employed by Southampton General Hospital and as a result of an agreement between your employer and the Trust you are hereby given permission to undertake a work placement at Southampton University Hospitals NHS Trust ("the Trust") in the Unscheduled Care Division for the period 1st November 2008 to 1st November 2010.
2. For the purposes of your employer insurance only, and for no other purpose, you will be regarded as an employee of the Trust in the proper performance of your duties during the placement, provided that at all times you exercise all reasonable skill and judgement and otherwise act in good faith.
3. Any duties you undertake will be under the direction and supervision of Sally List who will be responsible for ensuring that you receive an induction programme.
4. You will not be entitled to receive any pay from the Trust but if there is an agreement that you will be paid travelling and/or subsistence expenses, this will have been authorised by Sally List and be claimed through the appropriate financial procedures.
5. It is a condition of employment that employees engaged in health/health related care research shall comply fully with the Department of Health's Research Governance Framework (www.doh.gov.uk/research) and the Trusts Research and Development policy.
6. All placements are subject to a satisfactory medical screening, which should be undertaken prior to commencement, and **Criminal Records Bureau clearance**, which is required for all staff working with patients.
7. You shall not, during or after termination of your honorary contract, use improperly or disclose to others any confidential information about employees or patients of the Trust, or about the Trust's policies or finances. A breach of confidentiality during this contract will result in its termination.
8. Please sign and return the enclosed duplicate of this letter by way of confirmation of your agreement to the terms upon which the placement is to be made available.

Yours sincerely

Amy Williams
HR Co-ordinator

Form of acceptance

I hereby accept the offer of a work placement as mentioned in the foregoing letter.

Signature:

Date: 30.1.09

This offer, and acceptance of it, shall together constitute a contract between the parties.

Appendix K Participant Information Sheet

Participant Information Sheet - Phase 1 of study

Participant Information sheet

An exploratory study into the impact of bereavement on how people organise and go about their daily routines

You are invited to take part in a research study. Before you decide to take part in the study it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and talk to friends and relatives about the study if you wish.

Part 1 tells you the purpose of the study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

If something is not clear, or you would like further information, please contact Corinne Hutt Greenyer, School of Health Sciences, University of Southampton, SO17 1BJ; telephone: 023 8059 5286; email: cjhg@soton.ac.uk

Take time to decide whether or not you wish to take part.

Thank you for reading this.

Part 1

What is the purpose of the study?

In this study I would like find out about your life following bereavement. I am interested in how you live your life from day to day, and your experiences of carrying out everyday activities and routines following the death of your husband / wife. I am also interested in how things may have changed for you. Little is known about this aspect of bereavement. I hope that the findings from this study will help us to develop some understanding of this. We may then be able to develop services which might help people who experience difficulties in terms of getting back to everyday activities following bereavement.

Appendix K Participant Information Sheet

Why have I been invited?

You have been approached because I understand your husband / wife recently died. This information pack has been sent to you by (*Recruiter@Hospice*). You would be one of about twenty-five people I hope to speak to for this study.

What will happen to me if I take part?

If you decide to take part in the study you can complete and return the enclosed reply slip. I will then contact you to arrange a visit when I will answer any questions you have about the study. If you decide you are interested in taking part I will arrange a convenient time for us to meet. When we meet I will describe the study and go through this information sheet, which I will then give to you to keep. If you decide to take part I will then ask you to sign a consent form to show you have agreed to take part.

You are free to withdraw at any time, without giving a reason. If you do decide to stop participating in the study it may not be possible to withdraw the information you have already given. This will depend on the time at which you decide you do not wish to participate in the study any longer.

If you are happy to go ahead, I will talk with you about your daily life, the activities you do and the routines you might have, now and before your husband / wife died. This will take about an hour. If you agree, I would like to tape record this conversation.

As part of the study I hope to interview some people twice. The second interview will take place within one year of the first interview. I do not know at this stage whether you will be one of the people I will need to interview again. If you were then I would contact you again within the next year. Again, you would be asked for your consent to take part in a second interview, and you would be free to say no if you preferred.

Do I have to take part?

No, it is up to you to decide whether or not to take part.

What are the possible disadvantages and risks of taking part?

If you agree to take part in this study, I will do my best to keep any inconvenience and disruption to a minimum. I can come and see you at your home at a time

which is convenient for you. If you prefer not to be seen at home, I can meet you somewhere else local to you.

Sometimes people find it distressing to talk about how they are coping with their bereavement. You can of course stop the interview at any point if you feel upset. While every effort will be made to ensure that individuals cannot be recognised in any reports written, there is a small risk that someone could identify a participant. You may choose not to allow the use of the exact words you have said (direct quotations) in my reports. This would reduce the risk of you being identified still further. I will not use your name at all in anything written or in any presentations of the findings of the study.

If you are concerned about any aspect of the study, please contact Corinne Hutt Greenyer, School of Health Sciences, University of Southampton, SO17 1BJ; telephone: 023 8059 5286; email: cjhg@soton.ac.uk

What are the potential benefits of taking part?

I cannot promise that the study will help *you*. I hope that the information from this study may help to increase understanding about bereavement. This might provide information which can help to develop services to benefit people who need support. Your involvement may help to develop this understanding.

Will my taking part in the study be kept confidential?

Yes. All of the information about your participation in the study will be kept confidential unless something you say should give cause for concern about either your own or someone else's safety. The details are in Part 2 of this information sheet.

What happens when the study stops?

When the study finishes, all data will be held securely at the University of Southampton according to University guidelines. If you would like to know more about the results of the study I can provide a summary of the outcome for your information.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information about this is given in Part 2.

Appendix K Participant Information Sheet

Contact for further information:

Corinne Hutt Greenyer
School of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ
Telephone: 023 8059 5286
Email cjhg@soton.ac.uk

This completes Part 1 of the Information Sheet.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern or a complaint about this study you should contact Dr Abigail Burgess, Academic Adviser & Co-ordinator, in the Research Support Office at the School of Health Sciences (Address: University of Southampton, School of Health Sciences, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: 023 8059 8205; Email: A.L.Burgess@soton.ac.uk).

If you remain unhappy and wish to complain formally Dr Abigail Burgess can provide you with details of the University of Southampton Complaints Procedure.

Will my taking part in this study be kept confidential?

Yes, all information that is collected from you during the course of the research will be kept strictly confidential unless something you say during the interview should cause concern about your safety or that of someone else. Any information about you will have your name and address removed so that you cannot be recognised from it. All information will be kept in a secure, locked drawer and all information will be stored in accordance with the Data Protection Act (1998). Only the researcher and research supervisors will have access to the data.

Once the study has ended, all data collected will be stored for 15 years in a locked place with limited access and will then be disposed of securely.

Quotes may be used in any reports or publications as evidence of the findings; however no names will be used at all. You can refuse to give permission for direct quotes to be used.

What will happen to the results of the research?

The information shared in the interviews will be analysed. The findings will be written up and published in health care journals. You will not be identified in any publication. If you would like a summary of the results this will be sent to you.

Who is organising the study?

This study has been organised by Corinne Hutt Greenyer, postgraduate student at the University of Southampton and her supervisors Professor Julia Addington-Hall and Dr Jane Hopkinson.

Who has reviewed the study?

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an independent group of people called Research Ethics Committee before it goes ahead. This is to protect your safety, rights, wellbeing and dignity. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the Committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information on which to make an informed decision to take part or not. This study has been reviewed and given favourable opinion by the Southampton and South West Hampshire Research Ethics Committee A.

Appendix K Participant Information Sheet

Contact for further information:

If having read this information, you are happy to proceed please complete the enclosed reply slip and return it in the stamped addressed envelope.

If you would like any further information please contact Corinne Hutt Greenyer, School of Health Sciences, University of Southampton, SO17 1BJ; Telephone: 023 8059 5286; email: cjhg@soton.ac.uk

Thank you for reading this information sheet.

REC Ref: 08/H0502/137

(Version 5: 14/11/08)



An exploratory study into the impact of bereavement on how people organise and go about their daily routines

St. Barnabas has been asked to support some research being undertaken at Southampton University. It is an exploratory study into the impact of bereavement on how people organise and go about their daily routines.

This letter is being sent out with our invitation to the Time of Remembrance to everyone who was bereaved about three months ago. The enclosed papers provide more information about the study and what would be involved should you decide to participate. I am aware that as the study involves a particular group of people bereaved through the loss of a spouse, some of you will not fulfil the criteria for this study, but if you do, and you require further information you are very welcome to contact the researcher Corinne Hutt Greenyer either by telephoning 023 8059 5286; or by writing to her at the School of Health Sciences, University of Southampton, Highfield, Southampton. SO17 1BJ; or by email: cjhg@soton.ac.uk In this way we are able to retain your anonymity should you not wish to be involved.

The study hopes to find out how people who have been bereaved through the loss of a spouse live their lives day to day, and their experiences of carrying out everyday activities and routines. The researcher is also interested in finding out how these change following bereavement. The study has received ethical approval from the Southampton and South Hampshire Research Ethics Committee A (REC Ref: 08/H0502/137).

Appendix L Participant Introduction Letter

Those people who participate in this study will:

- Have been married to the person who died.
- Be aged 65 years or older and in good general health; any health problems do not prevent them from doing the things they want and need to do day to day
- Have been retired for 5 years if they worked, or their spouse will have been retired for 5 years before they died.
- Speak English.

If having read the information sheet you fulfil the criteria and are interested in taking part in the study it would be appreciated if you could complete the attached reply slip and return it in the envelope provided.

If receiving this letter causes you any problems or concerns please do not hesitate to contact me.

Thank you for your time.

Tim King

Bereavement Services Co-ordinator

REC Ref: 08/H0502/137

(Version 5: 15th December 2008)

Appendix M Participant Consent Form

Participant Consent Form – phase 1 of study



Study Number: REC Ref: 08/H0502/137

CONSENT FORM

Title of project:

An exploratory study into the impact of bereavement on how people organise and go about their daily routines – Phase 1

Name of researcher: Corinne Hutt Greenyer

Please initial
each box

1. I confirm that I have read and understand the information sheet dated 25/04/08 (version 3) for the above study. I have had opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

☐

3. I understand that this is a student project.

☐

Appendix M Participant Consent Form

4. I understand that all information and data collected from me, as part of the project, will be retained by the University of Southampton for fifteen years in line with University policy. ☐

5. I agree that the interview can be tape recorded. ☐

6. I agree to the use of direct quotations in any publications or presentations which arise from the findings of this study. ☐

7. I agree that the audio recording and transcription of my interview can be used for the purposes of: teaching students and to answer new research questions (secondary analysis). Yes ☐
No ☐

8. I agree to take part in the above study. ☐

Name of participant

Signature of participantDate

Name of researcher

Signature of researcherDate

One copy for participant; one copy for researcher
(Version 3: 25/04/08)

Appendix N Post-Interview Information Sheet



It is possible that some of the things we have talked about during the interview may cause you to feel distressed. This may not be immediately but if you find you suddenly feel more upset or distressed than you have done recently, it can help to talk to someone about these feelings. You may prefer to talk to a friend or relative that you know well, but sometimes it can feel easier to talk to someone else. If you feel distressed and would like to talk to someone else about your feelings or about things you have experienced since your bereavement the following contacts may be useful.

St Barnabas House

Tim King
Bereavement Services Coordinator
St Barnabas House Hospice
Columbia Drive
Worthing
West Sussex, BN13 2QF
Telephone 01903 524124

CRUSE

Alternatively you can contact CRUSE. CRUSE is a charitable organisation which provides support and advice following bereavement. The West Sussex branches are:

Chichester	01243 530202
Mid-Sussex	01293 531191
Worthing and district	01903 205900

Both of the contacts above will be able to offer you support either on a one-off basis or more regularly.

Corinne Hutt Greenyer
January 2009

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