University of Southampton

The Experience of Living with a Husband or Partner who has a Life-Limiting Illness

Anna Jepson

This thesis is submitted in partial fulfilment of the degree of Doctor of Clinical Psychology

School of Psychology

Faculty of Social and Human Sciences

June 2012

Word Count 19,998 words

Disclaimer Statement

I, the undersigned, confirm that the work that I have presented as my thesis is entirely my own work. Reference to, quotations from, and discussion of the work of any other person has been correctly acknowledged within the work in accordance with University of Southampton guidelines for the production of a thesis.

Anna Jepson

General Abstract

When an individual is cared for from within the household, this care-giver is most likely to be their spouse or partner. Research to date has explored the impact of life-limiting illness on spouses and partners, as well as other family members. Studies have described some of the ways in which a life-limiting illness can impact on a spouse or partner physically and emotionally; and the role changes that they may face. Often research publications have grouped together participants who differ from one another in terms of age and gender, and it can be argued that there is value in focusing more narrowly on specific groups; in order to gain a detailed, in-depth appreciation of their distinct experiences. The initial part of this thesis critically evaluates recent research investigating the impact on individuals who have a family member with a life-limiting illness. This includes identifying key themes arising across studies which highlight the multitude of ways in which life-limiting illness can affect family members. This is followed by an empirical paper detailing a piece of idiographic qualitative research which sought to explore the experiences of older women living with a husband or partner who have a life-limiting illness. Six over-arching themes emerged from the interviews which described these experiences.

Contents

Acknowledgements

I would like to thank the six participants, without whom this research would not have been possible, who generously shared their time and experiences. I am also very grateful to my research supervisor Dr Paul Beadon for his wisdom and guidance throughout this process. Finally I would like to thank Dr Becky Coles-Gale and Dr George Johnson for their invaluable support.

Literature Review Paper

The Impact of a Life-Limiting Diagnosis in a Family Member

Anna Jepson

University of Southampton

Abstract

This literature review critically considers recent research which has explored the impact of a life-limiting diagnosis in a family member. The philosophy of palliative care highlights the importance of the family system and it is also acknowledged that the needs of family members may differ from those of the patient. Databases were searched for key terms and article titles visually inspected, yielding 36 relevant papers for inclusion in this review. The majority of studies evaluated were found to include groups of participants with various different relationships to the patient. Some research has, however, focused on the experiences of specific groups of family members, such as spouses and partners, or parents. A broad ranging impact on family members was evident from the literature; including physical, emotional, and relational components. There was considerable variation in the themes that arose from the studies; however several key elements emerged, including feelings of helplessness, isolation, fatigue, and guilt, and the difficulty of managing unpredictability and witnessing the family member's decline. There would be value, in future research, in focusing on the experiences of specific, homogeneous, groups of participants, in order to gain a more detailed understanding of their experiences. In clinical practice, services could seek to help reduce the isolation of family caregivers. There are also particular psychological approaches which may lend themselves to working therapeutically with some of the difficulties identified.

Introduction

This paper will critically evaluate pertinent literature investigating the impact of a life-limiting diagnosis in a family member. Palliative care has been defined as “the active, holistic care of patients with advanced, progressive illness” (National Council for Hospice and Specialist Palliative Care Services; NCPC, 2002, p. 2). It is an approach that seeks to enhance the quality of life of both patients and their family members, including through the “treatment of pain and other problems, physical, psychosocial, and spiritual” (World Health Organisation; WHO, 2012). Research opportunities within the field of palliative care are expanding (Seymour et al., 2005). However despite an emphasis within palliative medicine on the wellbeing of the family as a unit, there are still aspects of the research concerned with the needs of family caregivers which are somewhat limited (Hudson et al., 2010). In clinical practice, family member’s needs may differ from those of the patient and are at risk of being overlooked (The National Institute for Clinical Excellence; NICE, 2004).

The terms ‘family member’ and ‘family caregiver’ are used somewhat ambiguously in the literature and have been applied to a variety of relationships including that of spouse, partner, parent, child, sibling, in-law, friend, and other (Spichiger, 2008; Spence et al., 2008; Yamagishi et al., 2010; Juarez, Ferrell, Uman, Podnos, & Wagman, 2008). NICE suggests that the concept of family includes “those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient” (2004, p. 155). It is this definition that will be used for the purposes of this review.

The majority of published studies have included heterogeneous groups of participants, comprising of individuals with a variety of different relationships to the patient. These will be reviewed initially and key themes highlighted. Studies exploring the experiences of specific groups (spouses or partners and parents respectively) will then be considered and themes common to each group discussed. Finally, over-arching themes relating to the impact of a life-limiting diagnosis in a family member will be identified and implications for clinical practice and future research considered.

Method

The databases psychINFO and MEDLINE were searched using key terms. For details of these see Appendix A. To filter the most up to date literature, results were restricted to publications from the last five years. This returned 1032 results. Titles and, where relevant, abstracts were inspected to determine the most relevant articles.

Two journals of particular relevance, ‘The International Journal of Palliative Nursing’ and ‘Palliative Medicine’ were also searched manually for articles published during the same period, yielding a further 33 papers. This generated a total of 86 articles, 36 of which were included in the final review. Inclusion criteria consisted of being an empirical paper or case study which sampled adult family members of individuals with life-limiting conditions who were, or had been, receiving palliative care, or who were at the end-of-life.

Articles which focused specifically on the experiences of children were excluded because a preliminary exploration of the research on this topic indicated that the issues facing children and young people differed from those affecting adults (for e.g. MacPherson and Emeleus, 2007a, b), and because a detailed exploration of children’s experiences was therefore not possible within the space constraints. Articles were also excluded where the primary focus was service evaluation. Appendix B details an excerpt from an inclusion/exclusion table.

Theoretical Review

Studies Sampling Heterogeneous Groups of Family Members

In a Dutch study, a cross-sectional questionnaire based design was used to survey 76 male and female informal caregivers of individuals with advanced cancer (Osse, Vernooi j-Dassen, Schade, & Grol, 2006). Most participants were spouses of patients but the sample also included family members and friends. Participants were asked about the most prevalent problems they experienced as caregivers. The most commonly rated items were “fear of an unpredictable future”, “accepting the patient’s disease”, “fatigue”, “depressed mood”, and “difficulty in showing emotion” (p.381). The quantitative nature of the research prohibited any further exploration of the unique *meanings* of these terms for individual participants. Furthermore the emphasis on pathology precluded participants from sharing positive aspects of their experience.

Further to Osse et al.’s (2006) findings that depressed mood was a concern for participants Tang, Li, and Liao (2007) reported high levels of “depressive distress” (p.249) within a sample of 170 Taiwanese family caregivers. In Tang et al.’s study individuals, 68% of whom were female, completed a battery of questionnaire measures to assess depression, perception of their relative’s distress, “stressors”, and “appraisal of the care-giving situation” (p.251). Over 75% of participants’ scores indicated clinical levels of depressive distress, with being the spouse of a patient a significant risk factor for this. Participants were also significantly more likely to be distressed if they judged care-giving as having “a substantial negative impact on their own health” (p. 253). Reporting better knowledge of the patient’s thoughts and feelings, and being more confident in taking care of the patient were associated with lower levels of distress.

Despite correlations between variables in this study causality cannot be inferred; an individual who was identified as less distressed may have felt more confident in their ability to provide care for their relatives. The authors also identified that it has been suggested higher cut-off scores should be used to identify clinical levels of depressive distress within Chinese and Taiwanese samples due to greater somatisation of psychological difficulties in this population.

In keeping with the findings of Osse et al. (2006), Spence et al. (2008) found the uncertainty of the future to be a concern for participants, who were witnessing the deterioration of their family members' health. In this study, conducted in Northern Ireland, seven individuals were interviewed about their experiences of caring for a family member with chronic obstructive pulmonary disease (COPD). The sample was predominantly female, interviews were analysed using content analysis.

Spence et al. (2008) also identified the physical impact of care-giving. Participants felt fatigued, linking this to difficulties with concentration and disrupted sleep. The emotional impact of care-giving included; feeling guilty, helpless, and frustrated. Additionally participants felt anxious and this was associated with the unpredictability of the situation and the patients' health. Participants needed to take on a number of new roles related to physical care, which could leave them feeling their own identity had been lost. Participants were also responsible for decisions about relatives' care despite their own limited understanding of COPD. In addition to the many difficulties and uncertainties, participants also spoke of satisfaction and reward derived from care-giving. The reliability of findings was enhanced by researcher triangulation.

The uncertainty of the future and unpredictable nature of the illness emerged again in the accounts reported by Spichiger (2008). In this qualitative study 10 patients with advanced malignant disease and 10 family members, male and female, were interviewed about their experiences of end-of-life care. Data were analysed using an approached based in interpretative phenomenology. Participants reported numerous losses including the prospect of a fore-shortened common future. The impact of care-giving was again notable in participants' accounts given individuals could spend several hours each day visiting the hospital. Experiences of health care were "generally positive" (p. 225) with empathy and consideration of staff valued. To enhance reliability interpretations were discussed with other qualitative researchers and with participants.

In a Swedish qualitative study, Persson and Sundin (2008) interviewed relatives or friends of individuals diagnosed with inoperable lung cancer, sampling equal numbers of men and women. A phenomenological, hermeneutic approach was employed and four main themes emerged. "Feeling dislocated in life" (p.382) comprised the unexpectedness of diagnosis, a sense of life coming to a standstill; and of paralysis. Similarly to Spichiger (2008) there was a sense of a newly-shortened future, with participants confronted by the impending loss. Participants also felt "powerless" (p.383) and identified a "loss of control over their own emotions and reactions" (p.383). Participants described their sense of being abandoned or deserted by others and consequent feelings of resentment.

The theme of "being in an altered relationship" (p.383) included feeling very close to the patient, in some cases to the point of "symbiosis" (p. 383). However there were also many losses, of freedom and the expected future and, for some participants, intimacy and equality in the relationship. "Being in a struggle" (p.384) captured the process of enduring distress, managing the prospect of their future loss, trying to live life in the present, and attempting to maintain their own functioning. The final theme "feeling secure" (p.384) involved confidence in their capabilities, accepting the situation and adapting to challenges, and looking to their own future. Conducting interviews 6 months after diagnosis the authors were able to capture a sense of transition. Participants had met with the interviewer for a previous interview; arguably this may have introduced bias in terms of participant’s responses and the analysis. It seemed, however, that participants were remarkably candid; in some cases expressing dissatisfaction with their relationship with the patient. This willingness to share ideas which are, perhaps, less socially acceptable may have been facilitated by the more established relationship with the researcher. The reliability of findings was enhanced by researcher triangulation.

Family members experiencing thoughts which could be considered less socially acceptable also featured in a Swedish study by Carlander, Sahlberg-Blom, Hellstrom, and Ternestedt (2010). Ten individuals, male and female, were interviewed between 6 and 12 months after the death of a family member from cancer. All participants had cared for relatives in their own homes. Data were analysed using interpretative description. The sub-theme “challenged ideals” (p. 1099) linked to the core theme “the modified self” (p.1101) and was connected to thoughts of violence against others, as well as feelings of boredom and restlessness. Other key themes that arose were “stretched limits” (p.1099) of intimacy and privacy, and “interdependency” (p. 1101) which related to meeting the expectations of numerous agencies including the patient, oneself, and society. It is noteworthy that interviews related to events of up to a year previously; consequently participants’ recall may have been subject to bias (Raphael, 1987).

Wong and Chan (2007) used a qualitative approach to explore the experiences of 20 Chinese family members of individuals in a palliative care unit in Hong Kong. Participants were predominantly female. Interviews were analysed using a phenomenological approach. Researchers identified three main themes. The first of these, “grief reactions” (p.2360) related to the emotional impact of the patient’s illness including feelings of sadness and of anger which accompanied thoughts that “the doctors had not tried their best” (p.2360). In keeping with Spence et al. (2006) feelings of helplessness were also expressed. These were related to wanting to help relieve the suffering of the patient, but being unable to do so.

Being “committed to care” (p.2361) emerged as a central theme with participants placing great value on time spent with relatives. Participants worried there would be a sudden deterioration in their relative’s health and hoped for a peaceful death. Participants were interviewed six weeks after the death, due to cultural considerations. The final theme “being with the patient at the last moment” (p.2361) reflected the importance placed on being present at this time, with participants expressing guilt and disappointment where this had not been possible. Although the retrospective nature of interviews may have influenced recall this also allowed participants to describe additional elements of their experiences related to the end-of-life. The study reliability was strengthened by the researchers explicitly identifying their preconceptions in a process akin to ‘bracketing’; temporarily putting aside: “the researcher’s own assumptions and experience” (Biggerstaff & Thompson, 2008, p.217). The authors also reported that data saturation was reached.

A commitment to care was also evident in the research findings of Shanmugasundaram and O’Connor (2009) who interviewed six individuals about their experiences of having a family member who had received palliative care. The sample included male and female Hindu, Sikh, and Christian Indian migrants living in Australia. Participants reported pressure to provide a traditional diet for their relative whilst they were receiving inpatient care. Some dietary requirements were associated with vegetarianism; the importance of diet was also related to the perception of food as medicine.

An important consideration for Hindu families was cleanliness and the importance of bathing in running water. Where culturally specific needs such as these could not be accommodated by staff this placed an added burden on family. Care-giving was experienced as hard, stressful, and physically tiring by participants. It was also seen as the final chance to care for relatives. Although predominantly retrospective, interviews were conducted within 12 months of the patient's death. The research focused primarily on participants' experiences of services; there may have been many other unexplored aspects of individuals' experiences.

In an American study conducted by Kehl, Kirchhoff, Kramer, and Hovland-Scafe (2009) thirty individuals were interviewed about a family member's end-of-life in one of three settings; a hospice, skilled nursing facility or the community. Thematic analysis was utilised and two challenges emerged across all three settings; "bearing witness" (p.5) and "experience of loss" (p.6). "Bearing witness" encompassed the difficulties of observing the patient's decline, both cognitive and physical and of seeing their helplessness. This was experienced as "especially difficult" (p. 5). The "experience of loss" referred not only to the death of the family member but to multiple, gradual, losses of "companionship", "care-giving role", and "the loss when the dying person did not recognise them anymore". (p. 6). Multiple losses were also evident in the accounts reported by Persson and Sundin (2008), Spichiger (2008), and Spence et al. (2008)

As noted in reference to other studies the accounts of participants may have been influenced by the retrospective nature of the interviews, with individuals participating after the death of their family member. Whether this influence should be regarded as bias depends upon the epistemological standpoint adopted. It can be argued, from a constructivist perspective, that there is no objective truth or reality (Reichertz & Zielke, 2008). Following this line of argument; that a person's account of their experiences may change over time does not make that account any less valid. Further, interviews such as those conducted by Kehl et al. (2009) may offer us an insight into the process of meaning-making that unfolds after the death of a family member.

A limitation of this study was that interviews were conducted by different researchers in each of the settings, potentially giving rise to inconsistencies in interview technique. However the authors reported that audio recordings were reviewed to address this issue. Additionally, reliability was increased by use of an audit trail, allowing for verification of the analysis.

Morasso et al. (2008) reported the results of a large-scale Italian study in which 1231 individuals were identified from thirty randomly selected health districts. The sample consisted of men and women who had cared for someone during their last three months of life. Participants included both family members and “other non-professionals” (p.1075). Semi-structured interviews were analysed using content analysis. Responses were categorised into “negative experience” (p. 1076) (which accounted for 65% of responses) “positive experience” (p.1075) (which accounted for 33% of responses) and “neutral experience” (p.1077) (which accounted for less than 2% of responses). Negative experiences included the themes “emotional suffering”, “care burden” and “powerlessness” (p.1076). Anger, fear, guilt, and remorse were all emotions described, echoing those expressed by participants in other studies. Guilt appeared associated with concerns that the participant should have done more to help their relative.

Positive aspects of the experience of care-giving included an increased sense of agency and confidence in one’s own abilities to cope. “Personal growth” (p.1077) was another theme; linked to finding the experience “meaningful” and “enriching” (p.1077). Participants also spoke of an increased closeness and strengthening of “family bonds”, and reduced conflict with the patient (p.1077). This study is notable for its large sample size, increasing the generalisability of findings. However data appeared to lack the richness of other qualitative studies on this subject, with limited elaboration of themes and brief quotations.

Linderholm and Friedrichsen (2010) interviewed 14 family caregivers, both male and female, about their experiences of caring for a relative or partner with cancer at home. Interviews were conducted between 3 and 12 months after the patient’s death and analysed using a hermeneutic approach. Caring was viewed as an obligation and “moral duty” (p. 31). As noted by Spence et al. (2008) participants carried a weight of responsibility whilst caring, including attending to personal care and medication; for which they sometimes felt unprepared. Despite this individuals controlled their emotions and did not express feelings of anger or fear. Building and maintaining good relationships with health care staff was seen as very important and participants felt vulnerable when this was unsuccessful. Overall individuals expressed a need for their feelings and experiences to be acknowledged by the health care team. The study included an exploration of participant’s experiences after the death of their family member and was therefore necessarily retrospective in design. The authors aimed to include a demographically varied population; presumably to increase the representativeness of the sample, however it is questionable whether this can be achieved with a small qualitative study. The analysis was confirmed by the second author, increasing reliability of results.

Hasson et al. (2010) interviewed 15 individuals in Northern Ireland who had cared for a family member with Parkinson’s disease before their death. Eleven participants were male and four female. Interviews were analysed using content analysis. Both physical and psychological consequences were reported by participants, including being physically and emotionally hurt by the patient. Physically individuals experienced exhaustion; psychologically they experienced feelings of isolation, helplessness and a loss of self-identity. As reported by Kehl et al. (2009) participants experienced distress due to witnessing the "physical and psychological deterioration of the patient" (p. 733).

Interviews took place between six months and two years after the death of the patient and consequently participants may have been at different points in the meaning-making process following bereavement. Participants were recruited though a support group and their experiences may not reflect those of all family members of individuals with Parkinson's disease. Two researchers analysed the transcripts independently, increasing reliability.

Similarly to Hasson et al. (2010), Ray and Street (2006) uncovered themes of isolation and of anxiety at witnessing the patient's loss of functioning in their exploration of individual's experiences of caring for a family member with motor neurone disease. Twenty four individuals were interviewed in this Australian study which included both men and women. "Primary caregivers" (p.37) were interviewed three times and "peripheral caregivers" (p.37) once. The majority of participants were the partners of patients, though the sample also included relatives and friends. Use of field notes were used to supplement information gathered through semi-structured interviews. Data were analysed using an ethnographic case study approach.

As noted a major theme which emerged from the data was "the visible body" (p.38), related to seeing a visible decline in the patient's condition. This was experienced as worrying and distressing by participants who were highly concerned about the possibility of patient injury, or choking. The physical deterioration of patients led to increased dependency on participants who were required to balance care for the physical body with their personal relationship with the individual. Care-giving also left participants very physically tired. In terms of isolation, participants spoke of “disconnection” (p. 39) and dwindling support networks. Individuals related this both to their own lack of energy and others’ lack of understanding.

Another factor which can be affected when a family member is diagnosed with a life-limiting illness (LLI) is health-related quality of life (HRQOL). In a longitudinal questionnaire-based Swedish study “significant others” (p.239) of patients with inoperable lung cancer were surveyed at three time points, including after the death of the patient (Persson, Ostlund, Wennman-Larsen, Wengstrom, & Gustavsson, 2008). Participants included both family members and friends. One month after diagnosis participants’ scores on a range of HRQOL dimensions were significantly lower than those of matched controls, indicating “worse functioning and wellbeing” (p. 242). These dimensions included “positive affect” (p.242), “negative affect” (p.242), “sleep problems” (p.242), and “cognitive functioning” (p.244). Aspects of HRQOL were found to fluctuate during the patient’s illness and after death but overall most dimensions were affected “to a substantial degree” (p. 244). The inclusion of a control group matched for age, sex, and marital status in this study allowed for comparison with the general population.

The effects of stress on the cognitive functioning of individuals who have family members receiving palliative care was investigated in more detail in a Canadian study by Mackenzie, Smith, Hasher, Leach, and Behl (2007). Twenty seven individuals participated; the majority of participants were female, with an average age of 60. Individuals were asked to complete a battery of standardised assessments.

Participants were found to be significantly less accurate on a test of selective attention and a test of recall than the age corrected norm. This was despite the fact that participants’ intelligence was “slightly above average” (p. 753). Episodic and working memory appeared unaffected. Twenty two of the original participants repeated the assessments after the death of the patient. This produced mixed results in terms of both improvement and deterioration in performance being exhibited. Potential confounds were considered and cognitive performance was found to be unrelated to the number of medications participants were taking, or to “health-related cognitive risk factors” such as high blood pressure (p.753). Overall, results suggest that an LLI can impact detrimentally on aspects of the cognitive functioning of family members.

Some studies have examined the impact of a specific phenomenon related to an LLI. Namba et al. (2007) interviewed 20 family members of cancer patients who had experienced terminal delirium in the two weeks prior to their death. Both men and women were included in this Japanese study. Interviews were analysed using content analysis. Participants’ perceptions of delirium varied widely as did the emotions evoked by it. Some participants were happy their family members were delirious rather than suffering, or perceived the patient as “dreaming” (p.590). Others found delirium distressing to witness or appeared to feel guilty that they could not prevent it. Some participants were anxious about being alone with the patient. The authors highlighted the importance of individually tailored support for families, particularly given their differing beliefs and emotional reactions.

The potential difficulties associated with retrospective accounts have been discussed previously but it is notable in this case that participants appear to have been interviewed as much as 5 years or more after the death of their relative. Furthermore the diagnoses of terminal delirium were made based on a retrospective review of patients’ medical charts and family members’ reports, compromising the reliability and validity of findings.

Two recent studies (Yamagishi et al., 2010; Reid, McKenna, Fitzsimons, & McCance, 2009) have explored family members’ experiences of having a relative with cancer related anorexia or cachexia. Reid et al. interviewed 15 patients with cancer cachaxia and 12 family members and friends in Northern Ireland. The sample included both men and women. Interviews were analysed initially with thematic analysis; eight interviews yielded particularly rich data and were subsequently analysed using interpretative phenomenological analysis (IPA).

Participants reported how “the visibility of their loved ones’ illness reinforced the state of their ill health” (p. 612) echoing the voices of participants in other studies who expressed their distress at witnessing the physical decline of their family members (Kehl et al., 2009; Hasson et al., 2010; Ray & Street, 2006). Conflict arose over the issue of food with patients feeling under pressure to eat. Participants, particularly female, experienced feelings of guilt when they were unable to entice the patient to eat and frustration when they prepared meals which were rejected.

Yamagishi et al. (2010) surveyed 452 bereaved individuals in Japan. Participants were family members of patients who had died of cancer. Eighty percent of those surveyed reported that their family member had developed cancer- related anorexia. Seventy percent of these participants described finding the experience “very distressing” or “distressing” (p.674). Similarly to the family members interviewed by Reid et al. (2009), sixty nine percent reported feelings of guilt and helplessness.

Key Themes

Research exploring the impact of an LLI in a family member varies in terms of its design, sample size, and cultural context. Nevertheless there are certain elements of the experience which arise several times across different studies.

Witnessing decline. It was particularly hard for individuals to witness the deterioration of their family members’ health including the cognitive and physical aspects of their decline, and seeing their helplessness. This was experienced as worrying and distressing. This visible evidence of the condition highlighted the family member's ill-health. Participants were concerned about the possibility of their relatives becoming injured and patients also became increasingly dependent on family members for support (Spence et al., 2008; Kehl et al., 2009; Hasson et al., 2010; Ray & Street, 2006; Reid et al., 2009).

Unpredictability. The unpredictable trajectory of the illness and possibility of a sudden deterioration in the family member's condition provoked anxiety. This was also related to fear and uncertainty about the future (Osse et al. 2006; Spence et al., 2008; Spichiger, 2008; Wong & Chan, 2007).

Powerlessness/ Helplessness. Feelings of powerlessness and of helplessness arose, with helplessness related to the desire to relieve the suffering of the patient but the inability to do so. Individuals whose family members had cancer related anorexia described feeling helpless when they were unable to tempt the individual to eat (Persson & Sundin, 2008; Spence et al. ,2008; Wong & Chan, 2007; Morasso et al., 2008; Yamagishi et al., 2010).

Multiple losses. The experience of loss related not only to the ultimate loss, the death of the family member, but to multiple, gradual, losses. These losses incurred by participants included freedom, the expected future, intimacy and equality in the relationship, the loss when the family member no longer recognised them, and the loss of their own previous identity (Persson & Sundin, 2008; Spence et al., 2008; Spichiger, 2008; Kehl et al., 2009).

Isolation. Participants' caring role could contribute to feeling isolated and disconnected from others. In some cases support networks dwindled. Participants attributed this both to their own lack of energy and to others' lack of understanding of the situation. Some family members described their sense of being abandoned or deserted by others, leading to feelings of resentment (Persson & Sundin, 2008; Hasson et al., 2010; Ray & Street, 2006).

Tiredness/Fatigue/Exhaustion. The physical impact of caring for a family member could leave individuals feeling exhausted. Fatigue was linked to difficulties with concentration and disrupted sleep (Osse et al. 2006; Spence et al., 2008; Hasson et al., 2010; Ray & Street, 2006).

Guilt. Feelings of guilt were associated with a belief that participants should have done more to help their family member. Some individuals with a relative experiencing delirium appeared to feel guilty that they could not prevent it. Where patients were suffering with cancer related anorexia or cachexia family members experienced feelings of guilt when they were unable to entice the patient to eat (Spence et al. ,2008; Morasso et al., 2008; Namba et al., 2007; Yamagishi et al., 2010; Reid et al.; 2009).

Anxiety/fear. The unpredictability of the situation and the patients' health was associated with anxiety for family members. Elements of the care-giving experience could also be frightening. In cases of terminal delirium some individuals were anxious about being alone with the patient (Spence et al., 2008; Morasso et al., 2008; Namba et al., 2007).

The studies reviewed so far have all included family members with varying relationships to the patient (e.g. spouse, sibling, daughter-in-law). Though arguably this may increase generalisability of findings it overlooks the possibility that there may be considerable variation in the way in which different members of the family are impacted by an LLI. Some research has addressed this issue by focusing more specifically on the experiences of one particular group.

Studies Focusing on the Experiences of Spouses and Partners

McLaughlin et al. (2010) explored the perceptions of 26 male and female spouses of individuals with Parkinson’s disease living in Northern Ireland. A qualitative approach was utilised with semi-structured interviews analysed using content analysis. The authors noted the uncertainty leading up to diagnosis with numerous tests being carried out and reported the “shock and anger” experienced by participants when diagnosis was confirmed (p. 179). This was accompanied by feelings of fear about the future. Participants also reported a lack of information from health care professionals at this time.

There were many burdens for participants associated with their care-giving role including the need to provide personal care and their spouses’ level of dependency on them. Financially participants were affected by loss of income due to sacrificing paid employment. Participants were impacted emotionally and this was associated with having a very limited social life and with the curtailment of activities. With diagnosis there also came a: “loss of future plans” (p.180). Stoicism was evident in the accounts of participants, who took on the role’s previously carried out by their spouse and who saw care-giving as “a spouse’s duty” (p. 179). It is noted in the paper that two researchers analysed the transcripts, however it is unclear whether they analysed the same transcripts independently in order to enhance the reliability of analysis.

Riley and Fenton (2007) interviewed nine individuals whose spouses had a chronic or terminal illness in their British study. Six participants were female and three male. Patients’ specific diagnoses were not provided, and interviews were analysed using thematic content analysis. Like McLaughlin et al. (2010) anger was described by participants, particularly in response to diagnosis. This was accompanied by feelings of shock, numbness, and disbelief. Participants found diagnoses hard to accept; many could not accept them at all. Feelings of uncertainty affected both participants’ ability to make decisions and their relationships with their spouses. Participants' physical and mental health was impacted by tiredness, sleep problems, stress, anxiety, and depression. Changes in their spouses such as aggression or memory loss were especially distressing. Most participants also described changes in their own personality as they learnt new skills and took on aspects of their spouse's role. Relationship changes included a: "loss of physical closeness" (p. 88) for some couples.

Riley and Fenton (2007) found also that there were a number of different attitudes towards death. Some participants expressed feelings of acceptance, some described resentment and guilt. There were fears of separation and being alone. Some participants reported avoided talking about death with their spouse, whilst others spoke about it a great deal, including helping to plan the spouse's funeral. Coping strategies included staying busy and trying not to focus on the situation. Two participants spoke of increased smoking or alcohol use. Two others spoke of the importance of their religious faith. It was notable that participants' appeared particularly distressed in comparison to some other studies. The authors acknowledged that because the researcher was known to be a palliative care counsellor, some participants "may have taken part in the study in order to access psychological support" (p. 87).

Feelings of anger upon realising the nature of the spouses' condition were also reported by Gunnarsson and Ohlen (2006), although for these participants the realisation seemed related less to the point of diagnosis than to a distinct moment at which they realised their spouse would soon die. Anger was also accompanied by despair and resignation. In this Swedish study 12 individuals were interviewed and data were analysed using a hermeneutic phenomenological approach. Participants were the spouses of individuals who had received home-based palliative care prior to their death. Nine participants were female and three male. Interviews were conducted between 6 and 12 months following the patient's death.

Other themes emerging from the interviews included the anticipation of the spouses' death. For some this period was associated with a sense of distance and difficulties in communicating and sharing emotions. Conversely, for others it was marked by an increased intimacy and togetherness characterised by love and sincerity. Participants lacked: "the space to grieve" (p. 342); individuals felt lonely, powerless and afraid, and experienced a: "sense of helplessness" witnessing their spouse's suffering (p. 343) whilst also attempting to remain composed.

Gunnarsson and Ohlen (2006) found also that most individuals were profoundly fatigued by the demands of care-giving, and that there was a tendency to subjugate their own needs. Participants were required to take an advocate role and to make difficult decisions, for instance regarding the medical care of their spouses, whilst also attempting to maintain a normal family life and routines. In this study, the interviewer had a prior relationship with participants which may have been a source of bias, or equally may have increased rapport. Reliability was enhanced by researcher triangulation.

The challenges of home-based palliative care were also explored in a Norwegian study by Hunstad and Svindseth (2011). Seven individuals participated, both males and females whose spouse had died within the last two years. Interviews were analysed using a phenomenological approach. As reported by Gunnarsson and Ohlen (2006) participants expressed the difficulty of witnessing the spouse's suffering. Individuals also described finding it hard to do anything to help at these times and feelings fluctuating between helplessness and competence. Again, similarly to Gunnarsson and Ohlens' findings, participants identified putting their own needs on hold in order to care. Care-giving was, at times, a burden for participants however individuals did not regret caring for their spouses at home.

The process of accepting their spouse's coming death was a gradual one with participants oscillating between acceptance and hope for survival. For many participants acceptance prompted "serious conversations" with their spouse (p.399), leading to a new and different intimacy. Religion also appeared a comfort for some. Researcher triangulation occurred with interview transcripts independently analysed by two researchers.

Two studies exploring the experiences of individuals in same-sex relationships in Ireland highlighted how the negative reactions of health care staff could exacerbate feelings of distress and isolation during a partner's LLI (Glackin & Higgins, 2008; Higgins & Glackin, 2009). Participants were seven individuals, three men and four women, whose same-sex partner had died. Five partners had died of cancer and two had died suddenly. Participants felt excluded in hospital settings if they were not seen as having status by staff. This related to incidents such as other family members being contacted with information about the patient's condition despite the participant being recorded as next of kin. One participant spoke of a healthcare professional's apparent anger upon learning the patient was in a same-sex relationship because they felt there was a risk of infection to staff. This study highlights the importance of health care staff's responses to family members and the role that staff can play in easing or exacerbating their distress. Reliability checks were not detailed.

An American study by Gardner (2008) focused on older couples' experiences of end-of-life. Thirty five individuals aged 55 or older with advanced cancer and their spouses or partners participated. Participants were interviewed as couples and individually, transcripts were analysed using grounded theory. Unlike the participants in Hunstad and Svinseth's study (2011), most partners "rarely, if ever, discussed death with each other" (p.147). The author also noted that some participants spoke more candidly when interviewed without their partner present. There was uncertainty about the illness and the future and for some this adversely affected the relationship. Individuals “struggled to redefine their roles” in light of new challenges (p. 145).

It was noted that some couples were working towards constructing a shared narrative of their experiences, including working together to maintain a positive outlook. Faith or religion were significant for some participants, though if couples did not share the same beliefs this could hinder the support process. Reliability of findings was enhanced by triangulation of couples’ accounts and researcher triangulation. Field notes and memos formed an audit trail.

Palm and Friedrichsen (2008) explored the experience of closeness in home-based palliative care in their Swedish study. Ten individuals were interviewed and data were analysed using a phenomenological approach. Participants were individuals whose spouses were receiving home-based palliative care. Seven men and three women took part. Participants spoke of a sense of togetherness, and physical and emotional closeness in everyday life. For some this included “physical closeness” (p. 8), for others simply the presence of their spouse. To maintain closeness it was necessary to live in the present moment and to prioritise closeness without allowing illness to dominate all of the time that the couple shared. Closeness was facilitated by the spouse continuing to live at home; in some cases couples continued to be able to share a bed. Participants needed time away from their spouses, but also experienced feelings of guilt about this.

Closeness was hindered by physical changes to the spouse’s body, pain, and feelings of unattractiveness related to the physical impact of illness. Communication could be adversely affected by changes in the personality of the spouse, including mood and cognitive ability. Participants sometimes repressed their feelings. These difficulties could lead to loneliness on the part of the participant. It was also necessary for participants to adjust to a new role and take on the responsibilities of physical care for their spouse. This left some feeling: “more like a caring nurse with duties than a partner in a loving relationship” (p. 10). Overall the experience of closeness changed as a result of LLI; strained in some ways and enhanced in others. Steps were taken to increase the reliability of analysis, including researcher triangulation and discussing findings with other researchers in the palliative care field. Bracketing was used to acknowledge the author’s pre-conceptions, which was particularly important since the author was a nurse working in a palliative care setting.

The impact of cancer related anorexia and cachexia on family members in general has already been discussed in this review (Yamagishi et al., 2010; Reid et al., 2009). However, a Swiss study conducted by Strasser, Binswanger, Cerny, and Kesselring (2007) explored the effects on couples more specifically. Nineteen men with advanced cancer and their female partners participated and both quantitative and qualitative methods were used. Focus groups and an interview were analysed using aspects of grounded theory. Participants also completed questionnaire measures. Quantitative analysis revealed that the women’s level of eating-related distress was significantly higher than that of their partners. Female participants also significantly overestimated their partner’s levels of pain, anxiety, depression, and nausea.

Female participants changed their cooking habits and began cooking patients’ favourite meals, they also felt hurt when their partners were unable to eat the food they had prepared, similarly to participants interviewed by Reid et al. (2009). Patients’ inability to eat was also a reminder to their partners of their impending loss and they attempted: “to fight the inevitable by cooking” (p. 134). Pressure was placed on patients to eat by their partners, both consciously and unconsciously. Quantitative findings achieved high levels of significance. Qualitative findings were presented to patients, partners and professionals to verify their validity.

Key Themes

In studies which explored the impact of having a spouse or partner with an LLI there were several aspects of the experiences described by participants which arose in more than one study. There were also five themes which emerged in three or more papers.

Changing Role. It was evident in several studies that individuals' roles had evolved from that of 'spouse' or 'partner' to accommodate additional responsibilities related to care-giving. This included engaging in physical care, taking on an advocate role and making complex decisions relating to the medical care of their spouses. There was also a need for individuals to take over aspects of the roles previously occupied by their partners. Participants described changes in their own personality as a result. For some redefining their roles in this way was a struggle. Taking on the responsibilities of physical care left some feeling more like a nurse than a partner (Gunnarsson & Ohlen, 2006; Gardner, 2008; Riley & Fenton, 2007; Palm & Friedrichsen, 2008).

Closeness. For some the period of their partners' illness was marked by an increased intimacy and togetherness characterised by love and sincerity. Acceptance of the partner's prognosis led some couples to engage in serious conversations which led to a new and different intimacy. Participants in one study spoke of a sense of togetherness, and physical and emotional closeness in everyday life. For some this included physical closeness, for others simply the presence of their spouse. (Gunnarsson & Ohlen, 2006; Hunstad & Svindseth, 2011; Palm & Friedrichsen, 2008).

Thoughts and emotions that were difficult to express. Not all couples experienced increased closeness during the course of the illness. In contrast, for some this was a period associated with a sense of growing distance and difficulties in communicating and sharing emotions. Some participants repressed their feelings; others avoided discussing the topic of death with their partner (Gunnarsson & Ohlen, 2006; Riley & Fenton, 2007; Palm & Friedrichsen, 2008).

Anger. Participants in three studies described feelings of anger in reaction to their partner's prognosis. In two studies this was at the point of diagnosis. Participants also expressed feeling shocked and numb at this time. In a third study anger was related to a distinct moment at which participants realised that their spouse would soon die. In these cases anger was accompanied by feelings of despair and resignation (McLaughlin et al., 2010; Gunnarsson & Ohlen, 2006; Riley & Fenton, 2007).

Religious beliefs. Participants in one study spoke of the importance of their religious faith in relation to coping with their partner's illness. Religion also appeared a comfort to some other individuals. However if couples did not share the same religious beliefs this could hinder the support process (Hunstad & Svindseth, 2011; Gardner, 2008; Riley & Fenton, 2007).

Studies Focusing on the Experiences of Parents Who Have a Child with a Life Limiting Illness

In a Dutch study Kars, Grypdonck, and van Delden (2011) explored the experiences of 42 parents of 22 children with advanced cancer. Individuals took part in semi-structured interviews, analysed using inductive thematic analysis. Parents described the "collapse of their parenthood" upon hearing the news that their child's illness was incurable (p. 262). This affected individuals' sense of identity and the hoped for and imagined future was lost. Parents needed to feel that they had done everything that they could for their child; some focused on prolonging life, others solely on symptom management. After being told their child's prognosis parents found that they were suddenly given more responsibility by healthcare staff for decision making. Though parents appreciated the increased recognition they were also left without a model to guide their decisions.

Most children were told the nature of their illness and witnessing the child’s response evoked feelings of powerlessness in parents. Parents also discussed death fairly openly with one another, and “forced themselves to keep going” for the welfare of their child (p. 264). This was aided by the routine of day to day life and the unconditional love they felt. During the course of the illness parents focused on making life as enjoyable as possible for their child and this was a source of pleasure for parents too, although the situation felt “fragile” (p. 265).

Parents were moved by incidents that highlighted their child’s identity, and there were often times when the child’s illness was not immediately apparent. As the child’s health declined parents wanted to be present for their child whilst they were suffering. Parents achieved this but felt exhausted and overwhelmed. In order to keep going parents stayed busy and damped down their emotions. A number of measures to increase reliability and validity of results were described by the authors; theoretical saturation was reached and researcher triangulation and the use of an audit trail increased reliability of the analysis. Peer review was employed and findings were discussed with experts in the field.

An emphasis on maintaining normality and keeping going was also evident in a Canadian study by Zelcer, Cataudella, Cairney, and Bannister (2010). Twenty five parents, both males and females, of 17 children who had died of brain tumours participated in semi-structured focus groups. Transcripts were analysed using thematic analysis. Continuing normal life as far as possible was a consistent theme and formed part of the families’ efforts to cope with the illness. Engagement in friendships and at school was therefore facilitated despite the progression of the child’s condition. Sources of strength for parents included holding onto the hope of a cure and seeing the resilience of their child.

Witnessing their child's decline involved experiencing both the child's loss of physical functioning and loss of the capacity to communicate. Many parents reported that their children were aware of their physical decline. Children were saddened and frustrated by no longer being able to participate in activities that they enjoyed. Loss of verbal and non-verbal communication created anger and frustration on the part of the child and other family members "at not being able to understand the child's wants and needs" (p. 227).

Parents were required to juggle competing responsibilities and to balance the needs of the unwell child with those of any other children, and with their jobs. Parents also needed to hold dual roles; to take responsibility for nursing the child whilst also wanting to be "just a parent" (p. 228). Another struggle for parents was if and how to speak to their child about death. Some parents noted that their child accepted the advanced stage of their illness before the parents did themselves. Parents who had not discussed death with their child sometimes later regretted this. Rich detailed descriptions of experiences emerged from this study, and the reliability of analysis was improved by researcher triangulation. It is notable however that accounts were retrospective and focus groups conducted up to 12 years after the child's death. Some potential participants were also excluded because their oncologist judged them to be at risk of experiencing "significant psychological repercussions" (p. 226). Whilst this is ethically defensible it is also likely to have influenced the study findings.

Another Canadian study, by Steele and Davies (2006) explored the experiences of parents whose children had a progressive illness. Twenty nine individuals were interviewed individually and transcripts were analysed using grounded theory. Detailed information about methodology and participant demographics was not included. Parents experienced many losses including "their dreams for the child and their life plans" (p. 578). This echoed the accounts of participants in Kars, Grypdonck, and van Delden’s study (2011) who described the loss of the imagined future.

Throughout the paper there is a profound sense of participants’ grief, which was described as being ever present although the intensity fluctuated. Parents grieved most intensely in the first 6-12 months after diagnosis. The sense of grief, fear, and uncertainty increased again each time a change occurred in the child’s condition and this left participants with the feeling that they were experiencing a “’roller coaster’ of grieving that they would be riding forever” (p. 578). The extent of the loss felt by participants was often unacknowledged by others including friends, family and healthcare staff.

Some parents felt a sense of helplessness and some were reported to be clinically depressed; two parents had considered or attempted suicide. Parents also reported deep sadness, tearfulness, anxiety attacks and feelings of guilt, which were associated with the genetic aspect of their child’s condition. Parents attempted to block out their suffering with many using prescribed anti-depressants, or self-medicating with alcohol or illegal drugs.

Some participants did experience “personal growth” and “created positive meanings out of the experience” (p. 579). There were also physical, financial, and spiritual consequences of the child’s illness. Physically parents were exhausted experiencing a chronic lack of sleep. Parents also suffered from health problems including back pain, migraines, and anaemia. Financially families were adversely affected via lost income as a result of giving up paid employment and through the many hidden costs related to the child’s illness such as making adaptations to the home. Spiritually, religious faith aided some parents, helping them to find peace. Others felt punished and let down by God.

The financial impact of a child’s illness was also felt by participants in a British study involving three mothers of children or young people with life limiting or life threatening illnesses (Runswick-Cole, 2010). The mothers were interviewed and themes in their accounts identified. The generalisability of findings is limited by the small sample size.

Participants experienced poverty related to low family income and considerable additional costs incurred catering for their children's needs. The mothers were also acutely isolated both physically, due to difficulty in leaving the house, and socially. Participants experienced a "lack of practical support" from family members who were perceived as having a "hostile" attitude towards their children (p. 818). Practical barriers including the complex care needs of their children, and increased isolation from friends. Participants also reported feeling different from other mothers. Support from professionals including social workers was valued by the women and continuity in the professionals working with the family was considered important, but did not always occur. Experiences of respite services were mixed with some barriers encountered. A key concern for participants was the future care of their children which was related to a lack of support, and limited choices and income. These factors resulted in the women living with a sense of uncertainty.

The theme of support, and of helpful and unhelpful support received by parents was further explored in a British study (Brewer et al. (2007). Participants were parents or guardians of young people with Juvenile Huntington's Disease. Eight women and four men were interviewed about their experiences and data were analysed using interpretative phenomenological analysis. Many parents had limited social support available. This was for a number of reasons including that family members had other commitments, or found the situation hard to cope with. The long-term nature of the illness also meant that friends had difficulty sustaining support over an extended period of time. Additionally, in many cases parents had already experienced the loss of their partner. Support from professionals was therefore all the more vital.

Support from professionals was experienced as helpful by participants when those professionals actively listened and demonstrated empathy. Openness, honesty, flexibility, and consistency of support were all valued. Professionals were experienced as unhelpful when parents felt blamed for the children’s challenging behaviour, and when they felt that they were not listened to. Inflexibility in adapting to the child’s needs and staff turnover led to instability which also exacerbated difficulties. Themes were clearly detailed, and illustrated with excerpts from interview transcripts. Reliability and validity checks were not described.

A Northern Ireland study by Price, Jordan, Prior, and Parkes (2011) explored the experiences of parents whose children had died as the result of an LLI. Sixteen women and nine men participated in the study. Parents were interviewed between 6 and 24 months after the death of their child. Themes within and across interviews were identified.

Evident within parents’ accounts was an “overwhelming need to be actively ‘doing’ something purposeful for their child” (p. 1386). There were four main ways in which parents achieved this. Through a process termed: “piloting” (p.1386) individuals strived to find their way through the uncertainty and chaos. Parents felt a lack of control and sense of disruption, and were required to make complex decisions relating to their child’s care and wider issues affecting the family. The process of: “providing” (p.1387) entailed “giving physically and emotionally to meet the needs and wants of their child” and the rest of the family (p. 1387). Fathers were typically concerned with providing financially, in line with the traditional male ‘provider’ role. The many challenges to be faced induced a range of responses including feelings of guilt, exhaustion, isolation and anxiety.

Parents were instrumental in: “protecting” (p.1388) both the dying child and other relatives and friends. This sometimes extended to protecting the child from the full knowledge of death. It also meant being with their child during the final moments of their life. “Preserving” (p.1388) related to maintaining routines and the functioning of the family, similarly to parents in other studies (Kars, Grypdonck, & van Delden., 2011; Zelcer et al., 2010). It was unclear from this study whether a specific methodological approach had been adhered to, however the authors described several ways in which the reliability and validity of analysis had been enhanced. These included researcher triangulation, use of memos, and the identification of outliers.

Preservation also featured in the narratives of parents interviewed by Kars, Grypdonck, de Korte-Verhoef, et al. (2011). Forty four parents of children with advanced cancer were included in the Dutch study; ten were interviewed after the death of their child and all others during the course of the illness. Both male and female parents participated. Interviews were analysed using grounded theory. Preservation in the context of this study referred to keeping the child alive both by seeking life sustaining interventions, and postponing or avoiding those that were judged to carry a risk of hastening decline. Parents experienced an “internal struggle between preservation and letting go” (p. 33), oscillating between the two and, in most cases, slowly progressing towards the latter. This transition was extremely difficult for parents who experienced “unbearable” feelings of loss (p. 30).

Two studies considered the role of gender in the experiences of parents who have a child with a life limiting illness. In a British study Ware and Raval (2007) interviewed eight fathers of children with progressive conditions. The interviews were analysed using interpretative phenomenological analysis. Participants described receiving the diagnosis as: “devastating” (p. 554); they felt: “powerless” (p. 554) and that: “the world now seemed...dangerous and uncertain” (p. 553). There was a sense of isolation and of being abandoned by professionals and betrayed by friends and family through a lack of support and recognition. Some individuals had a sense of personal growth and a change in their values.

Participants tried to make sense of their situation but none were able to do so. Those with religious beliefs found this a source of comfort at times. Individuals’ faith was sometimes shaken but not abandoned. Relationships with partners either grew stronger or were placed under strain and participants had less time and energy to devote to these relationships.

Participants felt that there were gender differences in the way that men and women responded and coped. They reported feeling constrained by gender roles and perceived men as being less open with their emotional responses and needing to appear strong; publicly and for their partner. This was despite the fact that participants generally felt that maintaining this mask was unhelpful. The fathers interviewed felt that women generally had wider support networks than men and that services were tailored more towards women. They hoped for improvements in services and greater support geared towards men. A number of measures were used to improve the reliability and validity of the study including the use of an audit trail and reflective diary. Results were also discussed with colleagues working in the field of childhood life limiting illness.

Schneider, Steele, Cadell, and Hemsworth (2011) looked specifically at gender differences on a range of psychosocial outcomes in parents and guardians of children with a life limiting illness. Two hundred and seventy three individuals participated in this Canadian study, 224 of whom were female. Parents completed a battery of standardised questionnaire measures in order to assess: “posttraumatic growth”, “meaning in care-giving”, “self esteem”, “optimism”, “spiritual involvement and beliefs”, “depression”, and caregiver burden (p.190).

Women were found to score significantly higher than men for depression and caregiver burden, and significantly lower for optimism. Women also had significantly higher scores for “meaning in care-giving” (p.192). There were further gender differences in the patterns of correlations between variables. These findings support the theory that there are differences in how male and female parents of a child with a life limiting illness are impacted upon. It is notable that although male and female participants were well matched for educational level there were many differences between them including the number of hours per week they spent caring and their employment status. These are factors likely to have influenced outcomes.

Key Themes

In studies which explored the impact of having a child with an LLI there were seven themes to the experiences described by parents which arose in three or more papers.

Unpredictability. Following their child's diagnosis the world was perceived as a more dangerous and unpredictable place and individuals strived to find their way through the uncertainty and chaos. Uncertainty relating to the future care of their children was a key concern for some parents, who had limited resources (Runswick-Cole, 2010; Price et al., 2011; Ware & Raval, 2007).

Tiredness/ fatigue/exhaustion. The many challenges faced by parents left them physically exhausted. Parents pushed themselves in order to be present for their child whilst they were suffering, despite feeling overwhelmed. Some parents also experienced a chronic lack of sleep. (Price et al., 2011; Kars et al, 2011; Steele & Davies, 2006).

Thoughts and emotions that were difficult to express. Parents felt unable to express particular thoughts and emotions for varying reasons. Parents faced a dilemma about if and how to speak to their child about death and some chose not to discuss it. Some male parents felt constrained by stereotypical gender roles and perceived it as less acceptable for men to be open with their emotional responses. Other parents suppressed their emotions to enable themselves to continue functioning (Kars, Grypdonck, & van Delden, 2011; Zelcer et al., 2010; Ware & Raval, 2007).

Powerlessness/ helplessness. Parents felt a sense of helplessness and powerlessness in response to receiving their child's diagnosis and their ongoing condition. Witnessing the child's reaction to diagnosis also evoked feelings of powerlessness in parents (Kars, Grypdonck, & van Delden, 2011; Steele & Davies, 2006; Ware & Raval, 2007).

Isolation/abandonment. Isolation was one of the many challenges faced by parents and the extent of the losses with which they were confronted during their child's illness was sometimes unacknowledged by others including friends, family, and professionals. This lack of support and recognition left some parents with a sense of being abandoned and betrayed. Parents found themselves isolated both physically, due to difficulty in leaving the house, and socially. Barriers to social support were numerous and included the attitudes of others, their children's complex care needs, family members other commitments or difficulty coping with the situation, and a sense of feeling different to other parents. In cases where children had inherited genetic conditions some parents had already experienced the loss of their partner (Steele & Davies, 2006; Runswick-Cole, 2010; Brewer et al., 2007; Price et al., 2011; Ware & Raval, 2007).

Witnessing decline/ suffering. In some cases the decline in the children's condition involved both a loss of physical functioning and a loss of the capacity to communicate. Parents reported that their children were saddened and frustrated by no longer being able to participate in activities that they had enjoyed. Loss of verbal and non-verbal communication resulted in feelings of anger and frustration on the part of children and other family members. Being present for the child whilst they were suffering was exhausting and overwhelming. Each time a change occurred in the child's condition this triggered an increased sense of grief, fear, and uncertainty in parents (Kars, Grypdonck, & van Delden, 2011; Zelcer et al., 2010; Steele & Davies, 2006).

Maintaining normality. Attempts to continue normal life as far as possible were illustrated by parents across different studies. This included maintaining routines and the functioning of the family and formed part of families' efforts to cope with the illness. Parents facilitated their child's engagement in friendships and at school despite the progression of their condition. Parents pushed themselves to keep going for the welfare of their child and tried to make life as enjoyable as possible (Kars, Grypdonck, & van Delden, 2011; Zelcer et al., 2010; Price et al., 2011).

Discussion

Overarching Themes

Recent research exploring the impact of a life-limiting diagnosis on family members has been considered. It is evident from the literature that effects are wide-ranging; including physical, emotional, psychological, and relational components. A matrix of key themes from each study is included in Appendix C. No themes appeared universal, and no single theme featured prominently in even a third of the papers discussed. This finding is perhaps unsurprising given that each study had a unique focus. Participant characteristics, for instance age, gender, nationality, and relationship to the patient, also varied considerably between and often within studies. Six themes featured most prominently and were evident in 8 or more of the 36 studies reported. The following summaries refer to the previously cited literature.

Powerlessness/helplessness. Feelings of powerlessness or helplessness featured in 11 studies. Helplessness was related to witnessing the patient's suffering, and being unable to relieve it. Individuals made attempts to remain composed in the face of their relative's suffering and some oscillated between feelings of helplessness and competence. For parents in particular there was a sense of helplessness and powerlessness evoked by receiving their child's diagnosis.

Isolation/ abandonment. A sense of isolation or abandonment by others was evident in 10 studies. Participants' caring role could contribute to feeling isolated and disconnected from others, both physically and socially. In some cases support networks dwindled and social lives became very limited. Isolation was associated both with family members own lack of energy and others' lack of understanding and recognition, and this impacted on family members emotionally. Some individuals felt excluded, abandoned, deserted, or betrayed by others including friends, family, and professionals, leading in some cases to feelings of resentment. Where children had inherited genetic conditions some parents were further isolated due to having already experienced the loss of their partner.

Witnessing decline. The difficulty of witnessing the family member's decline featured in 9 studies. It was very hard for individuals to observe the deterioration of their family members' health including their cognitive and physical decline, helplessness, suffering, and loss of the capacity to communicate. Participants were concerned about the risk of their relatives becoming injured and patients became increasingly dependent on family members for support. Parents witnessed their children's sadness, anger, and frustration and being present for their child whilst they were suffering was exhausting and overwhelming.

Fatigue/ exhaustion. Fatigue or exhaustion was mentioned in 9 studies. Individuals were exhausted by the physical impact and demands of caring for a family member, with some experiencing a chronic lack of sleep. This exhaustion impacted on both the physical and mental health of caregivers.

Guilt. Feelings of guilt featured in 9 studies. The basis of these guilty feelings varied; for some individuals feelings of guilt were related to a belief that they should have done more to help their family member, for others guilt was associated with the need for some time away from their unwell spouse. Where patients were suffering with cancer related anorexia or cachexia family members experienced feelings of guilt when they were unable to entice the patient to eat. Some parents also reported feelings of guilt associated with the genetic aspect of their child's condition.

Unpredictability. The concept of unpredictability was noted in 8 studies. The uncertain trajectory of the illness provoked feelings of anxiety and fears were expressed about the future; including the future care of children with LLIs, which was a key concern for some parents. For other parents the world was perceived as a more dangerous and unpredictable place following diagnosis. A sense of uncertainty adversely affected some couple relationships.

Limitations

The 'key' and 'overarching' themes identified were selected on the basis of their prevalence in the original studies discussed; for each sub-section the most frequently occurring themes were outlined. This method was used in the interests of adopting a systematic approach to the data; however it did not take account of variation in the quality of the studies included, or the richness and depth with which the themes were described.

The literature search was restricted to studies published within the last five years due to a desire to select the most up to date research and a need to be succinct. This review therefore favoured depth over breadth in relation to the literature. It is acknowledged however that there will be other valuable and significant papers which could not be included as a result.

Clinical and Research Implications

Research implications. A limitation of some studies featured was the heterogeneity of participants which created the potential for people in diverse circumstances to be grouped together. There was considerable variation evident in the themes that emerged from different studies; again highlighting that individuals in different situations had some very different experiences of care-giving. Consequently there is value in focusing on specific, homogeneous, groups of participants in order to hear their distinct voices more clearly. A detailed, in depth, understanding of the experiences unique to a particular group was evident in the studies of Ware and Raval (2007), who interviewed fathers of children with LLIs, and Runswick-Cole (2010), who interviewed mothers.

Due to limited space it was necessary to exclude studies which related to further groups of family members; for example children who have a parent with an LLI (e.g. MacPherson and Emeleus, 2007a, b). Future reviews could therefore focus on critically evaluating studies relating to additional groups of family caregivers who were not identified for inclusion in this paper.

Clinical implications. Research demonstrates the profound impact which a life-limiting diagnosis has on family members. It is essential that professionals demonstrate an awareness of this in their clinical work; including attending to and validating the feelings of guilt, isolation, exhaustion, and helplessness which patient’s family members may experience. Where appropriate services could help reduce isolation through facilitating supportive groups for care-givers. There may also be a need to provide or signpost towards respite care.

Where specialist psychological support is warranted there are specific approaches which may lend themselves to working therapeutically with some of the difficulties identified. A compassion-focused approach could facilitate holding a kinder view of the self and ameliorate feelings of guilt (Gilbert & Irons, 2005); mindfulness could be beneficial in enabling individuals to tolerate feelings of uncertainty or helplessness (Segal, Williams, & Teasdale, 2002).

References

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (ipa): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, *5*(3), 214-224. doi:10.1080/14780880802314304

Brewer, H., Smith, J., Eatough, V., Stanley, C., Glendinning, N., & Quarrell, O. (2007). Caring for a child with juvenile huntington's disease: Helpful and unhelpful support. *Journal of Child Health Care: For Professionals Working With Children In The Hospital And Community*, *11*(1), 40-52.

Carlander, I., Sahlberg-Blom, E., Hellström, I., & Ternestedt, B. (2011). The modified self: family caregivers' experiences of caring for a dying family member at home. *Journal Of Clinical Nursing*, *20*(7-8), 1097-1105. doi:10.1111/j.1365-2702.2010.03331.x

Gardner, D. (2008). Cancer in a dyadic context: older couples' negotiation of ambiguity and search for meaning at the end of life. *Journal Of Social Work In End-Of-Life & Palliative Care*, *4*(2), 135-159.

Gilbert, P., & Irons, C. (2005). Focused therapies and compassionate mind training for shame and self-attacking. In P. Gilbert (Ed.), *Compassion conceptualisations, research and use in psychotherapy* (pp. 263-325). East Sussex: Routledge.

Glackin, M., & Higgins, A. (2008). The grief experience of same-sex couples within an Irish context: tacit acknowledgement. *International Journal Of Palliative Nursing*, *14*(6), 297-302.

Gunnarsson, H., & Öhlén, J. (2006). Spouses' grief before the patient's death: Retrospective experiences related to palliative home care in urban Sweden. *Mortality*, *11*(4), 336-351. doi:10.1080/13576270600945527

Hasson, F., Kernohan, W., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H., &

Cochrane, B. (2010). An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine*, *24*(7), 731-736.

Higgins, A., & Glacken, M. (2009). Sculpting the distress: Easing or exacerbating the grief experience of same-sex couples. *International Journal of Palliative Nursing, 15*(4), 170-176.

Hudson, P., Trauer, T., Graham, S., Grande, G., Ewing, G., Payne, S., Stajduhar, K.I., & Thomas, K. (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine, 24*(7), 656-668.

Hunstad, I., & Foelsvik Svindseth, M. (2011). Challenges in home-based palliative care in Norway: a qualitative study of spouses' experiences. *International Journal Of Palliative Nursing*, *17*(8), 398-404.

Juarez, G., Ferrell, B., Uman, G., Podnos, Y., & Wagman, L. (2008). Distress and quality of life concerns of family caregivers of patients undergoing palliative surgery. *Cancer Nursing*, *31*(1), 2-10.

Kars, M., Grypdonck, M., & van Delden, J. (2011). Being a parent of a child with cancer throughout the end-of-life course. *Oncology Nursing Forum, 38*(4), E260-E271.

Kars, M., Grypdonck, M., de Korte-Verhoef, M., Kamps, W., Meijer-van den Bergh, E., Verkerk, M., & van Delden, J. (2011). Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. *Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer*, *19*(1), 27-35.

Kehl, K. A., Kirchhoff, K. T., Kramer, B. J., & Hovland-Scafe, C. (2009). Challenges facing families at the end of life in three settings. *Journal Of Social Work In End-Of-Life & Palliative Care*, *5*(3-4), 144-168.

Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, *33*(1), 28-36.

Mackenzie, C., Smith, M., Hasher, L., Leach, L., & Behl, P. (2007). Cognitive functioning under stress: evidence from informal caregivers of palliative patients. *Journal Of Palliative Medicine*, *10*(3), 749-758.

MacPherson, C., & Emeleus, M. (2007). Children's needs when facing the death of a parent from cancer: Part one. *International Journal of Palliative Nursing, 13*(10), 478-485.

MacPherson, C., & Emeleus, M. (2007). Children's needs when facing the death of a parent from cancer: Part two. *International Journal of Palliative Nursing, 13*(12), 590-597.

McLaughlin, D., Hasson, F., Kernohan, W., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2010). Living and coping with Parkinson's disease: perceptions of informal carers. *Palliative Medicine*, *25*(2), 177-182.

Morasso, G., Costantini, M., Di Leo, S., Roma, S., Miccinesi, G., Merlo, D., & Beccaro, M. (2008). End-of-life care in Italy: personal experience of family caregivers. A content analysis of open questions from the Italian Survey of the Dying of Cancer (ISDOC). *Psycho-Oncology*, *17*(11), 1073-1080.

Namba, M., Morita, T., Imura, C., Kiyohara, E., Ishikawa, S., & Hirai, K. (2007). Terminal delirium: families' experience. *Palliative Medicine*, *21*(7), 587-594.

National Council for Hospice and Specialist Palliative Care Services. (2002). *Definitions of supportive and palliative care* (Briefing No. 11). Retrieved from http://www.ncpc.org.uk/

National Institute for Clinical Excellence. (2004). *Improving supportive and palliative care* *for adults with cancer: The manual.* Retrieved from http://www.endoflifecareforadults.nhs.uk/publications/improving-supportive-and-palliative-care-for-adults-with-cancer

Osse, B., Vernooij-Dassen, M., Schadé, E., & Grol, R. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing*, *29*(5), 378-388.

Palm, I., & Friedrichsen, M. (2008). The lived experience of closeness in partners of cancer patients in the home care setting. *International Journal Of Palliative Nursing*, *14*(1), 6-13.

Persson, C., & Sundin, K. (2008). Being in the situation of a significant other to a person with inoperable lung cancer. *Cancer Nursing*, *31*(5), 380-388.

Persson, C., Ostlund, U., Wennman-Larsen, A., Wengström, Y., & Gustavsson, P. (2008). Health-related quality of life in significant others of patients dying from lung cancer. *Palliative Medicine*, *22*(3), 239-247.

Price, J., Jordan, J., Prior, L., & Parkes, J. (2011). Living through the death of a child: a qualitative study of bereaved parents' experiences. *International Journal Of Nursing Studies*, *48*(11), 1384-1392.

Raphael, K. (1987). Recall bias: a proposal for assessment and control. *International Journal Of Epidemiology*, *16*(2), 167-170.

Ray, R., & Street, A. (2006). Caregiver bodywork: family members' experiences of caring for a person with motor neurone disease. *Journal Of Advanced Nursing*, *56*(1), 35-43.

Reichertz, J., & Zielke, B. (2008). Editorial: Theories that matter: On some pragmatic aspects of social constructionism. *Forum: Qualitative Social Research, 9*(1). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/346/755

Reid, J., McKenna, H., Fitzsimons, D., & McCance, T. (2009). The experience of cancer cachexia: a qualitative study of advanced cancer patients and their family members. *International Journal Of Nursing Studies*, *46*(5), 606-616.

Riley, J., & Fenton, G. (2007). A terminal diagnosis: The carers' perspective. *Counselling & Psychotherapy Research*, *7*(2), 86-91. doi:10.1080/14733140701327909

Runswick-Cole, K. (2010). Living with dying and disabilism: Death and disabled children. *Disability & Society*, *25*(7), 813-826. doi:10.1080/09687599.2010.520895

Schneider, M., Steele, R., Cadell, S., & Hemsworth, D. (2011). Differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses. *Journal of Pediatric Nursing, 26*(3), 186-199.

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression. A new approach to preventing relapse.* New York: The Guildford Press.

Seymour, J., Payne, S., Reid, D., Sargeant, A., Skilbeck, J., & Smith, P. (2005). Focus. Ethical and methodological issues in palliative care studies: the experiences of a research group. *Journal of Research In Nursing*, *10*(2), 169-188.

Shanmugasundaram, S., & O'Connor, M. (2009). Palliative care services for Indian migrants in australia: experiences of the family of terminally ill patients. *Indian Journal of Palliative Care*, *15*(1), 76-83.

Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B., & Watson, B. (2008). Active carers: living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing*, *14*(8), 368-372.

Spichiger, E. (2008). Living with terminal illness: patient and family experiences of hospital end-of-life care. *International Journal Of Palliative Nursing*, *14*(5), 220-228.

Steele, R., & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal Of Palliative Nursing*, *12*(12), 576-585.

Strasser, F., Binswanger, J., Cerny, T., & Kesselring, A. (2007). Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliative Medicine*, *21*(2), 129-137.

Tang, S., Li, C., & Liao, Y. (2007). Factors associated with depressive distress among Taiwanese family caregivers of cancer patients at the end of life. *Palliative Medicine, 21*(3), 249-257.

Ware, J., & Raval, H. (2007). A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect. *Clinical Child Psychology And Psychiatry*, *12*(4), 549-565.

Wong, M., & Chan, S. (2007). The experiences of Chinese family members of terminally ill patients - a qualitative study. *Journal of Clinical Nursing*, *16*(12), 2357-2364.

World Health Organization. (2012). *Who definition of palliative care.* Retrieved 15th January 2012 from http://www.who.int/cancer/palliative/definition/en/

Yamagishi, A., Morita, T., Miyashita, M., Sato, K., Tsuneto, S., & Shima, Y. (2010). The care strategy for families of terminally ill cancer patients who become unable to take nourishment orally: recommendations from a nationwide survey of bereaved family members' experiences. *Journal Of Pain And Symptom Management*, *40*(5), 671-683.

Zelcer, S., Cataudella, D., Cairney, A., & Bannister, S. (2010). Palliative care of children with brain tumors: a parental perspective. *Archives Of Pediatrics & Adolescent Medicine*, *164*(3), 225-230.

Empirical Paper

The Experience of Living with a Husband or Partner who has a Life-Limiting Illness

Anna Jepson

University of Southampton

Abstract

Couple relationships may alter in a myriad of ways in the context of life-limiting illness. This research uses a qualitative, idiographic, approach in seeking to develop a greater understanding of what it means to be an older woman in a relationship who knows that her partner is dying and that time is limited, whilst also managing the effects of deteriorating health and symptoms such as fatigue and pain. To explore this question six women, aged 65 years or older, who had a husband with a life-limiting illness were interviewed about their experiences. Interviews were analysed using Interpretative Phenomenological Analysis and rich information about the women's relationships emerged from their accounts. This led to the development of six over-arching themes; holding uncertainty, living alongside dying, enduring partnership, attunement Vs alienation, preserving Vs relinquishing, and coming to terms. Twenty emergent themes were evident within these over-arching constructs, helping to elucidate the commonalities and variations in the women's narratives and offering insights into the relational aspects of life-limiting illness in older couples. Findings are discussed in relation to the existing literature and clinical and research implications are considered.

Introduction

An estimated 15% of households in England include an informal carer (NHS information centre, 2010). Where an individual is cared for by someone from within the household this is most likely to be their spouse or partner (Office for National Statistics; ONS, 2012).

Relationships in the Context of Illness

Many studies exploring the impact of chronic or life-limiting illnesses on relatives have included heterogeneous groups of participants; varying in terms of age, gender, and relationship to the unwell person (for e.g. Carlander, Sahlberg-Blom, Hellstrom, & Ternestedt, 2010; Osse, Vernooi j-Dassen, Schade, & Grol, 2006; Spichiger, 2008). Braun et al. (2009) highlighted the need for research studies that investigate the impact of care-giving to differentiate between spousal and parent-child relationships; suggesting that there may be important differences in terms of emotional responses, stress levels, and self-efficacy, depending on the nature of the relationship.

Physical and emotional impact on partners/ spouses. Spouses are usually the first to provide daily care and support if their husband or wife is unwell (Yorganson et al., 2010) and this can impact adversely on the care-giving spouse's well-being. Yorganson et al. interviewed couples in which both partners had chronic illnesses and identified that many had felt frustrated, overwhelmed, or depressed by the experience. The literature also suggests that spousal carers experience other ‘difficult’ emotions such as:

Anger. McLaughlin et al. (2010) interviewed spouses of individuals with Parkinson’s disease and reported the feelings of anger and of shock experienced by participants in response to their spouse’s diagnosis. Feelings of anger in reaction to the diagnosis of a spouse’s chronic or life-limiting illness were also expressed by individuals interviewed by Riley and Fenton (2007). Anger arose again in the accounts of participants in a study by

Gunnarsson and Ohlen (2006). In this study spouses of individuals who had received home-based palliative care were interviewed; anger related to the moment at which participants had realised that their spouse would soon die.

Distress. Strasser, Binswanger, Cerny, and Kesselring (2007) explored the impact of cancer related anorexia and cachexia on men with advanced cancer and their female partners. The female partner's level of eating-related distress was reported to be significantly higher than that of the men; they also significantly overestimated the level of anxiety, depression, pain, and nausea experienced by their partner. Similarly, research has indicated that spouses of men with prostate cancer report greater levels of emotional distress than do the men themselves (Northouse, et al. 2007).

Exhaustion. Gunnarsson and Ohlen (2006) also found that most participants were profoundly fatigued by the demands of caring for their spouses, a finding which is well-documented in the broader care-giving literature (e.g. Cangelosi, 2009; Usher & Cammarata, 2009; Black et al., 2010)

Changes in the relationship between partners/ spouses. ***Shifting roles.*** When an individual becomes ill, the relationship between partners changes, and may continue to alter over the course of an illness, with one partner providing increasing care for the other (Greenberg, Stacy, & Penzo, 2001). Gunnarsson and Ohlen (2006) found a tendency for individuals to subjugate their own needs when caring for their spouses; participants also reported being required to take an advocate role on behalf of their spouses, for instance making decisions regarding their medical care. Individuals interviewed by both McLaughlin et al. (2010) and Riley and Fenton (2007) described assuming responsibility for aspects of the roles previously carried out by their spouses. Palm and Friedrichsen (2008) explored the experiences of individuals whose spouses were receiving home based palliative care and found it was necessary for participants to take on a nursing role, providing physical care for their partners.

Role changes emerging in illness can be challenging for both parties; Robinson, Clare, and Evans (2005) suggested that in dementia, partners may have difficulty adjusting to the loss of the previous relationship and the new responsibility of care-giving. Gardner (2008) interviewed older couples where one partner had advanced cancer and identified that individuals: “struggled to redefine their roles” (p. 145) in light of the circumstances they faced.

Communication patterns. Individuals interviewed by Palm and Friedrichsen (2008) reported that communication within their relationships could be detrimentally impacted by changes in the personality of their unwell spouse, including their cognitive ability and mood. Participants sometimes repressed their feelings, and this could lead to feelings of loneliness.

Varying patterns of communicating about the spouse or partner’s illness and dying itself are also evident in the literature. Of the individuals interviewed by Riley and Fenton (2007), some reported avoiding talking about the prospect of death with their spouse, while others spoke about it in depth and helped to plan the spouse’s funeral. For many individuals interviewed by Hunstad and Svindseth (2011), whose spouses had received home based palliative care, acceptance of the impending loss of their spouse had prompted important discussions between the couple. Conversely the couples interviewed by Gardner (2008) rarely or never spoke about death with one another.

Shared narratives. Alongside adjusting to their changed role of caregiver there was a “loss of future plans” (p. 180) evident in the accounts of participants interviewed by McLaughlin et al. (2010). Individuals spoke of having been robbed and a sense that they had lost the life they once shared with their spouse. It could be suggested that chronic or life-limiting illness will disrupt the shared narratives and expected futures held by some couples, in an extension of the way that it can be considered to disrupt an individual's ongoing life story and identity (Hyden, 1997). Gardner (2008) noted how some couples interviewed had responded by working towards a new shared account of their experiences, including working together to sustain a positive approach.

Sexuality and intimacy. In exploring the experience of closeness between spouses in home-based palliative care Palm and Friedrichsen (2008) found that physical closeness was hindered by changes to the unwell partner's body, pain, and feelings of unattractiveness associated with the physical effects of illness. Forbat, White, Marshall-Lucette, and Kelly (2011) noted that in the case of prostate cancer in particular sexual functioning is likely to be affected, and that research suggests this can impact on both the unwell person and their partner. Gilbert, Ussher, and Perz (2010) interviewed 20 individuals who were caring or had cared for a spouse or partner with cancer about their sexual relationships. Some individuals reported being able to renegotiate the nature of sexual intimacy in the couple relationship; others struggled to do this in light of existing relationship difficulties, an emphasis on the act of penetrative sex, or a shift towards viewing the unwell partner as a dependent child or patient.

Spousal Bereavement

The impact of spousal loss. Bereavement is considered one of the most stressful life events that individuals encounter (Latham & Prigerson, 2004). Research has highlighted some of the risks that can be associated with bereavement in spousal partners:

A study of 4395 married couples conducted by Hart, Hole, Lawler, Davey Smith, and Lever (2007) revealed that individuals who had been bereaved were themselves at higher risk of dying than non-bereaved individuals. Hospitalisation of a spouse alone has been associated with an increased risk of death in older adults (Christakis & Allison, 2006). Additionally, it was reported by Latham and Prigerson (2004) that a complex grief reaction following the death of a partner increases risk of suicidality, even after controlling for post-traumatic stress disorder and major depressive disorder.

However, although “some bereavements endanger mental health” not every loss is harmful in this way (Murray-Parkes, 1985, p.11). Murray-Parkes posited that “the fact that bereavements and other losses can lead to good or bad outcomes makes it important for us to understand the intermediate variables that lead up to these different outcomes, and to identify people at special risk” (p.11).

Complicated grief. Prigerson et al. (1995) developed a scale designed to assess “complicated grief” (p.65) after noting a specific cluster of difficulties experienced by some bereaved spouses that were clearly distinct from symptoms of anxiety and depression. These included: “preoccupation with thoughts of the deceased, searching and yearning for the deceased, disbelief about the death...and not accepting the death” (p.66) and were predictive of long-term difficulties in the bereaved individual. Risk factors for the development of complicated grief have now been established, facilitating the identification of individuals who may be especially susceptible to high levels of distress following bereavement. Possible risk factors include feeling unprepared for the death of a loved one, and the presence of pre-existing attachment difficulties (Zhang, Al-Jawahri, & Prigerson, 2006). Researchers have also explored specific vulnerability factors for complicated grief in family carers (Ghesquiere, Haidar, & Shear, 2011) and identified that features of complicated grief may be present in carers of cancer patients before death (Tomarken et al., 2008).

Attachment and loss. Attachment theory (e.g. Bowlby, 1988) asserts that a person’s childhood relationship experiences will dispose them to particular patterns of relating to significant others in adulthood (Hazan and Shaver (1987). Attachment theory also contends that when an individual is faced with a significant transition, such as separation from a spouse (e.g. through death), their existing attachments patterns and early separation experiences will be activated (Lipson-Parra, 1990).

The attachment literature highlights why exploring spousal/partner relationships is so crucial and how these relationships can impact on the complexity of bereavements. Specifically Wayment and Vierthaler (2002) reported that different attachment styles were associated with different reactions to death of a loved one; greater levels of grief and depression were related to an insecure attachment style whereas securely attached individuals were less likely to be depressed. Stroebe (2002) also linked attachment style to bereavement outcome, with secure attachment associated with “adaptive grieving” (p.134) and insecure attachment related to chronic grief.

Developing the Research Focus

Existing research has considered many ways in which bereavement and chronic or life-limiting illness can impact upon family members and couples. What appears to be missing from the literature at present is a more in depth appreciation of how particular groups of individuals may be affected by these life-events.

It has been suggested that couple relationships alter in a myriad of ways in the context of life-limiting illness. One such change is to the accepted roles inhabited by the individuals in the relationship; as illness progresses one partner may be required to take on aspects of the role previously occupied by the other, or to take on a new role of advocate or nurse. Most research has not distinguished between the experiences of male and female care-givers and thus not attended to possible differences in the way women and men might experience a change in role.

Equally, although a couple’s shared narrative and expected future may be disrupted by life-limiting illness, to date there has been no exploration of whether the potential for disturbance in the narrative differs for older and younger couples; and whether this impacts upon how a partner or spouse’s life-limiting illness is experienced. Similarly communication patterns and the nature of the sexual relationship can change and it yet is unclear how these changes are experienced by women or men, or differ for older or younger individuals.

This present research seeks to develop a greater understanding of what it means to be an older woman in a relationship with a husband or partner who has a life-limiting illness; knowing that her partner is dying and that time is limited, whilst also managing the effects of deteriorating health and symptoms such as fatigue and pain. It is hoped that by taking a participant-led approach to interviewing, rich and detailed information will emerge about these women’s experiences of their relationships.

Method

Methodological Approach

Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009). IPA is an increasingly popular qualitative research methodology (Hefferon & Gil-Rodriguez, 2011), offering researchers both a “theoretical foundation” for and a “detailed procedural guide” to analysis (Brocki & Wearden, 2006, p.87). IPA is concerned with conducting a detailed, in-depth, exploration of the way that individuals understand significant experiences (Smith et al., 2009). IPA is ‘phenomenological’ in the sense that analysis must be rooted in the experience itself rather than seeking to fit experience into pre-conceived constructs; it is ‘interpretative’ in holding the position that humans seek to make sense of their worlds (Smith et al., 2009).

IPA is idiographic and requires the researcher to examine individual cases in detail (Smith et al, 2009). As such IPA adopts a “more microscopic lens” than some other qualitative approaches, which seek to identify common features across a number of interviews (Eatough & Smith, 2008, p.182). Cases are typically compared within IPA, however this comparison can be considered “fine-grained”; focusing on the meaning-making experience of the individual (Eatough & Smith, p.182).

Rationale for selecting IPA. This research was concerned with exploring the subjective experience of being an older woman, living with a husband or partner who has a life-limiting illness. IPA enables the researcher to develop a rich understanding of the individual’s lived experience (Howes, Benton, & Edwards, 2005) and was therefore well suited to this aim.

An important ethical consideration was to ensure the suitability of the research method for a palliative care context, in order to minimise any additional burden on those who chose to participate. Qualitative methodologies can be viewed as the most appropriate in some palliative care research because they can be tailored to meet the participant's level of energy and resources (Lee & Kristjanson, 2003).

The focus, within IPA specifically, on the individual's lived experience also emphasizes the role of participant as active "story-teller" rather than passive "responder" (Eatough & Smith, 2008, p.182). The significant implication of this is that in keeping with this philosophy interviews were participant-led. This enabled individuals to focus, during the interview, on those aspects of their experience which they deemed salient and which they found it *acceptable to share*.

Participant Recruitment

Participants were recruited from a specialist outpatient daycentre and monthly carers group run by a Hospice in the South of England. The most appropriate method of recruitment was considered at length, specifically whether the researcher should represent the research themselves or ask a member of staff at the Hospice to act in a "gatekeeper" role distributing information on their behalf. One potential difficulty associated with using a gatekeeper was that patients might feel a debt of gratitude to staff at the hospice and feel beholden to consent to the research. Having considered both approaches it was decided that the researcher would outline the research themselves and request that participants opt in by asking a member of staff, unaffiliated with the study, for an information pack (a copy of the information sheet in an A4 envelope; Appendix D). In practice most participants approached the researcher directly to ask for further information about the research.

Sample size

Smith et al. (2009) suggested that an appropriate sample size for an IPA study completed during a professional doctorate would be between 4 and 10 interviews. The rationale for selecting a small sample size is that a primary concern of IPA is detail and "quality, not quantity" (Smith et al, 2009, p.51) and that attempting to work with a data set which is too large could adversely affect the depth of analysis. Further, Hefferon and Gil-Rodriguez caution against a "broader, shallow" analysis "of many individuals" (2011, p.756) emphasising that "less is more in IPA" (p.757).

In light of these recommendations a sample size of 10 was initially sought and ultimately interviews were successfully completed with six individuals.

Inclusion and exclusion criteria

A purposive sample was used and inclusion criteria consisted of being female, aged 65 or older, and having a spouse or partner with a life-limiting illness. A relatively homogenous sample of individuals was included in the research in line with guidance from Smith et al. (2009). Homogeneity was sought due to a consideration that with a small number of participants it would not be possible to achieve a sample that was representative of the population as a whole. Rather, IPA allows for a detailed exploration of the experiences of a particular group. Using a group of individuals who are demographically similar enables the researcher to "examine in detail psychological variability within the group, by analysing the pattern of convergence and divergence which arises" (Smith et al., 2009, p.50).

The chosen demographics of the sample; being female, aged 65 or older, and having a spouse or partner with a life-limiting illness, were selected for both pragmatic and theoretical reasons. As previously outlined, it is advisable in IPA research to seek a homogenous sample and it was therefore necessary to narrow the inclusion criteria. Females were selected because in the United Kingdom women have a longer life expectancy than men (Office for National Statistics, 2010) and are therefore in theory more likely to outlive their spouses. A specific age range was selected due to a consideration that the ways in which couples' cope with illness "may be different at various phases of the life-span" (Berg & Upchurch, 2007, p.920).

Specifically, individuals aged 65 or older were selected because the majority of patients accessing adult specialist palliative care services in England, Wales, and Northern Ireland are aged over 65 (The National Council for Palliative Care, 2011).

It was chosen to focus on the experiences of individuals whose partners have a life-limiting illness; the ‘surviving partner’ rather than the individual who has a life-limiting illness themselves. It was anticipated that these would be different journeys which may give rise to different themes in the analysis. For example, D’ardenne (2004) reported there is evidence that “the ‘unaffected’ partner may paradoxically be more affected” than the individual who is unwell (p. 291). It was therefore necessary to focus on one set of experiences as part of the process of seeking homogeneity. The ‘surviving partner’ was chosen as the focus of this study given the aforementioned considerations surrounding bereavement outcomes and the impact of care-giving.

Sample characteristics

Six individuals participated in the research. All were women whose husbands had a life-limiting illness. The age of participants ranged from 65 to 87 years. The duration of the relationships ranged from 10 to 60 years with five of the six women who took part having been married to their husbands for the majority of their adult lives. Four of the women’s husbands had been diagnosed with cancer, one with asbestosis, and one with a neurological condition.

Procedure

Interview schedule. Prior to the interviews participants were asked to sign a consent form (Appendix E). All interviews began with an introduction that explained what the participant could expect (adapted with permission from Beadon, 2009; see Appendix F for introductory script). This included a reminder of the individual’s right to withdraw at any time and an assurance that there were no “right answers”; rather the interviewer was interested in hearing about the participant’s experiences in their own words.

Following this introduction the researcher continued by asking the participant “could you tell me about your relationship with your husband/partner?” This follows the IPA approach of using a single, open-ended, core question at the start of the interview with subsequent questions following on from the participant’s response to this opening question (Smith et al., 2009). This was adopted to help ensure that the content of the interview was led by the participant and that the researcher followed them into the areas of significance, concern, or interest they chose to discuss. This also allowed for the possibility of uncovering aspects of participant’s experiences that the researcher did not anticipate (Shaw, 2001).

Consequently no other fixed questions were used, though further enquiry was made if judged by the researcher to be appropriate, for instance: “How do you feel that your relationship has been affected by your husband's illness?” At the end of the interview each participant was asked, of their experience of the interview: “How has it been today, talking with me about your experiences?”

An iterative approach was used and after the first interviews the researcher gained a sense of some specific areas to be curious about in subsequent interviews (Smith et al., 2009). Some topics of interest are included in figure 1. It is important to note that these topics were held in mind tentatively, the main focus of interviews being simply to follow each participant’s narrative.

Figure 1. Topics of interest

The time around diagnosis:

- What was this like?
- Thoughts, feelings, actions

How has life changed since diagnosis?

How has the relationship changed over the course of the illness?

How do they manage, separately and as a couple?

Details of interviews. Three participants were interviewed at the Hospice and three in their own homes, in accordance with their preferences. The duration of interviews ranged from 58 to 78 minutes with interviews gently brought to a close at a point that felt appropriate to the researcher and participant. This generally occurred when there was a sense that the most salient material had been covered. Towards the end of each interview individuals were asked whether there was anything additional that they would like to share about their experiences. In one case the researcher detected that the participant may benefit from being signposted towards further support and it was mutually agreed to finish the interview at this time in order to discuss this further. Participants were given a debriefing statement after the interviews (Appendix G).

All interviews were conducted by the researcher, and were audio recorded and later transcribed. All participants and other individuals mentioned by name were assigned a pseudonym in order to preserve their anonymity.

Data Analysis

Analysis of scripts first required the researcher to become immersed in the data. Emerging, preliminary, and finally super-ordinate themes, across participants, were then identified (Howes et al., 2005). Following the guidelines proposed by Smith, Jarman, and Osborn (1999) and Smith et al. (2009) each transcript was read through a number of times and interesting passages highlighted and commented upon. In subsequent readings possible themes began to emerge from the data and these were noted.

Once each transcript had been examined in this way connections between themes were explored within and across participant's accounts. The process of mapping out these connections gave rise to a number of super-ordinate themes, each comprised of a sub-set of emergent themes. At this stage each theme was organised in a master table, along with the extracts from the interviews that supported the themes and the line and page number for each extract (Appendix H). The analysis was carefully reviewed and in some cases themes were subsequently collapsed together or renamed to increase their coherence and better reflect the data.

Quality Assurance

"IPA explicitly recognises the interpretative facet of the approach" and thus it can be argued that IPA researchers are "under a certain obligation" to address the issue of reflexivity (Brocki & Wearden, 2006, p.92). Reflexivity entails being aware of "the ways in which the researcher and the research process have shaped the collected data" (Mays and Pope, 2000, p.51). Measures, including researcher triangulation and use of a reflective journal, were therefore used to help ensure the quality of the analysis conducted.

A reflective journal was used to note the researcher's thoughts and observations at various points and record a "clear account of the process of data collection and analysis" (Mays and Pope, 2000, p 51). This enabled the researcher to consider the role of their own expectations and experiences in shaping the analysis. An extract from the reflective journal is included in Appendix L.

Researcher triangulation was also employed (Shaw, 2001). The researcher's primary supervisor, a clinical psychologist in specialist palliative care with experience of using IPA, reviewed one transcript and conferred with the researcher regarding emergent themes. A trainee clinical psychologist with experience of using IPA also reviewed the emergent themes and extracts from one transcript and shared their ideas and observations. Further to this the researcher met with two clinical psychologists, including the primary supervisor, to discuss the table of themes (Appendix I). Following these discussions some adjustments were made in order to increase the coherence of themes.

Ethical Considerations

Ethical approval to conduct the research was granted by The University of Southampton Psychology Department's ethics committee, an NHS local research ethics committee (Appendix J), and the Hospice ethics committee (Appendix K).

Results

Interpretative phenomenological analysis of the interview transcripts yielded nine super-ordinate themes, comprised of thirty nine emergent themes, related to the experience of being in a relationship with a husband or partner who has a life-limiting illness. These themes are detailed in table 1; a master table of themes is also included in Appendix H accompanied by the extracts which supported each theme. A case study illustrating how some of the themes occurred in one participant's narrative is included in Appendix M.

Of the constructs that arose from the interviews, some were already well-established in the literature. It was also acknowledged that it would be important to describe themes in sufficient depth; and that it would not be possible to report all thirty nine emergent themes in detail within the space constraints. Therefore the decision was made to focus on describing six super-ordinate themes that were either less well documented in existing research; related specifically to the characteristics of the population being studied (i.e. that revealed something about the unique experiences of older female care-givers); or reflected particularly rich participant accounts and thus warranted more in-depth consideration. These six themes appear in bold in table 1.

The three super-ordinate themes excluded were 'Connectedness Vs Isolation', 'Self as a Carer', and 'Coping'. The sense of isolation often described by caregivers has been well documented in previous research; particularly in relation to the experiences of parents who have children with a life-limiting illness (Steele & Davis, 2006; Runswick-Cole, 2010; Brewer et al., 2007; Ware & Raval, 2007; Price, Jordan, Prior, & Parkes, 2011). The risk of social isolation has also been discussed in terms of other family caregivers, such as relatives of elderly veterans (Reed & Weicherding, 1999). Furthermore the importance of effective social support for caregivers of individuals with substantial functional difficulties has been highlighted (Ownsworth, Henderson, & Chambers, 2010).

The theme ‘Self as a Carer’ related to the changes in role and identity encountered by participants and the physical demands of caregiving. The challenges associated with adjusting to a new role when a spouse has a chronic or life-limiting illness have been illustrated in a number of studies; spousal caregivers may be called upon to provide physical assistance and personal care (McLaughlin et al., 2010; Palm & Friedrichsen, 2008), they may take on aspects of the roles previously occupied by their spouse (Riley & Fenton, 2007; McLaughlin et al., 2010) and they may assume the role of advocate, for instance making healthcare decisions on behalf of their spouse (Gunnarson & Ohlen, 2006). This may also lead to a subjugation of their own needs (Gunnarson & Ohlen, 2006).

The coping styles utilised by caregivers have also been discussed in previous research (for e.g. Riley & Fenton, 2007; Hooper, Williams, Sarah, & Chua, 2007; Lee, Czaja, & Schulz). Studies have, for example, explored the relationship between type of coping strategy and caregiver resilience in caregivers of individuals with Alzheimer’s disease (Wilks, Little, Gough, & Spurlock, 2011); and the relationship between religious and spiritual coping and wellbeing in individuals caring for elderly relatives (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009). Additionally type of coping strategy has been found to influence levels of anxiety and depression in caregivers of individuals with Alzheimer’s disease (Garcia-Alberra et al., 2012).

Table 1

Over-arching and emergent themes

Super-ordinate themes	Emergent themes
Holding uncertainty	The uncertain course of the illness
	Uncertainty about own and others' emotions/coping
	Tolerating uncertainty
Living alongside dying	Witnessing husband's physical frailty and suffering
	Witnessing the progression of the illness
Enduring partnership	Spending a lifetime together
	In good times and in bad, in sickness and in health
	Shared, unspoken, understandings
	Love and closeness
Attunement Vs Alienation	Empathic understanding
	Mutual protectiveness
	Disconnection (and re-connection)
	Internal Vs External attributions about behaviour
Preserving Vs Relinquishing	Relinquishing aspects of life together
	Preserving aspects of life together
Connectedness Vs Isolation	Imprisoned by illness
	Disconnected from others
	Connected with others
	Reluctance to burden others
	Relating to Vs Different from others
	Society's aversion to illness and dying
Self as a Carer	Congruent or incongruent with self-concept
	Husband's needs come first
	Taking on aspects of husband's role
	From partnering to parenting
	Vigilance and preparedness
	Exhaustion
	Being an older woman and a carer
Coping	Problem solving
	Carrying on
	Shared use of humour
	Shared religious beliefs
	Being in the present moment Vs Escapism
Coming to terms	Acceptance
	Illness more acceptable in older people
	Having lived a good life
	Dying and death
	Anticipating widowhood
	Own mortality

The following sections present the six over-arching themes and twenty accompanying emergent themes.

Holding uncertainty

Participants described living day to day with the unpredictable trajectory of their husband’s illness. How they and others would feel and behave in the future as the illness progressed was also unknown and could be a source of concern. Two participants spoke about how they tolerated these uncertainties.

The uncertain course of the illness. The speed at which their husband’s health would deteriorate; and the length of time that they would have together as a couple were unknown:

“We’re spending the time together, because who knows. We don’t know. So we’re spending time together as much as possible. We always have done but probably a little more now” [Sylvia, p14. 380-382]

This reflected the fact that it was not always possible for medical professionals to accurately forecast life-expectancy:

“Cancer is not an exact science, it might be the end tomorrow or it might go on for some years” [Valerie, p9. 242-243]

Alongside an ongoing uncertainty related to the rate of illness progression, some women spoke about the daily fluctuations in their husband’s health which made it difficult to arrange social activities or to plan ahead:

“We try but sometimes he’ll say, you know, [...][1] perhaps we’ll go out to lunch tomorrow or maybe we’ll go to the cinema or something and then that next day comes and he’ll say “I don’t really feel like it today”” [Emma, p9. 246-248]

Uncertainty about own and others’ emotions/coping. One participant reflected on her concerns about how she might cope as her husband’s illness progressed:

---

[1] Used to indicate omitted text

"I think it's more worried about the future, about how, how I'll be able to manage" [Emma, p6. 155-156]

Participants also expressed uncertainty about how they and other family members would react after their husband's death:

"It's quite difficult, it's a mixture of feelings, really. And how it'll all work out I don't know. How I'll feel when he dies I've no idea" [Julia, p3. 67-68]

Tolerating uncertainty. Two women spoke about how they accepted the numerous uncertainties that they faced; one suggesting that life would be more difficult if we knew what the future held:

"Isn't it a good job we don't know what's coming? We'd be horrified wouldn't we?" [Sylvia, p16. 452-453]

Another participant explained that she chose to focus on the present rather than dwell on what might happen:

"I don't think about that, I mean that doesn't say it doesn't worry me, it worries me but I don't think about it too much until it happens" [Emma, p5. 128-130]

Living alongside dying

Participants shared moving accounts of living alongside and witnessing their husband's suffering, frailty, and decline. They were not passive observers of their husband's experience; rather they were intimately connected with it and there was a strong sense of how painful this was for some of the women interviewed.

Witnessing husband's frailty and suffering. Participants used powerful language to describe the deterioration in their husband's physical health and well-being, with one woman likening her husband's appearance to images she had seen of concentration camp victims:

"They used to show photographs of these people in Belsen and they had bars round like this, and you could count every rib, [...] Well Charles is the same now" [Caroline, p3. 84-87]

Another used the metaphor of a dying bird, explaining:

"It's as if his feathers are dropping off him" [Valerie, p8. 216]

Two women reflected with a deep sense of sadness on the changes in their husband:

"He's so, he's such a very interesting and intelligent man normally and he makes me cry" [Caroline, p12. 341-342]

Feeling powerless to stave off these changes was a source of anguish:

"He wasn't eating I was absolutely beside myself, I was, I couldn't, he just didn't want anything" [Sylvia, p6. 148-149]

Witnessing the progression of the illness. Participants lived with an awareness of the inevitability of the progression of their husband's illness:

"We just knew that it was going to get worse, that it would kill him, just like cancer does because there's no cure for it" [Janet, p2. 53-54]

Some women spoke about being confronted with the knowledge that their husband was becoming increasingly ill:

"There are times when he's so ill that you can literally see, and don't kid yourself, you can literally see he's dying before your very eyes" [Valerie, p8. 207-209]

One participant illustrated the significance of the physical changes related to her husband's illness and how she anticipated that the future progression would impact on her:

"I think emotionally, erm, probably as he gets worse perhaps can't talk or when he can't walk at all or is almost bedridden I think then the emotional side will kick in more because, erm, I'll be losing my husband. He's still there but I will be losing him really" [Emma, p7. 171-174]

Enduring partnership

All of the women who were interviewed were in long term partnerships of ten years or more; most had been married to their husbands for more than forty years. Participants spoke about their husbands in the context of having spent a lifetime together; weathering many storms and coming to develop shared, implicit understandings. Some of the women also gave consideration to the importance of this love and closeness in their lives.

Spending a lifetime together. Participants reflected on the length of their marriages and the meanings they ascribed to this. Two women spoke of regarding this as evidence of a strong partnership:

"If at the end of 56 years you are still friends than you have achieved something" [Valerie, p8. 197-198]

Two women remarked on the fact that they were now faced with the loss of the person that they had shared such a large part of their life with:

"I shall miss Nicholas, because we've spent a lifetime together" [Julia, p6. 150-151]

In good times and in bad, in sickness and in health. All of the relationships had, latterly, endured the challenges associated with serious illness. Participants also spoke of having shared other difficult times as a couple:

"We've had some good years and we've had some very bad years. And Charles' been evenly tempered all the way through" [Caroline, p16. 443-444]

Alongside discussion of these difficult periods some women affectionately referenced the more minor frustrations and irritations of everyday married life:

"He says to me "I'm a pest" I said "yes you're a pain in the backside but then you've always been so tell me something I don't know" you know, but he just laughs. He said "am I really a pain in the backside?" I said "no, I'm only joking", I said "I love you to bits, but you can be blooming annoying sometimes" [Janet, p21. 597-599]

Shared, unspoken, understandings. Three participants commented on the nature of their relationship with their husband, identifying that they knew one other in such a way that some things could be mutually acknowledged without needing to be explicitly communicated:

"We both notice it. We don't have to keep mentioning it" [Emma, p9, 242]

"And Mike feels the same, that we both have this very strong faith. We don't sort of talk about it, we just have it" [Sylvia, p8. 204-205]

Love and closeness. The importance of love, affection, friendship, and connectedness in the couple relationship was evident in the dialogues of participants:

"You become not two persons but one, really truly" [Valerie, p9. 224-225]

"The greatest thing you can have, is to be contented and love somebody and have somebody love you" [Sylvia, p18. 519-520]

Attunement Vs Alienation

The women interviewed conveyed a sense of empathy for their husband's situation and there was a mutual protectiveness evident in some narratives. Most of the women also spoke, in varying depth, of times at which they had felt disconnected or alienated from their husbands. Three women made attributions about their husband's behaviour as being due to either internal or external factors and the meaning which they ascribed appeared to influence the feelings this evoked in them.

Empathic understanding. Participants expressed an awareness of how their husbands might be emotionally and physically affected by illness:

"You have to consider the one that's ill and is slowly giving up all that he's able to do" [Julia, p13, 355-356]

"Well if I had to do all of that I'd be so wide awake I wouldn't know how to go back to sleep but he's so exhausted he can't *wait* to go back to sleep, you know. But it is, it's the most horrible thing and I, as I said to you just now, I wouldn't wish it on anybody, no" [Janet, p15. 419-422]

Mutual protectiveness. In some accounts there was a sense of the couple's protectiveness towards one another:

"I don't want to be out all the time leaving him 'cause it's unfair you know that he's not out so much" [Emma, p7, 196-197]

"But he knew, he knew, I mean it was him that was saying "we ought to get rid of this now, [referring to the couple's boat] I don't want you to be lumbered with getting rid of it"" [Emma, p10. 258-259]

Disconnection (and re-connection*).* Many of the women expressed feeling that there was, or had one time been, a distance or disconnectedness in the relationship. For most this was related to a point in the illness when their husband did not appear to be aware of their feelings and experiences:

"I got angry with him because his emotions were so different and sometimes he didn't seem to even know that I was on the planet and it was a horrible feeling to have. He didn't seem to bother whether I was, what ever I was doing, whether I wasn't feeling well or what *ever*. He just, he just wasn't interested" [Sylvia, p2. 55-59]

One woman also spoke about the process of re-connecting with her husband as he became more emotionally present:

"It was like somebody coming out of a [pause] a deep sleep. And, or like a chrysalis that was coming out and opening. It was beginning to be Mike again. I could see it, not every day, but I could sense it. That he was coming out of [pause] it was like as though he's been in a coma" [Sylvia, p5. 120-123]

Internal vs external attributions about behaviour. In the accounts of three of the women there were passages that suggested the interpretations that they had made about their husband's behaviour. It appeared that external attributions about difficulties (that they were associated with the husband's illness or treatment) were less distressing than internal attributions (that they were under the husband's control). One woman spoke in a way that indicated she felt that there had been an *internal* change to her husband:

"Yeah he is different. Because he doesn't, not in his head in my head; these are all thoughts from me, that he hasn't a care about me anymore, it's all himself, he's all selfish inside. I don't know. I suppose people do change" [Caroline, p8. 210-212]

An extract from an interview with another woman demonstrated that she perceived a change in her husband's behaviour as being caused by an *external* issue, his illness:

"You know just think, "it's not *his* fault" it's not as if he's turned his back on me and said "I don't want you any more", it's nothing like that" [Emma, p11. 294-295]

Preserving Vs Relinquishing

Participants acknowledged both elements of their relationships which had been unavoidably relinquished and those which had been sustained; in some women's accounts there seemed to be an oscillation between holding on to and letting go of things that were valued.

Relinquishing aspects of life together. Participants described letting go of different facets of their relationships. Some spoke about giving up previously enjoyed shared activities. One woman spoke about the transition to sleeping in a different bedroom from her husband:

"Obviously you miss having a cuddle when you go to bed. If you've been married a long time it just goes with the territory you know" [Janet, p9. 254-256]

Preserving aspects of life together. Another participant, who identified herself and her husband as sociable people, explained that despite changes in her husband's physical health they had managed to maintain this aspect of their lives:

"But if it's nice we go out, you know, we might not be walking anywhere far [laughs] well he wouldn't be walking, but erm, no we still have a social life we still go out, ah, we still see friends, erm, and we manage" [Emma, p7, 197-199]

Coming to Terms

Participants reflected on the process of coming to accept their husband's condition; most expressed feeling that it would be worse for a young person to be affected by life-limiting illness and several spoke of having lived a good life and raised a family. The women also considered the future; the end of their husband's life, the prospect of widowhood, and their own mortality.

Acceptance. Two women shared insights into the gradual process of coming to terms with their husband's illness. For one this seemed to be related to a shift away from a focus on the unfairness of the situation:

"But you can't change it, you can't, you can't go on *all* the time thinking "it's unfair" [Emma, p6. 164-165]

Another woman spoke about her experiences as having been something of a voyage of discovery, explaining that her anger had slowly lessened as she sought to understand more about the illness:

“I’ve been through all sorts of stages on this, it’s like a journey that you go on” [Valerie, p13. 358-359]

Illness more acceptable in older people. Despite the sadness evident in their narratives four of the women also conveyed a clear sense that they felt it would be worse for a child or a young person to suffer with a life-limiting illness:

“I mean you hear of young people dying, like that footballer the other week died of cancer didn’t he, 48 or something like that. Another one has got leukaemia. And they’re young people, they haven’t even lived their life, well we’ve been there done that you know, we’ve done everything” [Caroline, p18. 498-502]

Having lived a good life. The idea that it is especially tragic when illness affects young people seemed connected to another aspect of some women’s narratives; that they and their husbands had lived a full life. Participants spoke variously of having led an exciting life, having a sense of contentment, and having brought up a family. Some of the women viewed themselves as fortunate:

“We were counting our blessings the other night because we’ve got such marvellous family and because we’ve moved so many times” [Caroline, p7. 200-201]

“We’ve had our lives and we’ve had a jolly good life” [Valerie, p11, 287]

Dying and death. Looking to the future two women reflected that they hoped the final stages of their husband’s illness would not be drawn out:

“But it’s not nice and I just hope one day whenever it is he’ll just hopefully go to bed and go to sleep and that’ll be it, because I would hate him to have a choking fit, or a coughing session which would exhaust him and he could probably get another mini-stroke [...] So I just hope it'll be quick, whatever it is, you know, it's going to be whatever it is but that's how I would like it to be, for his sake more than anybody else's you know" [Janet, p24. 669-675]

Anticipating widowhood. Four participants shared their feelings about the prospect of life without their husbands. Two women emphasised that they did not want to become widows:

"But I can't imagine Charles not being there, you know, after so many years of marriage. I don't think I'll survive afterwards because I lived so so much, erm, in his care" [Caroline, p18. 515-517]

Two other women expressed having a mixture of feelings about the death of their husband. One woman explained that there would be an element of relief that it would mean the end of such a difficult time. Another reflected that she saw herself as a very independent person and was not frightened at the thought of being on her own:

"I know you must get some couples that are very very close and one doesn't know how they're going to exist without the other. But I'm not that way inclined" [Julia, p6. 148-150]

Own mortality. The final theme that emerged from the interviews related to participant's sense of themselves as ageing. Four of the women interviewed referred to their sense of mortality; indicating that due to their own age or health problems outliving their husband was not a foregone conclusion:

"Don't forget as I said, Mike's not bound to be the first one to go" [Sylvia, p18. 503-504]

Discussion

This study sought to explore the experience of being an older woman in a relationship with a husband or partner who has a life-limiting illness. Nine over-arching themes and thirty nine accompanying emergent themes were identified that described this experience.

Discussion of Themes

Holding uncertainty. Living with the myriad uncertainties surrounding the progression of their husband's illness emerged as a major construct from the women's interviews. This uncertainty was related to both the unpredictable nature of the illness trajectory and to concerns about the women's and other's future emotions and coping.

Difficulties associated with uncertainty have also been noted in previous research that has considered the effects of life-limiting illness on family members. In a survey of informal caregivers of individuals with advanced cancer, participants were asked to indicate the most frequently occurring problems that they experienced in their care-giving role. "Fear of an unpredictable future" was the most commonly endorsed of the questionnaire items, experienced by 80% of those surveyed,(Osse, Vernooi j-Dassen, Schade, &Grol, 2006, p.380) though no further information was available regarding which aspects of the future were perceived as frightening.

Spence et al. (2008) interviewed family caregivers of individuals with chronic obstructive pulmonary disease. Again, it was reported that participants found "the unpredictability of the future" to be "a major cause for concern" (p.369). It seemed that this concern may have related to anxiety about the possibility of rapid fluctuation or deterioration in the relative's health as it was explained that caregivers worried about leaving their family member alone in case they became acutely unwell.

Furthermore the physiological and emotional effects of unpredictability have been widely documented in social psychology research; leading Greco and Roger (2001) to conclude that “uncertainty constitutes a powerful stressor” (p.520). This was evident in a study by Monat, Averill, and Lazarus, (1972) which measured physiological reactivity and self-report ratings of tension whilst manipulating participants’ sense of certainty about receiving an electric shock. A similar study conducted by Katz and Wykes (1985) found participants to be less distressed when anticipating predictable rather than unpredictable electric shocks, with participants also reporting experiencing predictable shocks as less aversive.

The construct *‘holding uncertainty’* in the current study is therefore in-keeping with the broader psychological literature around the consequences of uncertainty and unpredictability. It also serves to highlight specific areas of uncertainty experienced by women whose husband’s have a life-limiting illness and the ways they sought to manage this unpredictability.

Living alongside dying. The experience of living alongside and witnessing both their husband’s suffering, and the progression of his condition, was a second key construct to arise from the women’s accounts. This theme links to findings from other qualitative studies, most notably those of Kehl, Kirchhoff, Kramer, and Hovland-Scafe (2009) who interviewed thirty individuals about their experiences during the end stages of a family member’s life.

Kehl et al. (2009) used the term: “bearing witness” (p.5) to conceptualise participant’s reports of “being an observer to the experience of the dying person” (p.5) including being confronted by the cognitive and physical aspects of their decline and seeing their helplessness. The theme “bearing witness” as described by Kehl et al. appears to relate most closely to the emergent theme ‘*witnessing the progression of the illness’* included in this present research since both are concerned with the impact of living alongside the other person’s advancing condition.

The theme: “the visible body” was used by Ray and Street (2006, p.38) to depict the way in which caregivers related to the physical changes in relatives with motor neurone disease. Seeing the deterioration in their family members physical functioning could be distressing and frightening for participants. Participants interviewed by Hunstad and Svindseth (2011) described having found it difficult to cope with witnessing the physical suffering of spouses receiving home-based palliative care including their “nausea, fatigue, and pain” (p.400). The findings of both studies seem to link to the emergent theme ‘*witnessing husband’s frailty and suffering’* outlined in the present research; they differ in being primarily concerned with the unwell person’s physical distress rather than both their physical and emotional suffering.

Enduring partnership. A further construct evident in the data was that of the *‘enduring partnership’* which featured in many of the women’s accounts. Though not all of the component emergent themes related specifically to the impact of illness, they nonetheless formed an integral part of the stories that participants told about their relationships, and illustrated the context in which life-limiting illness had occurred.

Participants shared examples of difficulties that had arisen during the course of their relationships, and there was a sense that marriage involved outlasting struggles and challenges as well as enjoying happier times. This echoes the narratives of the couples who shared their stories of lasting partnerships with Reibstein (2006). Reibstein observed that these couples’ accounts suggested “anything from portions of days to weeks, months, and even longer periods fraught with difficulties” and identified that “it is the proportion of good to bad, pleasant to unpleasant, that counts, as well as the expectation that difficulties will both occur and recede" (p.217).

This poses the question of whether couples in long-term partnerships might be better equipped to cope with the demands of life-limiting or other serious illness due to having developed, over a long period of time, the skills to help manage potential threats to the relationship.

The importance of the emergent theme: '*love and closeness'* was particularly evident in the interviews of three women who took part in the present research. Each spoke warmly about their husband and conveyed a sense of a mutually loving relationship. Though it was not evident within this present study, previous research has suggested that the experience of closeness can change in relationships when one partner has a life-limiting illness; with this closeness becoming fraught in some respects and enhanced in others (Palm & Friedrichsen, 2008).

Attunement Vs Alienation. The fourth super-ordinate theme described the way in which participants interacted with and related to their husbands. There was a dichotomy evident between times when the two partners were attuned to one another's needs, and times when there was a sense of alienation or disconnection. *Attunement* captured the '*empathic understanding'* which some women demonstrated, and the '*mutual protectiveness'* apparent in the narratives. This '*mutual protectiveness'* emerged from the examples some women shared of their husbands expressing concern for them, and considering their needs.

At other points in the women's accounts there were clear examples of having felt alienated from their husbands. Where it was related to their husband's illness this alienation seemed to occur when their husband was not emotionally responsive or did not show insight into the woman's feelings or the possible impact of the illness upon them. This resonates with the theme: “suffering from loss of intimacy and reciprocity” reported by Persson and Sundin (2008 p.383) from their interviews with informal caregivers of individuals with inoperable lung cancer. Person and Sundin (2008) explained that caregivers felt a loss of closeness to the unwell person and that a shift in roles caused by illness altered the balance of the relationship resulting in a state where the caregiver ‘gave’ without requesting anything back.

Three of the women interviewed for the present study made statements which related to interpretations that they had made about their husband’s behaviour; specifically whether they attributed a change in behaviour to internal factors (related to their husband’s personality) or external ones (related to the effects of the illness). One woman clearly stated that she wished she had realised earlier that it was her husband’s treatment which was responsible for changes in his emotional responsiveness; it therefore appeared that the distinction between internal and external factors was significant to her.

The concept of internal and external attributions about events has been discussed within social psychology (Shaver, 1975). Shaver described the individual as an “active perceiver” (p.114) who seeks to explain and predict the actions of others through a process of attribution. These attributions include attempting to distinguish whether behaviour is due to the environment or “personal disposition” (p.30)

The findings discussed raise the question of whether there might be a less detrimental impact on caregivers who perceive continued reciprocity and attunement within the relationship during illness. A related issue is whether the impact of a perceived loss of attunement might be mediated or moderated by the attributions that the caregiver makes about the unwell person’s behaviour.

Preserving Vs Relinquishing. Participants described how over the course of their husband’s illness aspects of their life together as a couple had been lost, whilst others had been maintained. This process formed the basis of the fifth theme *preserving vs. relinquishing.* In some cases there was a sense of couples alternating between the two states whilst delaying the inevitable losses for as long as possible.

This super-ordinate theme is similar to the construct of "'letting go' and 'preservation' in relation to loss" identified by Kars et al. (2011 p.29) from interviews with parents of children with advanced cancer. Kars et al. observed that participants experienced an "internal struggle" (p.29) and oscillated between the two processes with the balance gradually shifting towards 'letting go' as the illness progressed. The concept of preservation had a slightly different meaning in Kars et al. than in the present study; Kars et al. used this term to describe parent's attempts to prolong their child's life, in the current study it is used to describe aspects of the relationship which were sustained in the face of advancing illness.

'Preserving vs. relinquishing' also parallels the dual process model of coping with bereavement developed by Stroebe and Schut (1999); originally used to describe the process by which people come to terms with the loss of a partner. Stroebe and Schut proposed that bereaved individuals oscillate between loss- and restoration-orientations, with: "loss-orientation" (p.212) entailing a focus on the deceased person, including the continuing bond with them and: "restoration-orientation" (p.213) involving coping with other tasks and adjusting to life without them. In the context of the current study *preserving* would be most closely aligned with loss-orientation and *relinquishing* with restoration-orientation.

Coming to terms. The sixth and final super-ordinate theme to emerge from the interviews was that of '*coming to terms'*. This construct detailed issues surrounding the women's reluctant acceptance of their husband's illness including their thoughts on having lived a full life and their reflections that illness was in some ways more tolerable in the old than the young. Participants spoke about the prospect of their husband's death including their hopes that the dying process would not be traumatic or prolonged. They also considered a future without their husbands and acknowledged their own mortality.

Returning to the concept of narratives; it was previously suggested that life-limiting illness could disrupt a couple's shared narrative and their expected future. It was also noted that it is presently unclear whether the potential for disturbance in the narrative differs for older and younger couples. The present research did not seek to address this question directly, however it is interesting to note that the women spoke of *'having lived a good life'* and of life-limiting illness being particularly distressing in young people; these aspects of the women's accounts suggest that the narratives of older couples may be less disrupted by life-limiting illness than those of the young.

The super-ordinate theme '*coming to terms'*, more than any other, appeared to reflect the life-stage of the participants and to reveal something about the particular way that older adults might adapt to or come to terms with the prospect of losing a spouse. The women's accounts bring to mind the: "eight stages of man" developed by Erikson (1950, p.219), particularly the final stage of: "ego integrity vs. despair" (p.231). The women's narratives evoke Erikson's work with their evident acceptance of the life-cycle; the personal and relational growth that weaves its way through their accounts; and their reconciliation with the prospect of their own eventual death.

Limitations of the Study

Participants recruited to this study were selected purposively in order to facilitate interviews with a relatively homogenous group of individuals. Thus all participants were female, aged 65 or older and had a husband with a life-limiting illness. The emphasis on homogeneity within IPA research has been previously discussed and it is acknowledged that this necessarily limits: “empirical generalizability” (Smith et al., 2009, p51); meaning it cannot be taken for granted that research findings will apply to broader populations.

In the context of the current study some themes appeared to relate specifically to older female caregivers, and findings could not therefore be assumed to represent the experiences of the wider care-giving population. It is notable however that IPA researchers can seek to enhance the “theoretical transferability” of findings (Smith et al., 2009, p.51) by describing themes in sufficient depth that readers are able to determine the degree of transferability to alternative contexts. Smith et al. contend that theoretical transferability can also be increased by discussing the study sample in the context of existing research. It is believed therefore that although the findings of the present study cannot claim generalizability they can offer transferability.

A related issue is that of sampling. It was estimated by the researcher that slightly more than half of the women who were informed about the research opted to participate in it. This raises the question of how those individuals who chose to take part in the study may have differed from those who did not; it is impossible to know the answer, however, it could be speculated that individuals who did not wish to take part were less comfortable with the idea of sharing their private experiences, were concerned that they would find the interview emotionally painful or distressing, viewed the prospect of an interview as an additional burden, or were simply not interested in the idea of reflecting on their experiences in this context. Whatever the reasons it must be concluded that the research cannot claim to reflect the experiences of all women in this position.

Clinical Implications

The study findings are of interest clinically and suggest some areas which health professionals in palliative care contexts could hold in mind when working with the population studied. The interviews highlighted the difficulty of living with the uncertainty surrounding life-limiting illness, a finding which is also evident in the wider literature. Within the field of psychological therapy some third-wave cognitive behavioural approaches such as mindfulness based cognitive therapy (Segal, Williams, & Teasdale,2002 and dialectical behaviour therapy (Linehan 1993 a, b) have been developed which may help individuals to tolerate uncertainty and other distressing emotions.

Professionals could also hold in mind the potential for life-limiting illness to present threats to the attunement of the couple. Findings from the present study indicate that attributions made about the location of difficulties (whether within or outside of the person) may influence their impact. This relates to ideas from narrative therapy and suggests the potential usefulness of narrative practices such as externalising. Externalising involves objectifying and personifying an individual’s difficulties, in order to separate the problem from the person themselves (White and Epston, 1990).

It may also be helpful to provide psycho-education around the potential physical and psychological impact of both life-limiting illness and treatments such as chemotherapy for patients and their family members in order to help normalise some of the changes that they may experience.

Future Research

The findings suggest some avenues for future research both qualitative and quantitative. Some potential questions posed which might be best addressed through the use of quantitative methods are: is there a less detrimental impact on caregivers who perceive continued reciprocity and attunement in their relationships? And is the impact of a perceived loss of attunement mediated or moderated by the attributions that the caregiver makes about the unwell person’s behaviour?

In terms of qualitative methodologies; there are a number of ways in which the findings of this study could be built upon. Firstly, the current research sought to include a relatively homogeneous sample of participants; however there was variation in terms of the husbands' illness with four having been diagnosed with cancer, one with asbestosis, and one with a neurological condition. One way of developing the current study would be to explore the impact of a specific illness, or to compare the impact of two different illnesses and map the areas of overlap and divergence.

Secondly, information was not specifically sought regarding religious beliefs or ethnicity, and it would be very interesting to explore the experiences of female caregivers in different cultural contexts; perhaps comparing the accounts of women from individualist and collectivist cultures.

Thirdly, given the questions posed about whether couples in long-term partnerships might be better equipped to cope with the demands of life-limiting illness, and whether the shared narratives of older couples might be less disrupted, it would be worthwhile interviewing younger women who have a husband with a life-limiting illness in order to explore these ideas further.

Finally, it would be valuable to conduct interviews with older men living with a wife of partner with a life-limiting illness; in order to discover whether there are similarities and differences in men's and women's accounts.

References

Beadon, P. (2009). *An exploration of the effect of a life-limiting diagnosis on an individual's relationship with their body: A qualitative study* (Unpublished doctoral dissertation). University of Southampton, Southampton.

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult lifespan. *Psychological Bulletin, 133*(6), 920-954.

Black, S., Gauthier, S., Dalziel, W., Keren, R., Correia, J., Hew, H., & Binder, C. (2010). Canadian Alzheimer's disease caregiver survey: baby-boomer caregivers and burden of care. *International Journal of Geriatric Psychiatry, 25*(8), 807-813.

Bowlby, J. (1988). A secure base: Clinical applications of attachment theory. London: Routledge.

Brewer, H., Smith, J., Eatough, V., Stanley, C., Glendinning, N., & Quarrell, O. (2007). Caring for a child with juvenile huntington's disease: Helpful and unhelpful support. *Journal of Child Health Care: For Professionals Working With Children In The Hospital And Community, 11*(1), 40-52.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (ipa) in health psychology. *Psychology and Health, 21*(1), 87-108.

Cangelosi, P. (2009). Caregiver burden or caregiver gain? *Journal of Psychosocial Nursing and Mental Health Services, 47*(9), 19-22. doi:10.3928/02793695-20090730-04

Carlander, I., Sahlberg-Blom, E., Hellström, I., & Ternestedt, B. (2011). The modified self: family caregivers' experiences of caring for a dying family member at home. *Journal of Clinical Nursing, 20*(7-8), 1097-1105. doi:10.1111/j.1365-2702.2010.03331.x

Christakis, N., A., & Allison, P. (2006). Mortality after the hospitalisation of a spouse. *The*

New England Journal of Medicine, 354(7), 719-730.

D'ardenne, P. (2004). The couple sharing long-term illness. *Sexual and Relationship Therapy, 19* (3), 291-308

Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. In C. Willig and W.Stainton Rogers (Eds.), *The sage handbook of qualitative research in psychology* (pp.). London: SAGE.

Erikson, E. H. (1950). *Childhood and society.* London: Imago Publishing.

Forbat, L., White, I., Marshall-Lucette, S., & Kelly, D. (2012). Discussing the sexual consequences of treatment in radiotherapy and urology consultations with couples affected by prostate cancer. *BJU International*, *109*(1), 98-103. doi:10.1111/j.1464-410X.2011.10257.x

Garcia-Alberca, J. M., Cruz, B., Lara, J. P., Garrido, V., Gris, E., Lara, A., & Castilla, C. (2012). Disengagement coping partially mediates the relationship between caregiver burden and anxiety and depression in caregivers of people with alzheimer's disease. results from the Malaga-ad study. *Journal of Affective Disorders, 136,* 848-856.

Gardner, D. (2008). Cancer in a dyadic context: older couples' negotiation of ambiguity and search for meaning at the end of life. *Journal Of Social Work In End-Of-Life & Palliative Care*, *4*(2), 135-159.

Ghesquiere, A., Haidar, Y., & Shear, M. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work In End-Of-Life & Palliative Care, 7*(2-3), 216-240.

Gilbert, E., Ussher, J., & Perz, J. (2010). Renegotiating sexuality and intimacy in the context of cancer: the experiences of carers. *Archives of Sexual Behavior*, *39*(4), 998-1009.

Greco, V., & Roger, D. (2001). Coping with uncertainty: The construction and validation of a new measure. *Personality and Individual Differences*, 3, 519-534.

Greenberg, S., Stacy, M. G., & Penzo, J. A. (2001). Spousal caregiving: In sickness and in health. *Journal of Gerontological Social Work, 35*(4), 69-82.

Gunnarsson, H., & Öhlén, J. (2006). Spouses' grief before the patient's death: Retrospective experiences related to palliative home care in urban Sweden. *Mortality*, *11*(4), 336-351. doi:10.1080/13576270600945527

Hart, C. L., Hole, D. J., Lawlor, D. A., Davey Smith, G., & Lever, T. F. (2007). Effect of conjugal bereavement on mortality of the bereaved spouse in participants of the renfrew/ paisley study. *J Epidemiol Community Health, 61,* 455-460.

Hazan, C., & Shaver, P. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality & Social Psychology*, *52*(3), 511-524. doi:10.1037/0022-3514.52.3.511.

Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. *The Psychologist, 24*(10), 756-759.

Herrera, A. P, Lee, J. W., Nanyonjo, R. D., Laufman, L. E., & Rorres-Vigil, I. (2009). Religious coping and caregiver well-being in mexican-american families. *Aging & Mental Health, 13*(1), 84-91.

Hooper, L., Williams, W. H., Sarah, E. W., & Chua, K-C. (2007). Caregiver distress, coping and parenting styles in cases of childhood encephalitis. *Neuropsychological Rehabilitation: An International Journal, 17*(4-5), 621-637.

Howes, H., Benton, D., & Edwards, S. (2005). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health*, *20*(1), 129-142.

Hunstad, I., & Foelsvik Svindseth, M. (2011). Challenges in home-based palliative care in norway: a qualitative study of spouses' experiences. *International Journal of Palliative Nursing*, *17*(8), 398-404.

Hyden, L-C. (1997). Illness and narrative. *Sociology of Health & Illness, 19*(1), 48-69.

Kars, M., Grypdonck, M., de Korte-Verhoef, M., Kamps, W., Meijer-van den Bergh, E., Verkerk, M., & van Delden, J. (2011). Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. *Supportive Care in Cancer: Official Journal of The Multinational Association of Supportive Care in Cancer, 19*(1), 27-35.

Katz, R., & Wykes, T. (1985). The psychological difference between temporally predictable and unpredictable stressful events: Evidence for information control theories. *Journal of Personality and Social Psychology, 48*(3), 781-790.

Kehl, K. A., Kirchhoff, K. T., Kramer, B. J., & Hovland-Scafe, C. (2009). Challenges facing families at the end of life in three settings. *Journal Of Social Work In End-Of-Life & Palliative Care*, *5*(3-4), 144-168.

Latham, A. E., & Prigerson, H. G. (2004). Suicidality and bereavement: Complicated grief as psychiatric disorder presenting greatest risk for suicidality. *Suicide Life Threat Behav, 34*(4), 350-362.

Lee, C. C., Czaja, S. J., & Schulz, R. (2010). The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups. *Journal of Gerontology: Social Sciences, 65B*(2), 185-194.

Lee, S., & Kristjanson, L. (2003). Human research ethics committees: Issues in palliative care research. *International Journal of Palliative Nursing, 9*(1), 13-18.

Linehan, M. M. (1993). *Cognitive-behavioural treatment of borderline personality disorder.* New York: The Guildford Press.

Linehan, M. M. (1993). *Skills training manual for treating borderline personality disorder.*

New York: The Guildford Press.

Lipson-Parra, H. (1990). Development and validation of the adult attachment scale: Assessing attachment in elderly adults. *Issues in Mental Health Nursing, 11*(1), 79-92.

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *BMJ, 320,* 50-52.

McLaughlin, D., Hasson, F., Kernohan, W., Waldron, M., McLaughlin, M., Cochrane, B., & Chambers, H. (2010). Living and coping with Parkinson's disease: perceptions of informal carers. *Palliative Medicine*, *25*(2), 177-182.

Monat, A., Averill, J. R., & Lazarus, R. S. (1972). Anticipatory stress and coping reactions under various conditions of uncertainty. *Journal of Personality and Social Psychology*, *24*(2), 237-253.

Murray Parkes, C. (1985). Bereavement. *British Journal of Psychiatry, 146,* 11-17.

NHS Information Centre Social Care Team. (2010). *Survey of carers in households 2009/10.* Retrieved from http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/survey-of-carers-in-households--2009-10-england

Northouse, L. N., Mood, D. W., Schafenacker, A., Montie, J. E., Sandler, H. M., Forman, J. D., Hussain, M., Pienta, K. J., Smith, D. C., & Kershaw, T. (2007). Randomised clinical trial of a family intervention for prostate cancer patients and their spouses. *Cancer, 110*(12), 2809-2818.

Office for National Statistics, Statistics Bulletin. (2010*). Life expectancy at birth and at age 65 by local areas in the united kingdom, 2007-09*. Retrieved from http://www.ons.gov.uk/ons/publications/index.html

Office for National Statistics. (2012). *Measuring national well-being: Households and* *families, 2012.* Retrieved from http://www.ons.gov.uk/ons/rel/wellbeing/measuring-national-well-being/households-and-families/art---households-and-families.html

Osse, B., Vernooij-Dassen, M., Schadé, E., & Grol, R. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing, 29*(5), 378-388.

Ownsworth, T., Henderson, L., & Chambers, S. K. (2010). Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumour and other cancers. *Psycho-Oncology*, *19*, 1116-1122.

Palm, I., & Friedrichsen, M. (2008). The lived experience of closeness in partners of cancer patients in the home care setting. *International Journal of Palliative Nursing*, *14*(1), 6-13.

Persson, C., & Sundin, K. (2008). Being in the situation of a significant other to a person with inoperable lung cancer. *Cancer Nursing, 31*(5), 380-388.

Price, J., Jordan, J., Prior, L., & Parkes, J. (2011). Living through the death of a child: a qualitative study of bereaved parents' experiences. *International Journal Of Nursing Studies*, *48*(11), 1384-1392.

Prigerson, H., Maciejewski, P., Reynolds, C., Bierhals, A., Newsom, J., Fasiczka, A., Frank, E., Doman, J., & Miller, M. (1995). Inventory of Complicated Grief: a scale to measure maladaptive symptoms of loss. *Psychiatry Research*, *59*(1-2), 65-79.

Ray, R., & Street, A. (2006). Caregiver bodywork: family members' experiences of caring for a person with motor neurone disease. *Journal of Advanced Nursing, 56*(1), 35-43.

Reed, D. M., & Weicherding, M. (1999). Factors of caregiver isolation in a rural midwest area. *Home Health Care Services Quarterly, 17*(4), 13-24.

Reibstein, J. (2006). *The best kept secret: Men and women’s stories of lasting love*. London:

Bloomsbury.

Riley, J., & Fenton, G. (2007). A terminal diagnosis: The carers' perspective. *Counselling & Psychotherapy Research*, *7*(2), 86-91. doi:10.1080/14733140701327909

Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health, 9*(4), 337-347.

Runswick-Cole, K. (2010). Living with dying and disabilism: Death and disabled children. *Disability & Society*, *25*(7), 813-826. doi:10.1080/09687599.2010.520895

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). *Mindfulness-based cognitive therapy for depression. A new approach to preventing relapse.* New York: The Guildford Press.

Shaver, K. G. (1975). *An introduction to attribution processes.* Cambridge, MA: Winthrop Publishers.

Shaw, R. (2001). Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update, 10*(4), 48-52.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: SAGE.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology* (pp.218-240). London: Sage.

Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B., & Watson, B. (2008). Active carers: living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing, 14*(8), 368-372.

Spichiger, E. (2008). Living with terminal illness: patient and family experiences of hospital end-of-life care. *International Journal Of Palliative Nursing*, *14*(5), 220-228.

Steele, R., & Davies, B. (2006). Impact on parents when a child has a progressive, life-threatening illness. *International Journal Of Palliative Nursing*, *12*(12), 576-585.

Strasser, F., Binswanger, J., Cerny, T., & Kesselring, A. (2007). Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliative Medicine*, *21*(2), 129-137.

Stroebe, M. (2002). Paving the way: from early attachment theory to contemporary bereavement research. *Mortality*, *7*(2), 127-138. doi: 10.1080/13576270220136267

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224.

The National Council for Palliative Care. (2011). *National survey of patient activity data for specialist palliative care services. Mds full report for the year 2009-2010*. Retrieved from http://www.ncpc.org.uk/library

Tomarken, A., Holland, J., Schachter, S., Vanderwerker, L., Zuckerman, E., Nelson, C., Coups, E., Ramirez, P. M., & Prigerson, H. (2008). Factors of complicated grief pre-death in caregivers of cancer patients. *Psycho-Oncology, 17*(2), 105-111.

Usher, B., & Cammarata, K. (2009). Heart failure and family caregiver burden: an update. *Progress in Cardiovascular Nursing*, *24*(3), 113-114.

Ware, J., & Raval, H. (2007). A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect. *Clinical Child Psychology And Psychiatry*, *12*(4), 549-565.

Wayment, H., & Vierthaler, J. (2002). Attachment style and bereavement reactions. *Journal of Loss & Trauma*, *7*(2), 129-149. doi:10.1080/153250202753472291.

White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.

Wilks, S. E., Little, K. G., Gough, H. R., & Spurlock, W. J. (2011). Alzheimer’s aggression: Influences on caregiver coping and resilience. *Journal of Gerontological Social Work, 54*(3), 260-275.

Yorganson, J. B., Roper, S. O., Wheeler, B., Crane, K., Byron, R., Carpenter, L., Sandberg, J. G., Sheffield, R., & Higley, D. (2010). Older couples’ management of multiple-chronic illnesses: Individual and shared perceptions and coping in type 2 diabetes and osteoarthritis. *Families, Systems & Health, 28*(1), 30-47.

Zhang, B., El-Jawahri, A., & Prigerson, H. (2006). Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *Journal of Palliative Medicine*, *9*(5), 1188-1203.

Appendix A

Key search terms

Impact	AND	Mental health	AND	Palliative	AND	Family member
OR		OR		OR		
Experience		Depression		Terminal		OR
		OR		OR		Relative
		Anxiety		Dying		OR
		OR				Sibling
		Attachment				OR
		OR				Child
		Distress				OR
		OR				Parent
		Spiritual				OR
		OR				Partner
		Emotional				OR
		OR				Spouse
		Financial				
		OR				
		Educational				
		OR				
		Role				
		OR				
		Communication				
		OR				
		Conflict				

Appendix B

Extract from Inclusion/Exclusion Table

Article	Included/Excluded	Reason for Exclusion
Shanmugasundaram & O'Connor (2009)	Included	
Morasso et al. (2008)	Included	
Gelfman, Meier, & Morrison (2008)	Excluded	Focus of article is service evaluation
Wong and Chan (2007)	Included	
Maryland, Williams, & Ellershaw (2008)	Excluded	Article is a literature review of measures used with family members
Kehl, Kirchhoff, Kramer, & Hovland-Scafe (2009)	Included	
Hunstad & Svindseth (2011)	Included	
Hudson, Thomas, Quinn, & Aranda (2009)	Excluded	Focus is service evaluation
Hudson et al. (2010)	Excluded	Article is a literature review focusing on measures
Gunnarsson & Ohlen (2006)	Included	
Kennedy & Lloyd-Williams (2009)	Excluded	Article relates to experiences of children
Gardner (2008)	Included	
Glacking & Higgins (2009)	Included	
MacPherson & Emeleus (2007)	Excluded	Article relates to experience of children

Appendix C

Page1/8

Matrix of Key Themes

	Heterogeneous Samples	Wong & Chan (2007)	Spichiger (2008)	Spence et al. (2008)	Persson & Sundin (2008)	Osse et al. (2006)	Morasso et al. (2008)
Impact	Unpredictability	X	X	X		X	
	Difficult accepting					X	
	Fatigue/ exhaustion			X		X	
	Sleep problems			X			
	Depression					X	
	Difficultly expressing emotion					X	
	Powerless/ helpless	X		X	X		X
	Isolation/ abandonment				X		
	Shock of diagnosis				X		
	Anticipating loss		X		X		
	Closeness				X		X
	Family cohesion						X
	Lost intimacy				X		
	Building own life				X		
	Guilty			X			X
	Anxiety/ Fear			X			X
	Frustration			X			
	Witnessing decline			X			
	Responsibility/ decisions			X			
	Medical role			X			
	Satisfaction/ rewards			X			
	Multiple losses		X	X	X		
	Sadness	X					
	Anger	X					X
	Commitment	X					
	Increased self-efficacy						X
	Societal expectations						
	Moral duty						
	Loss of identity			X			
	Cognitive functioning						
	Quality of Life						

	Heterogeneous Samples	Tang et al. (2007)	Hasson et al. (2010)	Linderholm & Friedrichsen (2010)	Carlander (2010)	Kehl et al. (2009)	Ray & Street (2006)
Impact	Unpredictability						
	Difficult accepting						
	Fatigue/ exhaustion		X				X
	Sleep problems						
	Depression	X					
	Difficultly expressing emotion						
	Powerless/ helpless		X				
	Isolation/ abandonment		X				X
	Shock of diagnosis						
	Anticipating loss						
	Closeness						
	Family cohesion						
	Lost intimacy						
	Building own life						
	Guilty						
	Anxiety/ Fear						
	Frustration						
	Witnessing decline		X			X	X
	Responsibility/ decisions			X			
	Medical role			X			
	Satisfaction/ rewards						
	Multiple losses					X	
	Sadness						
	Anger						
	Commitment						
	Increased self-efficacy						
	Societal expectations				X		
	Moral duty			X			
	Loss of identity		X				
	Cognitive functioning						
	Quality of Life						

	Heterogeneous Samples	Yamagishi et al. (2010)	Namba et al. (2007)	Mackenzie et al. (2007)	Persson et al. (2008)	Reid et al. (2009)	Shanmugasundaram & O'Connor (2009)
Impact	Unpredictability						
	Difficult accepting						X
	Fatigue/ exhaustion						
	Sleep problems				X		
	Depression						
	Difficultly expressing emotion						
	Powerless/ helpless	X					
	Isolation/ abandonment						
	Shock of diagnosis						
	Anticipating loss						
	Closeness						
	Family cohesion						
	Lost intimacy						
	Building own life						
	Guilty	X	X			X	
	Anxiety/ Fear		X				
	Frustration					X	
	Witnessing decline					X	
	Responsibility/ decisions						
	Medical role						
	Satisfaction/ rewards						
	Multiple losses						
	Sadness						
	Anger						
	Commitment						
	Increased self-efficacy						
	Societal expectations						
	Moral duty						
	Loss of identity						
	Cognitive functioning			X	X		
	Quality of Life				X		

	Partners/ Spouses	McLaughlin et al. (2010)	Gunnarson & Ohlen (2006)	Hunstad & Svindseth (2011)	Gardner (2008)	Riley & Fenton (2007)	Palm & Friedrichsen (2008)
Impact	Unpredictability				X		
	Difficult accepting					X	
	Fatigue/ exhaustion		X			X	
	Sleep problems					X	
	Depression					X	
	Difficultly expressing emotion		X			X	X
	Powerless/ helpless		X	X			
	Isolation/ abandonment	X					
	Shock of diagnosis	X				X	
	Anticipating loss		X				
	Closeness		X	X			X
	Family cohesion						
	Lost intimacy		X			X	
	Finances	X					
	Guilty					X	X
	Anxiety/ Fear	X				X	
	Frustration						
	Witnessing decline			X			
	Responsibility/ decisions		X				
	Changing role		X		X	X	X
	Satisfaction/ rewards						
	Multiple losses						
	Sadness						
	Anger	X	X			X	
	Commitment						
	Increased self-efficacy			X			
	Societal expectations						
	Moral duty	X					
	Loss of identity			X			
	Maintaining normality		X				
	Religion			X	X	X	

	Partners/ Spouses	Strasser et al. (2007)	Glackin & Higgins (2008)/ Higgins & Glackin 2009	Parents	Kars, Grypdonck, & van Delden (2011)	Zelcer et al. (2010)
Impact	Unpredictability			Unpredictability		
	Difficult accepting			Difficult accepting		
	Fatigue/ exhaustion			Fatigue/ exhaustion	X	
	Sleep problems			Sleep problems		
	Depression			Depression		
	Difficultly expressing emotion			Difficultly expressing emotions/thoughts	X	X
	Powerless/ helpless			Powerless/ helpless	X	
	Isolation/ abandonment		X	Isolation/ abandonment		
	Shock of diagnosis			Shock of diagnosis		
	Anticipating loss	X		Anticipating loss		
	Closeness			Closeness		
	Family cohesion			Family cohesion		
	Lost intimacy			Lost intimacy		
	Finances			Finances		
	Guilty			Guilty		
	Anxiety/ Fear			Anxiety/ Fear		
	Frustration			Frustration		X
	Witnessing decline	X?		Witnessing decline/suffering	X	X
	Responsibility/ decisions			Responsibility/ decisions	X	
	Changing role			Changing role		X
	Satisfaction/ rewards			Satisfaction/ rewards		
	Multiple losses			Multiple losses		
	Sadness			Keeping busy	X	
	Anger			Anger		X
	Commitment			Child's Identity important	X	
	Increased self-efficacy			Personal growth		
	Societal expectations			Societal expectations		
	Moral duty			Moral duty		
	Loss of identity			Loss of identity	X	
	Maintaining normality			Maintaining normality	X	X
	Religion			Religion		

	Parents	Brewer et al. (2007)	Runswick-Cole (2010)	Steele & Davies (2006)	Price et al. (2011)
Impact	Unpredictability		X		X
	Difficult accepting				
	Fatigue/ exhaustion			X	X
	Sleep problems			X	
	Depression			X	
	Difficultly expressing emotion				
	Powerless/ helpless			X	
	Isolation/ abandonment	X	X	X	X
	Shock of diagnosis				
	Anticipating loss			X	
	Closeness				
	Family cohesion				
	Lost intimacy				
	Finances		X	X	
	Guilty			X	X
	Anxiety/ Fear			X	X
	Frustration				
	Witnessing decline/suffering			X	
	Responsibility/ decisions				
	Changing role				
	Satisfaction/ rewards				
	Multiple losses				
	Keeping busy				
	Anger				
	Child's Identity important				
	Personal growth			X	
	Societal expectations				
	Moral duty				
	Loss of identity				
	Maintaining normality				X
	Religion			X	

	Parents	Schneider et al. (2011)	Ware & Raual (2007)	Kars, Grypdonck, de Korte-Verhoef, et al. (2011)

Impact	Unpredictability		X	
	Difficult accepting			X
	Fatigue/ exhaustion			
	Sleep problems			
	Depression	X		
	Difficultly expressing emotions/thoughts		X	
	Powerless/ helpless		X	
	Isolation/ abandonment		X	
	Shock of diagnosis			
	Anticipating loss			
	Closeness		X	
	Family cohesion			
	Lost intimacy			
	Building own life			
	Finances			
	Anxiety/ Fear			
	Frustration			
	Witnessing decline			
	Responsibility/ decisions			
	Changing role			
	Satisfaction/ rewards			
	Multiple losses			
	Keeping busy			
	Anger			
	Child's Identity important			X
	Personal growth		X	
	Societal expectations		X	
	Moral duty			
	Loss of identity			
	Maintaining normality			
	Religion		X	

Appendix D

Information Sheet for Participants

Participant Information Sheet: 08/12/2011 – Version 02

The Experience of Living with a Husband or Partner who has a Life-Limiting Illness

Please read this information sheet carefully. If you consent to take part in the study described here, then you will be asked to sign the consent form, a copy of which will be given to you. If you have any questions, or are uncertain about anything, then you should not sign until your problems have been resolved and you are completely happy to volunteer.

If you would like to take part in this research, or if you would like to ask me some questions before you decide whether or not to take part, then I would ask that you leave a message for me with [redacted], PA to Psychology, at [redacted] [redacted] (telephone: [redacted]). She will pass on your details to me and I will get back to you.

Details of this study

I am Anna Jepson, a Trainee Clinical Psychologist at the University of Southampton and I am inviting you to take part in a study that I am conducting. This study aims to explore what it is like being a partner to someone who has a life-limiting illness and would involve speaking to me about your experiences. Participation may not be of any benefit to you personally, and it is possible that you may find it upsetting. Some people may find it helpful to talk about their experiences, however this will not be therapy and if you feel that you need help or support there are a number of services available to you at the [redacted]. This research will form part of my doctorate and by taking part it is you who would be helping me.

Before you decide whether or not to take part I would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

So far there has only been a limited amount of research exploring the way partners of people with life-limiting illnesses feel about their experiences. The purpose of this study is to explore these experiences in more depth in order to understand them better.

Why have I been invited?

You have been invited to take part because you are attending either the [redacted] or a Carers Day run by [redacted] and because I would be interested in hearing about your experience as a woman whose husband or partner has a life-limiting illness.

What will happen to me if I take part?

The research that you are being invited to take part in would require you to be interviewed, by me, for up to an hour. During the interview you would be asked to share any feelings, thoughts, ideas and experiences to do with your relationship with your partner.

This interview can take place either in a private room at the [redacted] (on a day when you and your partner would already be attending [redacted], if this is more convenient) or in your own home, depending on where you would feel most comfortable.

The interview will be tape recorded. Should you wish to take a break during the interview or complete the interview over two or more meetings this can be arranged.

Do I have to take part?

It is up to you to decide to join the study. I will describe this study and go through this information sheet. If you agree to take part I will then ask you to sign a consent form. You are free to withdraw your participation or choose to end the interview at any time, without giving a reason. This would not affect the care received by you or your partner.

What are the possible disadvantages and risks of taking part?

Some people may find it upsetting discussing sensitive issues such as their partner's illness. If you do feel upset after taking part we can talk about the support available for you and I can arrange for you to be seen by [redacted] psychology service.

What are the possible benefits of taking part?

So far there has only been a limited amount of research exploring the way partners of people with life-limiting illnesses feel about their experiences. It is hoped that by exploring these experiences this research will contribute to psychologists' understanding of this area. Participation may not be of any benefit to you personally. This research will form part of my doctorate and by taking part it is you who would be helping me.

Will my taking part in the study be kept confidential?

Yes. Information that identifies you will not be viewed/ listened to by anyone other than the researchers involved in this study. The researchers involved in this study are myself, Anna Jepson, and my supervisors: Paul Beadon and Becky Coles-Gale, both Clinical Psychologists [redacted] [redacted].

The audio recording of the interview will be transcribed onto a password protected computer and the recording deleted. All information that identifies you will be removed from the transcribed interview. This interview will be stored securely for 15 years at the University of Southampton. All information will be subject to the conditions of the Data Protection Act 1998 and subsequent instruments.

When the research is written up your identity will be kept confidential: if you can be specifically identified by any material, your permission will be sought in writing before it is published. Other material, by which you cannot be identified, will be published or presented at meetings with the aim of benefiting others.

What will happen to the results of the study?

It is intended to publish the results of the study. If this happens then your anonymity will be preserved. If you choose to take part then you will be asked if you would like to be informed when the research has been published.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the NRES Committee South West – Central Bristol.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to me or my supervisors: Paul Beadon or Becky Coles-Gale and we will do our best to answer your questions (telephone: [redacted]). If you remain unhappy and wish to complain formally, please contact the Chair of the Psychology Ethics Committee, University of Southampton, Southampton, SO17 1BJ. Phone: [redacted].

What do I do if I want to know more?

I would be happy to speak to you some more about the study and answer any questions that you might have before you decide whether or not you would like to take part. If you have any questions please feel free to ask them now or on the day of the interview. You can contact me, Anna Jepson, by leaving a message for me with [redacted] at [redacted] [redacted] (telephone: [redacted]) and I will get back to you.

Thank you for taking the time to read about this study.

Anna Jepson
Trainee Clinical Psychologist

Appendix E

Consent Form for Participants

Study Number: [redacted]

CONSENT FORM: 08/12/2011 – Version 02

Title of Project: The Experience of Living with a Husband or Partner who has a Life-Limiting Illness

Name of Researcher: Anna Jepson

Please initial box

1. I have read and understood the information sheet dated 08/11/2011, version number 2 and have had the opportunity to ask questions which have been satisfactorily answered. ☐
2. I understand that my participation is voluntary, that I am free to withdraw from this study at any time without giving any reason, and that doing so will not affect the care received by me or my partner. ☐
3. I understand that the interview will be recorded and that these audio-recordings will be transcribed and then deleted. The transcribed interviews will be kept on a password protected computer and all information that identifies me will be removed. These interviews will be stored for 15years at the University of Southampton in a secure office and will not be used for any purpose other than this study. ☐
4. I understand that I might be anonymously quoted verbatim in relevant research papers, publications and presentations. ☐
5. I understand that relevant data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
6. I agree to participate in this study. ☐

Name of volunteer	Date	Signature
________________________	___________	____________
Name of person taking consent	Date	Signature
______________________	___________	_____________

If you would like to receive a copy of the typed interview transcript, the completed research, or to be notified when the research is published please let me know how I can contact you:

I would like you to contact me by post and my address is:

....

....

....

....

....

....

I would like you to contact me by email and my email address is:

....

Appendix F

Introductory Script for Participants

“Thank you for agreeing to meet with me for this interview today.”

“I’m going to start by giving you some information about the interview process so that you can know what to expect. Please feel free to stop me and ask any questions that you have as I go along.”

“As I explained in the information sheet, this interview will form part of my research. I will record our interview and afterwards I will turn the audio recording into a written transcript of the interview.”

“This interview is about womens’ relationship with their husband or partner when that husband or partner has a life-limiting illness. This can mean different things to different people and this interview will be a conversation about your experiences.”

“During the interview I will be very interested to hear about your experiences and about your thoughts, feelings and ideas about those experiences. There are no right or wrong answers at all. This interview is about you and you are the expert on you.”

“You are free to share anything about your experiences that you would like to without fear of judgement but equally of course you can choose to keep anything private that you want to. I will respect any wish you have to move on or away from any particular part of our discussion.”

“When I write up the interview I will remove any information that identifies you, such as peoples’ names and the names of places. Only myself and my supervisors Dr Becky Coles-Gale and Dr Paul Beadon will be allowed to listen to the recording of our conversation and this recording will be deleted after I have transcribed it. The typed transcription of our conversation will have all information that identifies you removed. It will then be stored securely at the University of Southampton.”

“The interview will take about an hour but this is only a rough guide, it can be longer or shorter than this. If you become uncomfortable or tired during the interview and wish to reschedule or continue on another day then this is absolutely fine.”

“It is very important to me that if you feel that you no longer wish to take part in the research or would like to stop the interview that you feel able to tell me. I will not mind at all and will be happy to delete any recording of our interview while you watch.”

“Do you have any questions so far?”

“To begin then: could you tell me about your relationship with your husband/partner?”

Further enquiry may be made if this is judged by the interviewer to be appropriate, for instance:

- “How do you feel that your relationship has been affected by your [partner or husband's] illness?”

At the end of the interview each participant will be asked about their experience of the interview:

“How has it been today, talking with me about your experiences?”

Appendix G

Debriefing Statement for Participants

The Experience of Living with a Husband or Partner who has a Life-Limiting Illness

Debriefing Statement: 08/12/2011 – Version 02

The aim of this research is to explore the experience of living with a husband or partner who has a life-limiting illness. Currently there is a lack of research in this area and consequently it is hoped that this research will provide a valuable insight into these experiences. Because this is a relatively unexplored subject there are no prior expectations about the findings that will emerge from these interviews.

If you feel upset about anything that we have spoken about today, or are concerned that you may become upset later on then please raise this with me and we can discuss the sources of support available to you.

If you have any further questions about this research please contact me, Anna Jepson, by leaving a message for me with [redacted] at [redacted] (telephone: [redacted]) and I will get back to you.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Psychology Ethics Committee, University of Southampton, Southampton, SO17 1BJ. Phone: [redacted].

Thank you for your participation in this research.

Appendix H

Master Table of Themes

Super-ordinate theme	**Emergent theme**	**Excerpt**	**Participant**	**Line**
Holding uncertainty	Uncertain course of the illness	It’s it has be assessed every six weeks and every ache and pain you think “oh what is it? What is it?” Which is not good. And we know intellectually that you mustn’t be like that but you can’t really help it cause you wonder “could this be starting up again?”	Sylvia	108-111 (4)
		We’re spending the time together, because who knows. We don’t know. So we’re spending time together as much as possible. We always have done but probably a little more now	Sylvia	380-382 (14)
		So I am very lucky. Erm, however long it goes on	Sylvia	503 (18)
		We’ll think about it if he’s not changed too much in the next few weeks	Emma	203-204 (8)
		We try but sometimes he’ll say, you know, perhaps we’ll perhaps we’ll go out to lunch tomorrow or maybe we’ll go to the cinema or something and then that next day comes and he’ll say “I don’t really feel like it today”	Emma	246-248 (9)
		We are waiting for the results of that scan	Valerie	65 (3)
		Cancer is not an exact science, it might be the end tomorrow or it might go on for some years	Valerie	242-243 (9)
		I’d like John to be well enough for us to perhaps have two weeks holiday on that ship with all its ability to spoil you. But we’ll have to see	Valerie	298-300 (11)
		Recently it was a case of “we’ll give you another scan and see how you’re getting on” but we’ve not heard any more	Valerie	452-453 (17)
		Wishing, willing him to live	Valerie	364 (14)
		“We might not be coming but we’ll keep our fingers crossed”	Janet	64-65 (3)
		“Well will Gerry walk her down the aisle or won’t he?”	Janet	72-73 (3)
	Uncertainty about own and others’ emotions/coping	I think it’s more worried about the future, about how, how I’ll be able to manage	Emma	155-156 (6)
		I don’t know how my daughters will cope	Emma	349 (13)
		So yes I do worry a little bit about “am I going to be able to cope if he	Emma	145-146 (6)

		get's worse?"		
		It's quite difficult, it's a mixture of feelings, really. And how it'll all work out I don't know. How I'll feel when he dies I've no idea	Julia	67-68 (3)
		How we'll be when it all end, or when Nicholas dies and we don't have that, him to look after I don't know. I would think we'd probably come through it	Julia	398-400 (14)
		Our eldest daughter has always had her dad on a pedestal and always will have. So she will feel very upset I would say. As well as our eldest granddaughter [...]. And, err, I don't know, can't look round corners can you	Julia	400-403 (14)
		No one can say really	Julia	405 (14)
		"What are you going to do if I die?"	Valerie	229-230 (9)
	Tolerating uncertainty	It's in the lap of the Gods	Sylvia	410 (15)
		I've never really been a great big future person, and it's a darn good job I haven't. Isn't it [ ] But I don't see how you can start making a lot of plans. You can't. Cause look what's happened to us. It's be the last thing I would have thought of	Sylvia	413-418 (15)
		Isn't it a good job we don't know what's coming? We'd be horrified wouldn't we?	Sylvia	452-453 (16)
		I don't think about that, I mean that doesn't say it doesn't worry me, it worries me but I don't think about it too much until it happens	Emma	128-130 (5)
		I would cross that bridge when it happens	Emma	115 (5)
		As for the future, I know that's going to be rough and I can't answer how my feelings will be then, I'm sure they'll be worse, but... that does with the future doesn't it really	Emma	451-452 (16)
		I can't do anything about it so there's no point ruining my life worrying about it all the time anyway. And to a certain extent I try to do that with James	Emma	143-144 (6)
		And I think I could be neurotic by now if I wanted to be, so I'm not. I'm fairly calm person	Emma	134 (5)
Living alongside dying	Witnessing husband's physical frailty and suffering	He got very short of breath and he used to puff and blow	Janet	56 (2)
		He'd had a chest infection	Janet	62 (3)
		It was a very difficult year last year because he was very frail	Janet	82 (3)

		He started to be really poorly again	Janet	86-87 (4)
		He's on oxygen from the time he gets out of bed in the morning to the time he goes to bed at night	Janet	132-133 (5)
		Gerry was very ill. He wasn't eating and in the end he collapsed	Janet	78 (3)
		He said "I'm just existing really"	Janet	136 (5)
		He said to me before Christmas "I really don't want to go on anymore, I've had enough and if I could just go to sleep and disappear that'd be great, he said, everybody'd have a much better life"	Janet	138-140 (5)
		He's already signed the form says if he goes, you know, out of it he does not want to be resuscitated. He said "I cannot see any point in coming back to this, only worse"	Janet	385-387 (14)
		He had the most horrendous feeling of sickness, he couldn't bear to move his head, and he's already started to get a cough	Janet	87-88 (4)
		Years not months, my husband was suffering	Valerie	53/54 (2)
		He now has to live with a stoma bag	Valerie	66 (3)
		You see somebody who is so desperately ill	Valerie	241-242 (9)
		He lost three stone in hospital, he came home really dreadful	Valerie	218 (8)
		It is very very sad remembering the day that I met him when he was aged 22 and we were dancing	Valerie	220-221 (8)
		It's as if his feathers are dropping off him	Valerie	216 (8)
		The more tired he gets the more slurred he becomes	Emma	45 (2)
		I'm sure it will get me down at times, bound to, but I think it's going to get me down because of seeing him and then that will affect me, and then thinking "I, I can't necessarily manage all of this"	Emma	148-150 (6)
		"I don't want to leave everything to you so you know I can go and get couple of spoons out of the drawer" erm, he did this the other night and he fell over	Emma	58-59 (3)
		This time his legs just seem to have gone	Emma	109 (4)
		"you'll go flat on your face if you don't come forward, please come forward"	Emma	125-126 (5)
		He wasn't eating I was absolutely beside myself, I was, I couldn't, he	Sylvia	148-149 (6)

		just didn't want anything		
		He's so, he's such a very interesting and intelligent man normally and he makes me cry	Caroline	341-342 (12)
		Because he's shaking so. He can't even write a letter these days	Caroline	365-366 (13)
		Not so much physically caring as seeing a man who was *so* self-assured	Caroline	379-380 (14)
		It's pathetic to see him sit there with his chicken-like legs, cause he hardly wears any trousers, he's let modesty go to the wall, counting his pills	Caroline	414-415 (15)
		I'm so sad to see Charles losing weight.	Caroline	527 (18)
		He went completely bald when he was having the chemo and the radiotherapy. He was like, you won't know anything about this but during the war in the concentration camps there was one called Belsen and they used to show photographs of these people in Belsen and they had bars round like this, and you could count every rib, there was no...Well Charles is the same now. And he's never been a fat man. But he did weigh 14 stones at one time, now he barely touched 10	Caroline	83-88 (3)
		Well he can't write properly now cause his hand is shaking too much	Caroline	198 (7)
		He wears pads which he wouldn't like me to talk about	Caroline	77-78 (3)
		He went to the post office one day, this is before I bought him the walker, and he fell	Caroline	104-105 (4)
		But he's aged so quickly you know	Caroline	355 (13)
		And it takes him *ages*. He goes to the precinct and back, that's about all he does	Caroline	110-111 (4)
	Witnessing the progression of the illness	As he gets worse, which he is doing	Janet	131 (5)
		We just knew that it was going to get worse, that it would kill him, just like cancer does because there's no cure for it	Janet	53-54 (2)
		But it's just another progression of the illness	Janet	282 (10)
		So the oxygen is the only thing that helps really. Having said that when he goes to bed at night he's motionless, he's resting and he doesn't need it. But there probably will be a time when he'll be on it twenty four seven	Janet	412-414 (15)

		Well it’s gradually got more and more that Gerry’s got more and more sick and is more and more dependent on me and can do less and less and now he can do virtually nothing	Janet	268-269 (10)
		Gerry’s health had got *a lot* worse. Erm, he was on concentrated oxygen at the time, but only as and when he needed it	Janet	70-71 (3)
		It’s not going to get any better it’s going to get worse	Janet	375-376 (14)
		There are times when he’s so ill that you can literally see, and don’t kid yourself, you can literally see he’s dying before your very eyes	Valerie	207-209 (8)
		Realistically you’re looking at someone who *is* dying	Valerie	217 (8)
		Now it’s quite obvious that he is getting quite ill. Well he is ill. But things are more difficult for him	Julia	63-64 (3)
		Her husband does outside jobs for us that Nicholas can no longer do. Cause he virtually can’t do anything now	Julia	176-177 (7)
		You have to consider the one that’s ill and is slowly giving up all that he’s able to do	Julia	355-356 (13)
		I know things aren’t going to improve at the moment. In fact Nicholas is going downhill quite rapidly really	Julia	409-410 (15)
		Must be a good eighteen months but of course his legs have got worse over that period of time	Emma	211-212 (8)
		But I know what’s coming with him, that he’s unavoidable	Emma	144-145 (6)
		Trying to get these things sorted before [sigh] before its sort of too late for James to talk it through you know and so on	Emma	467-468 (17)
		I think emotionally, erm, probably as he gets worse perhaps can’t talk or when he can’t walk at all or is almost bedridden I think then the emotional side will kick in more because, erm, I’ll be losing my husband. He’s still there but I will be losing him really	Emma	171-174 (7)
		We know it’s going to be worse or more relying on	Emma	179-180 (7)
		There’s a lot happened in those three years, not at the beginning thank goodness though certainly the last half of that it’s come quite fast	Emma	223-224 (8)

		We know it's...he is gradually getting worse. In fact sometimes it's not gradual	Emma	242-243 (9)
Attunement Vs Alienation	Empathic Understanding	It was horrible. And it must have had a terrible effect on him.	Sylvia	75-76 (3)
		During his chemotherapy, err, I would take him out for a ride in the car. Because he loves to go out for a ride on his own	Sylvia	85-86 (3)
		And that upset him desperately	Sylvia	160-161 (6)
		But I felt he had a right to be angry, why not?	Sylvia	243 (9)
		So he has worked very hard. And he's tired I suppose. We all get tired when we get older	Caroline	278-279 (10)
		Can be frustrating for two of us, erm, not just one	Emma	45-46 (2)
		My feelings are more for James rather than "poor me". He thinks its poor me and I think its poor you so [laughing], erm, which is probably ah.., the right way of looking at it	Emma	453-454 (16)
		But I do think it's a little bit unfair on, on him and if you like yes a little bit unfair on me, but far more so on him than on me	Emma	49-50 (2)
		It's me that's having my life altered a bit and I'm the healthy one so, but James feels that more than I do I think	Emma	190-191 (7)
		He probably finds it frustrating for himself, ahm, but you just adapt to these things, just carry on with life really	Emma	290-291 (11)
		You have to take his feelings into account as well, so you can't override everything he says cause that's unkind	Julia	351-353 (13)
		You have to consider the one that's ill and is slowly giving up all that he's able to do	Julia	355-356 (13)
		I suppose it's his life and if that's how he wants it then quite honestly that's fine by me cause I can't see any point in him perhaps having a seizure or a massive heart attack and coming out being paralysed as well on top of it and not being able to speak, that would be just too much for him to cope with, you know	Janet	387-390 (14)
		Well if I had to do all of that I'd be so wide awake I wouldn't know how to go back to sleep but he's so	Janet	419-422 (15)

		exhausted he can't *wait* to go back to sleep, you know. But it is, it's the most horrible thing and I, as I said to you just now, I wouldn't wish it on anybody, no		
	Mutual protectiveness	"I don't want to leave you" I said "just stop there" I said "you don't want to leave me" I said "I could possibly go before you", because Mike's [...] years younger that I am. I said "so, stop, you can, I'm listening to what you're saying and I know what you mean but let's hope that I can keep going"	Sylvia	243-246 (9)
		I said to him "are you frightened?" he said "not really, no" "no" he said "I'm more bothered about leaving, if I have to leave you, that's the thing"	Sylvia	448-450 (16)
		He's worried about me for the future, well if he has any worries it would be that	Caroline	339-340 (12)
		But I'm angry with them too because they don't come to see Charles. Now he's been a very good Father to them	Caroline	175-177 (7)
		I don't want to be out all the time leaving him 'cause it's unfair you know that he's not out so much	Emma	196-197 (7)
		If I was one of these that would always crying and saying "oh no oh you poor thing" and, you know, "what are we gonna do?" and so on [sighs] I don't think that's gonna help James at all	Emma	177-178 (7)
		He really feels almost bad enough now relying on me so much	Emma	179 (7)
		I don't want to be one of these that's this emotional person... Because I don't think it helps him at all and at the moment I can probably keep that well down. At the moment	Emma	180-182 (7)
		But he knew, he knew, I mean it was him that was saying "we ought to get rid of this now, I don't want you to be lumbered with getting rid of it"	Emma	258-259 (10)
		But to have them staying for a week is is a lot for James, I mean he then has to make this effort to keep going and then he says "and it's a lot for you too"	Emma	274-275 (10)
	Disconnection (and re-connection)	I got angry with him because his emotions were so different and sometimes he didn't seem to even know that I was on the planet and it	Sylvia	55-59 (2)

		was a horrible feeling to have. He didn't seem to bother whether I was, what ever I was doing, whether I wasn't feeling well or what *ever*. He just, he just wasn't interested		
		I felt fed up really that I was doing all this for him and there was no feedback at all. Not the slightest. I'm trying to think of any...then obviously he's back to his old self again now thank goodness. It was a very very difficult time. A *very* difficult time	Sylvia	62-64 (3)
		He was emotionless really. And it's not like him and it was very very upsetting. I can't really think of any, of anything else that is ...[pause]. I try to well I had a lot of weeps on my own and tried to stem a lot of the things but sometimes I got extremely cross, very cross. Because I felt he couldn't care less. And I don't think he could to be quite honest because I don't think he even knew what was happening. I think he hadn't a clue, it was horrible	Sylvia	71-76 (3)
		And I got very very panic stricken. And he never even, he just sat, absolutely, it's just not Mike, absolutely deadpan. As though... I was just in such a state and I pulled in one over and he never, he just didn't seem to, I don't know	Sylvia	91-93 (4)
		Mike, when he was going through his treatment was different. A different person. And we had moments when I was very very down because I didn't really realise what the treatment was doing to him and err he wasn't the same person at all. It affected him greatly. I got very, occasionally I got quite angry with him	Sylvia	51-55 (2)
		He wasn't interested in *anything*. He couldn't concentrate on reading, which he loves, he likes his gardening, he couldn't do anything at all. His concentration was nil. He didn't want to watch television, he didn't want to do anything at all. So that's just a little, that's how it was. It was horrible. It really was a horrible time	Sylvia	96-100 (4)
		Chemotherapy took a terrible toll on	Sylvia	103-104 (4)

		his [pause] mind, shall I say		
		All I can describe it as, a complete void, he's got no emotions, no concern about anything else apart from the pills he has to take	Caroline	64-65 (3)
		I miss all of the little things, cause he doesn't do *anything* anymore	Caroline	372 (13)
		I could always rely on Charles. He'd come in from [working] all day, take his coat off and just help whenever wherever I was doing, he would just come in and help. Now he won't even lift a cup from the table unless you ask him to. Now he won't even get dressed without you saying "I suggest you wear this today"	Caroline	68-71 (3)
		We never went to bed at night without him setting the table first for breakfast the next morning. None of that happens	Caroline	75-76 (3)
		As regards helping with a meal or any of the, oh I can't describe, all the ways he used to help me. But now he doesn't even see the need to be done, you know	Caroline	92-94 (4)
		But as regards anything else, just not interested. We watch television, don't know how much takes in, but watches what I want to watch	Caroline	220-222 (8)
		He'll do anything I want to do, but I would like some input from him sometimes but I get none	Caroline	224-225 (8)
		And he said "all I can describe it as complete void inside" so he's got no emotions, no interest in whatever's going on in other parts of the world you know, or this world	Caroline	337-339 (12)
		So he's done a lot of charitable work, in fact he got a medal for fifty years charity work, and he did that pottery, and he was good sketcher at one time. Now, he doesn't want to do anything like that	Caroline	395-397 (14)
		I don't know what my feelings are really. I care about him. But I haven't forgiven him. So I suppose that's the best way to put it really. And I feel very very sad for him	Julia	61-63 (3)
		I think if he hadn't gone off as he had I would be more upset, or more *emotional* than I appear to be. And then I think to myself "I shan't really know until he dies". So it's a funny, I'm at a funny place. I think [pause]	Julia	298-302 (11)

		he, I think he knows that, he realises that I'm at a strange place looking after him		
		It's physically, mentally draining, but he has no idea	Janet	154 (6)
		He's mortified when he realises he's been rude but unless I say anything he won't know	Janet	241-242 (9)
		But he just assumes that I'm always going to be there looking after him and waiting on him, which is virtually what I do	Janet	466-467 (17)
		And If I got here at quarter past he said to me "your late". I said "and?" "oh" and he's realised he's said the wrong thing, and I said "you know, I've got a hundred and one things to do before I get here" "mmm, sorry". But every time I came in he'd say to me "you're not as early as yesterday" and that *really* used to annoy me	Janet	513-516 (18)
		It's like well they're there but they're only there half of them, you know what I mean, the rest of them doesn't exist	Janet	142-143 (5)
		Was getting a bit sort of fed up with him. You know, wishing, willing him to live and then when he came home he was such a pain in the leg	Valerie	363-365 (14)
		It was like somebody coming out of a...a deep sleep. And, or like a chrysalis that was coming out and opening. It was beginning to be Mike again. I could see it, not every day, but I could sense it. That he was coming out of....it was like as though he's been in a coma	Sylvia	120-123 (5)
	Internal Vs External attributions about behaviour	And now I've found out that it *is* the effects of the treatment that were doing it to him	Sylvia	59-60 (3)
		I just wish that there was more to help one when you are in that situation, to be able to just say "this is the treatment that's doing this, this isn't the *person* this is completely not the person that you know"	Sylvia	81-83 (3)
		It's just learning to cope with a different person	Caroline	202-203 (7)
		Yeah he is different. Because he doesn't, not in his head in my head; these are all thoughts from me, that he hasn't a care about me anymore,	Caroline	210-212 (8)

		it's all himself, he's all selfish inside. I don't know. I suppose people do change		
		You know just think, "it's not *his* fault" it's not as if he's turned his back on me and said "I don't want you any more", it's nothing like that	Emma	294-295 (11)
Enduring partnership	In good times and in bad, in sickness and in health	Not because he's got this illness, not because things aren't good	Emma	67 (3)
		We've always got on, we've obviously had the odd rows like we all do	Emma	34 (2)
		We don't row, occasionally there's the odd slightly crossed word	Emma	40-41 (2)
		I usually walk in and say "oo sorry" and he'll go "no no it's all my fault"	Emma	54 (2)
		My life being stopped because of his life, but I don't bear a grudge about that, it's the way it is	Emma	48-49 (2)
		I've got used to that over the years...probably years ago it bothered me a bit more than it ever would now	Emma	91-92 (4)
		I've always worked on the business of never ever, if you've had a row, going to sleep on the row and continuing it	Valerie	205-206 (8)
		These are things that go on in one's married life	Valerie	529 (20)
		Lot of people think we're a dear Darby and Joan couple who've lived forever and we're ever so sweet. We're not anything of the sort [laughs]	Valerie	508-509 (19)
		I think we've done quite well, really, within relationships, for what we've had to, erm, put up with and sort out. I think we've done quite well in that respect. It showed that we probably had a very good, strong, relationship in the first place	Julia	378-381 (14)
		Although our relationship was still good it was different. It, erm, it's difficult to say what it was...I don't think he was quite so honest	Julia	46-47 (2)
		It got to a stage where it was it was a long term, we had our 40th wedding anniversary, and erm things weren't good. But then in a long term relationship you don't expect it to always be the right thing	Julia	47-49 (2)
		He says to me "I'm a pest" I said "yes you're a pain in the backside but then you've always been so tell me	Janet	597-599 (21)

		something I don't know" you know, but he just laughs. He said "am I really a pain in the backside?" I said "no, I'm only joking", I said "I love you to bits, but you can be blooming annoying sometimes"		
		We've had some good years and we've had some very bad years. And Charles' been evenly tempered all the way through	Caroline	443-444 (16)
	Love and closeness	Feeling wise it's just the same	Emma	46 (2)
		We still feel the same about each other	Emma	51 (2)
		There's ways and means of being close anyway, erm, which you know I think we are	Emma	289-290 (11)
		But, it *is* take it from me that love is the greatest thing out. Real strong love	Sylvia	516 (18)
		The greatest thing you can have, is to be contented and love somebody and have somebody love you	Sylvia	519-520 (18)
		If you love them you just want the best for them, and I want for Mike. I want the best for Mike. And because I love him, and I just want the best for him	Sylvia	341-343 (12)
		You become not two persons but one, really truly	Valerie	224-225 (9)
		We do love each other and we are the best of friends	Valerie	221-222 (8)
		But you still need, in your life, although you're quite self-sufficient and you can get on and do things there's still *part* of that person that requires the support and love of other people	Julia	241-243 (9)
	Shared, unspoken, understandings	He knows obviously that I care	Emma	187 (7)
		We both notice it. We don't have to keep mentioning it	Emma	242 (9)
		And Mike feels the same, that we both have this very strong faith. We don't sort of talk about it, we just have it	Sylvia	204-205 (8)
		We sat and looked at each other	Valerie	102 (4)
		You'll say something and the other one will say "you know I was just thinking that"	Valerie	223-224 (9)
	Spending a lifetime together	We've been married forty five years	Emma	33 (2)
		We probably went out about five or six times before we got married...but here we are forty five years later, so, you know	Emma	96-97 (4)
		When you've been married a long	Valerie	222 (8)

		time		
		It's just the way it's all developed over 56 years	Valerie	226 (9)
		If at the end of 56 years you are still friends than you have achieved something	Valerie	197-198 (8)
		Being married to John for a long long time	Valerie	212 (8)
		It's a good relationship. We've been married 55 years, so it's a long-term relationship	Julia	29-30 (1)
		I shall miss Nicholas, because we've spent a lifetime together	Julia	150-151 (6)
		If you've been married a long time it just goes with the territory you know	Janet	255-256 (9)
		But I can't imagine Charles not being there, you know, after so many years of marriage	Caroline	515-516 (18)
		I just know him from school days. We met at the youth club... And we know each other so well	Caroline	59-61 (3)
		We've been together all these years and we never bore each other	Caroline	201-202 (7)
		We've both grown up, we went to the same school together	Caroline	323-324 (12)
Connectedness Vs Isolation	Imprisoned by illness	We're locked into all the hospital appointments	Valerie	89 (4)
		We've had our wings clipped and I don't like the situation of being restricted	Valerie	187-188 (7)
		I like going on cruises and I like catching planes and going out to see our son	Valerie	185-186 (7)
		We are now locked into the world of cancer	Valerie	35 (2)
		Things are drawing in and closing in on you	Valerie	100
		Since John had the operations...we're not able to do the long distance flights	Valerie	87-88 (4)
		I think my boundaries are very confined now. They're sort of shrunken and I don't particularly like that	Julia	258-259 (9)
		Being confined to the house	Julia	262 (10)
		So boundaries in all respects have narrowed. And you can't just pack up and clear off. You're stuck	Julia	270-271 (10)
		I'm stuck in there seven days a week virtually all day	Janet	201 (7)
		But if he takes a turn for the worst, well we're back to square one again which means I can't go anywhere unless my son's there, or we have a	Janet	215-217 (8)

		sitter		
		I don't seem to be able to, I can't go out for a coffee with my friend, I can't go out and have lunch with her	Janet	228-229 (8)
	Disconnected from others	Beautiful friends, I've been so neglectful of them [becomes tearful] because all my, everyday's, all my days are taken up with other things on my mind. And they've always, still sending me cards and Easter cards. [sighs] Ringing up	Caroline	462-464 (17)
		No humanity skills you know, no compassion there	Caroline	132-133 (5)
		And her Mum and Dad died, a few years ago, and they were always helping them you know, and it's always been the same, wives always get involved with their own family rather than the man's family. Perhaps me, I put them off	Caroline	135-138 (5)
		But I'm angry with them too because they don't come to see Charles. Now he's been a very good Father to them	Caroline	175-177 (7)
		And I'm not acting but they can't believe when I am down, I am down, you know. They can't believe that	Caroline	508-509 (18)
		We don't really see an awful lot of people	Sylvia	545-546 (19)
		I think the Church is, they've failed us miserably since Mike's been ill. Failed us miserably. Erm, and I'm very disgruntled about it	Sylvia	179-181 (7)
		Well I am a bit hurt at the people that don't bother but I think well, we aren't all alike	Sylvia	306-307 (11)
		Our daughter and husband and children went to live [abroad]	Janet	60 (3)
		With moving around like we have, yes we have got friends[...]but they're friends that we haven't had for all of our lives, like some people they've got, they've got cousins, aunties, uncles, and they're all living in this little community	Emma	381-383 (14)
		I'm not sure that I'll be able to be there and keep managing the stairs" you know so we sort of opted out of that	Emma	202-203 (8)
		But that's becoming a little bit more difficult because he's beginning to think it it's a lot for him to then keep up, not a pretence, but to keep up the fact that regardless even though	Emma	279-282 (10)

		they're friends you want to chat, you want to sort of try and make a bit more effort in going out, even though you've got the wheelchair it's all an effort		
		Wish the good friends lived closer [laughs] but they don't. None of them	Emma	431 (15)
		People just probably forget really, they've got their lives and they carry on with their lives and they know that, you know, James' not well and they're friends and they come round and we see them when we're out but, [sighs] I'm not sure that they would want to get too involved in helping me, but maybe if I asked they would	Emma	424-427 (15)
		People who step back and don't really want to know you	Valerie	22/23 (1)
		There were various ones that had taken about six steps back and I thought to myself "oh well I don't really think they want to know"	Valerie	408-409 (15)
		Various people that I've known for years and years and years and then all of a sudden you have been dropped and I think to myself "huh! I thought you were my friends?!" you see, so yes you do get a little bit of ruffled feelings	Valerie	418-420 (16)
		We are not surrounded by family, or the support of a family	Valerie	84 (4)
		I haven't got the energy these days to go doing dinner parties	Valerie	121 (5)
		Other people who have been silent and embarrassed and don't really know what to say	Valerie	395-396 (15)
	Connected with others	They come over for Charles 80th birthday but we talk on the phone all the time	Caroline	130-131 (5)
		We have lots and lots of friends	Caroline	196 (7)
		She rang me about twenty past seven every morning saying "are you alright?"	Valerie	389 (14)
		So she came over, she sorted the kitchen sink and then there was something else with the vacuum cleaner	Valerie	393-394 (15)
		There have been some friends who have been so helpful	Valerie	395 (15)
		And then you pick up threads and	Valerie	430-431 (16)

		you haven't lost them after all		
		Want to be helpful and keep in contact	Valerie	22 (1)
		Our sons phone and we have Skype conversation	Valerie	86-87 (4)
		It's really neighbours and friends and, latterly, [Hospice] that do provide the support	Valerie	85/86 (4)
		Out of it has come a firm friendship from this couple	Valerie	249 (9)
		Now the two men, my husband and the husband of this couple, are firm friends	Valerie	255 (10)
		There are lots and lots of times people come here for morning coffee and so on. So, erm, I do cling on to things	Valerie	374-375 (14)
		And then all of a sudden normal relations have been resumed	Valerie	412-413 (15)
		So [Son] came and helped me get him out of bed	Janet	91 (4)
		Having my eldest son [...] with us has been a godsend	Janet	306-307 (11)
		But it's been brilliant. So, but yes I couldn't have managed without him [Son], I'd have been on my *knees* by now I think	Janet	319-320 (12)
		And others have been absolutely incredible, doing all they can	Sylvia	280 (10)
		They did a rota for all the neighbours to take him, except when he was going to see the Doctor and then I went with him. But they had to ask me, they'd like to do it	Sylvia	291-293 (11)
		I had two of the ladies came from the Hospice that I met. They came last Friday [...]. And Mike. We had a lovely afternoon	Sylvia	546-548 (19)
		We had a lovely afternoon, we had lots of laughs	Sylvia	552-553 (20)
		Thank goodness I have my daughter that kept coming down from [another part of the country]. That was a great help. She was wonderful and I used to ring her	Sylvia	76-78 (3)
		My daughter came straight from work from [another part of the country], it's a four hour run, and she came	Sylvia	146-148 (6)
		[Daughter] came down to be with us	Sylvia	427-428 (15)
		And then she sent me the flowers "Happy Mother's Day for my wonderful Mum with all our Love...."	Sylvia	465-466 (17)

		We still have a social life we still go out, ah, we still see friends	Emma	198-199 (7)
		So then the next problem is well hang on then now what am I going to do with with James? Erm, and that's where, this is what I'm talking about, this is where the long standing friends came forward	Emma	408-410 (15)
		I said "are you sure?" and he said "yeah fine, I'll be his nurse-maid, I'll get my own back on him" sort of thing,	Emma	413-414 (15)
		I said "are you positive?" "Absolutely" you know, and they're good friends	Emma	416-417 (15)
		And if they lived closer they would. But they don't live closer and they can't leave their homes and come down and do the looking after bit. But when it was necessary, they did	Emma	421-423 (15)
		I went next door and got the young couple next door and doink up he came	Emma	63 (3)
		She'd do it, she always says "well if there's anything you want me to do just let me know and I'll do it"	Emma	363-364 (13)
		Even the little 'uns are helpful "we'll help you Granddad, we'll do this, don't worry we'll do it"	Emma	372-373 (13)
		I have support you see, I have support networks	Julia	220 (8)
		I've got her as a very good friend. And I went and stayed with her for a while [...] and we used to have long days of discussing life and things	Julia	309-311 (11)
		I'm lucky in that respect. I've got some very good friends. You know those that you don't have to explain things to	Julia	313-314 (11)
		And with the friend of mine who I saw last week it's very easy to talk to her and always has been. But as I say I've got some really good friends, so, that is really helpful	Julia	322-324 (12)
		I've got very very good friends. Because I lack family I've always made quite good friends. So I'm lucky in that respect. And I appreciate them, so I tend to try and keep in touch as much as I can	Julia	157-159 (6)
		But they're all very good and they're quite understanding, and I've always been lucky to be able to say that I have made these very good friends,	Julia	162-164 (6)

		so that's quite nice		
		They're very important, particularly to me because I don't have, apart from my immediate family, a large extended family	Julia	211-212 (8)
		He's very lucky with his daughters. Erm, they say nothing but they help us a lot so we're quite luck on that score	Julia	64-65 (3)
		But I need to stay near the girls because the girls have been very very good	Julia	101-102 (4)
		Well [Daughter] supports us, [...]. So we get a lot of support in that respect, so if you want to talk about anything you can talk to her	Julia	170-172 (6)
		The [...] [Daughter] comes every week and she'll clean the house, and if the weather's reasonable she'll cut the grass and her husband does outside jobs for us that Nicholas can no longer do	Julia	175-177 (7)
		I do delegate it out if I find someone to do it like I've got a very good son-in-law	Julia	342-343 (12)
		We've got quite a strong family unit	Julia	371-372 (13)
		We have a good relationship. I know that I can call on them if I want to which is quite nice	Julia	204-205 (8)
		I'm going to [...], taking my eldest granddaughter [...]	Julia	123-126 (5)
		She's very pleasant personality so I suppose she brings us a lot of laughs and she spends [...] having dinner in the evenings with us, cause we try and support her	Julia	181-184 (7)
	Reluctance to burden others	If it's the middle of the night you can't really go and get the next door neighbours or it's it's probably unfair	Emma	111-112 (4)
		I don't expect her to help to look after him, she's got she has to work part time obviously 'cause she's got the [...] kiddies	Emma	355-356 (13)
		I don't feel that I should have to rely on somebody whose, erm, well she's got her own life [...] it's a very busy life anyway	Emma	358-359 (13)
		I don't expect her to have to perhaps change her life too much, erm, to help me with mine. I tend to feel that's slightly unfair on her	Emma	361-362 (13)
		Well she's still only young she she can't be burdened too much although she would always be willing	Emma	371-372 (13)

		to do anything		
		I just feel it's wrong for her to take on a big chunk of looking after	Emma	385-386 (14)
		Maybe it's me thinking I shouldn't really ask but you don't ask, you don't know do you?	Emma	428-429 (15)
		But you can't expect people that you haven't known for years and years I don't think	Emma	423 (15)
		And I suppose if I did ask them to, but I couldn't ask them to help me, I I, although I think if I did they probably would, but I think you need long-standing friends, long, long standing friends and they don't live close	Emma	389-391 (14)
		But I'm *emphatic* that we don't bring her into everything because it isn't fair. She shouldn't have to bear the burden of her father	Julia	172-174 (6)
		Cause it's away from the family, and you don't, I don't need to burden the girls with what I think	Julia	324-325 (12)
		They couldn't do any more for us. And I don't expect them to because they have their own lives	Caroline	149-150 (6)
		People say "well you need to *ask* for help to get it" but when you consider how other people, what burdens your other family have got. You can't really	Caroline	253-255 (9)
		We don't ask the boys for anything because they've all got their own lives to lead	Caroline	447-448 (16)
	Relating to Vs Different from others	And when she said I felt very sad because I knew how awful it was for her	Sylvia	68-68 (3)
		I am meeting a lot of people that are in the same position as we are in and I am in and it's so interesting to find all the different things that they're going through	Sylvia	557-559 (20)
		Going round the room, talking and listening to other people, a lot of my things dissolved and dispersed...I see what other people are going through and it's a bit like me	Sylvia	571-574 (20)
		Very interesting to meet other people who are also carers	Valerie	30 (2)
		She and I again compared notes	Valerie	33/34 (2)
		I find it easier to listen to other people and their problems and talk to them than I would talking about myself, because I don't think I have	Julia	217-219 (8)

		the type of problems that a lot of people have		
		So a lot of people are more needy in an emotional sense I suppose than I am	Julia	237-238 (9)
		And when I go to the carer days I'd rather go in the form of a helping capacity rather than for being helped, if you can understand that	Julia	248-250 (9)
	Society's aversion to illness and dying	Whatever is going on might be catching	Valerie	24 (1)
		Really asking whether or not he's still alive and how they're going to address the Christmas card	Valerie	41/42 (2)
		Society doesn't really want chapter and verse on how you are, they're just being polite really	Valerie	377-378 (14)
		People don't want to hear all that, they're just saying "hi, how are you?" and the best thing to say is "I'm okay thanks"	Valerie	380-381 (14)
		Other people who have been silent and embarrassed and don't really know what to say	Valerie	396 (15)
		They don't really know how to cope with John and they seem very awkward and embarrassed. And John too is embarrassed with them	Valerie	397-399 (15)
		When they ask me about John, they lower their voice!	Valerie	401 (15)
		But this is society's not knowing how to cope with the situation that they are presented with. And it's their problem not mine.	Valerie	404 (15)
		Two lots of our neighbours have not spoken to us and they've always been chatty. And I feel, we both feel, it's because they're scared. I can only think it can be that. That they don't lets sort of, don't want to know	Sylvia	277-280 (10)
		People have their own things to think about and if they are scared and they don't want to, it's a horrible thing really. Or they might think that you're going to ask them to do things	Sylvia	268-288 (10)
		But a lot of people *don't like* visiting places like this, they don't like coming to see people, do you know what I mean, they don't like hospitals and sickness and people not well	Janet	526-527 (19)
Preserving Vs Relinquishing	Relinquishing aspects of life	No, that was one of the major things probably in the, in his life. And and in	Emma	265-266 (10)

	together	mine to a certain extent because we spent a lot of time sailing, you know.		
		We've always been social people so we're always out a lot, as I say we always had a house full of people and that's changed	Emma	270-271 (10)
		And he said "I'm not coming" and I said "what do you mean you're not coming" and he said "I've decided by August I won't be well enough, so I'm not coming" so I said "well I'd better stop it all" and he "no no you can't do that, because you said"	Emma	400-402 (14)
		That was a major thing for him, erm, but it was the right thing, I mean he's sensible enough to say "no I'm not going to sit on it and have a cup of tea or have a glass of wine and do a bit of polishing, that's not me, on a boat I sail it". So it went	Emma	263-265 (10)
		We sailed, we had a Yacht. James is a round the world Yachty so you know just not, not being able to sail was a big thing for him	Emma	248-249 (9)
		Because I thought that's definitely the, erm, a big cut-off point for somebody whose sailed, I'm not talking about somebody who just pops on [...] to have a little sail, this is a proper round the world Yachty. For somebody who's done sailing like that even just to get rid of our little boat in comparison to the forty-five footers he used to take, was a was a big, a major thing in his life. "I now know I will not be sailing again"	Emma	252-256 (9)
		That year obviously we were supposed to go [abroad]. We didn't go	Janet	76-77 (3)
		We don't go out, we don't do things together	Janet	143-144 (6)
		Like before all this kicked in we'd say "well next Tuesday, if it's nice, we'll go out for the day". And so we'd do a picnic lunch and I'd make a flask of coffee and we'd go	Janet	188-189 (7)
		We now sleep in separate bedrooms for a start	Janet	247 (9)
		Obviously you miss having a cuddle when you go to bed. If you've been married a long time it just goes with the territory you know	Janet	254-256 (9)
		I can't spend my money on going to the theatre...I can't spend money on	Valerie	119/120 (5)

		inviting people for meals		
		One of the things I do miss is I used to like going to the theatre	Valerie	432 (16)
		Being able to go, say, if Nicholas was in good health being able to say “right” and go somewhere. We can’t do any of that now. Erm, the last time he and I went on holiday was last year in June and it wasn’t very good because he became so ill	Julia	262-265 (10)
		We went for a weekend, [...]. We’d only been there one night and we had to come home again cause Nicholas was taken ill	Julia	268-270 (10)
		We don’t go out like we used to do. Not that we were terribly hectically social people	Sylvia	349-350 (13)
	Preserving aspects of life together	We kept the boat as long as we could	Emma	251 (9)
		He said it a few times and I said “no – keep it”	Emma	252 (9)
		I wanted to keep it as long as possible before the decision was made because I, probably I wouldn’t want him to have to know in his mind that that was it	Emma	256-258 (10)
		We still go out as much as we possibly can, and we really do	Emma	271-272 (10)
		But if it’s nice we go out, you know, we might not be walking anywhere far [laughs] well he wouldn’t be walking, but erm, no we still have a social life we still go out, ah, we still see friends, erm, and we manage	Emma	197-199 (7)
		There’s nothing wrong with this, this has always been a good mind and I said to him “you’re far too active, just be quiet” I said “I can’t cope with that at this time of night” you know [laughs] messing about	Janet	208-209 (8)
		Obviously, although he’s ill and it’s terminal, his brain is fine	Janet	583 (21)
		We went to [local theatre] and it was [...] which is my favourite classical piece [...] you know. And it was, we walked there and we walked back.	Caroline	222-224 (8)
		And if we want to go out we can, we went yesterday to [local stately home] and had a bit of lunch which was nice	Sylvia	357-358 (13)
		Last August we had a week away with all the family and this is what we’re doing this year, because it works out	Julia	265-267 (10)
Self as a Carer	Congruent or	I’m tired and I’m fed up and I don’t	Julia	372-374 (13)

	incongruent with self-concept	like being in this place at the moment, I don't mean here but in the place that I find myself. And being a carer, I can think of a much better job to do than being a carer. It's very difficult		
		He's looked after well. So much so that I now feel that I have no identity. I think that probably goes for a lot of carers. You find that your life decreases and your boundaries draw in. And you become, well just a carer you're not a person really	Julia	69-72 (3)
		I think the greatest thing about, for me, being a carer is that I've become exactly that. And I don't seem to be anything other than a carer. So I don't feel that I'm a person. I find that very difficult	Julia	256-258 (9)
		"Oh thank you for looking after me" I said "don't be so silly" he went "I suppose come to think of it you've been doing this all your life anyway" [laughs] so there we go	Emma	71-73 (3)
		Like most wives, mothers, you you know, you do look after them, you do the shopping, you do the cooking, you do the clearing up	Emma	75-76 (3)
		If carers are going to come in and dress him and that I mean I've been doing that for a long time anyway and if they don't need to feed him because I do that	Emma	151-153 (6)
		I believe, and maybe I'm wrong, that nobody else can care for the husband like I can. I want to be able to	Sylvia	222-223 (8)
		I am a great carer. I *care* that's what I mean. I *care* about people desperately. And sometimes I wish I didn't. But you can't switch yourself off can you?	Sylvia	317-318 (11)
		I have to be careful about looking after people, that I don't overdo it. I like everybody to be comfortable, err, regardless of who or what. They have to be, as far as I'm concerned, people have to be comfortable	Sylvia	331-333 (12)
	Husband's needs come first	It's like having a large baby, everything revolves round Gerry	Janet	130-131 (5)
		She said "have a lovely birthday", I said "well I think it's going to be one of those scenarios where my birthday comes and goes and we'll	Janet	118-120 (5)

		celebrate it when Gerry's better"		
		I now feel that I don't have a life	Janet	130 (5)
		It just seems that life is just Gerry Gerry and Gerry and that's it basically	Janet	227-228 (8)
		"Well I can't afford to be ill, cause if I'm ill who's going to look after me?"	Janet	289 (11)
		It's all geared up for Gerry so *I* just have to make do with legging it up and down stairs all the time	Janet	475-476 (17)
		It happens over a period of time, where you're always there. And sometimes I think I'm a piece of furniture. And...I suppose everything has to be centred around the person who is ill, and so you become a necessity, but you're always there so it's almost like being a nothing really. You're a necessity but not [sighs] a person in your own right. I'm a carer and I think those words sum it up really	Julia	116-121 (5)
		The bedroom is not a restful place anymore	Caroline	115-116 (4)
		And now we, well we *do* what Mike wants to do. And I'm not being a martyr or wearing a hair shirt when I say that, because I am not...erm, I'm not really bothered	Sylvia	354-356 (13)
	Taking on aspects of husband's role in addition to own	I think it's just the, having constantly the burden of shouldering everything that there is to do	Julia	347-348 (12)
		It's a huge job really, cause you have to take on the things that your partner used to do, like gardening, fixing things in the house, going off to get this one or that one, if you, you know if he was able to. But it all comes in to one person, which is as I see it, me.	Julia	339-342 (12)
		There's lots of things, he used to do any long journeys- he'd do the driving, I now do all the driving	Janet	258-259 (9)
		At one time I'd never think about helping him out to the car or, he always used to come out last, switch off the light, lock the door, check it, and then I'd be waiting, you know, down the slope	Janet	280-281 (10)
		Cause he always dealt with all the finances, I mean I never, I wouldn't even know how much our mortgage is, I'll have to find out now	Janet	324-325 (12)
	From partnering to	And I think "it's just like having a big	Janet	300-301 (11)

	parenting	kid”		
		When he was ill I couldn’t leave him on the loo, cause the vertigo he’d lose his balance and want to fall off the loo. So I literally had to stand in front of him while he went to the loo which is not the best of things to have to do, but I didn’t have an option	Janet	381-383 (14)
		He can’t do anything I do *everything* for him now virtually, apart from as I said cleaning his teeth. When he was ill I even had to do that	Janet	550-552 (20)
		It’s got to change a relationship because... he can’t do anything much for himself. I mean he can’t make a cup of tea, can’t get socks on, on really bad days can’t much on himself anyway. So it does, it changes the whole relationship	Julia	281-284 (10)
		It reverts back really that your caring for a, not a child, but you go back to those years when people can’t care themselves so you have to look out for all of that. So it’s sad really [pause]	Julia	276-278 (10)
		And I think personal things break down. You have to look after the person that’s ill in many different ways to what you had to before, you know, in hygienic ways, clean them up and keeping them clean and all that. So it becomes a very *different* life	Julia	271-274 (10)
		He was a very difficult patient initially	Valerie	362 (13)
		In fact he doesn’t speak, if I’m around he lets me do all... “oh you do that”	Caroline	362-363 (13)
		Perhaps I’m too domineering you know, I can be too domineering. But somebody has to lead the ship	Caroline	242-243 (9)
		Instead of me being able to rely on him, which I have done for many years	Caroline	421-422 (15)
		He had everything under control. I used to say he was a control freak [laughing], now he’s not, totally dependent on me	Caroline	437-438 (16)
		To be a Nurse in other ways	Caroline	203 (7)
	Vigilance and preparedness	Would perhaps break something, which would create a lot more problems than he’s got now	Emma	116-117 (5)
		I leave him with his cup of coffee and	Emma	192-193 (7)

		his glass of squash and the remote control and the paper and his book		
		If I'm out for longer, a longer period, then we just try and get things organised	Emma	195 (7)
		I'm there to make sure he doesn't fall and so on	Emma	154-155 (6)
		It's to do with just probably caring about what he's doing and he's sometimes doing the wrong thing and doesn't listen to me	Emma	67-68 (3)
		I can understand but I worry that he shouldn't be doing it	Emma	121-122 (5)
		He'll say "your nagging me!" and I go "well I'm not really" but I probably am but I'm not meaning to, I'm meaning to say "be careful, do this"	Emma	41-42 (2)
		I worry about him falling and he does things which I say, I keep telling him "please don't do that" and he'll still do it	Emma	56-57 (3)
		"John is tucked in the armchair watching telly and he's got the heating on, and he's got the note of my mobile number"	Valerie	366-367 (14)
		It's it has be assessed every six weeks and every ache and pain you think "oh what is it? What is it?" Which is not good. And we know intellectually that you mustn't be like that but you can't really help it cause you wonder "could this be starting up again?"	Sylvia	108-111 (4)
		I think one has to be careful because you can become a blooming nuisance if you're not careful with it. Can smother them if you're not careful. I do, I am, try not to be a smotherer. I try to stand back a bit	Sylvia	334-336 (12)
		You've got to think ahead	Caroline	204 (8)
		You've got to have your head tuned in all the time, and it's wearing, it's very wearing	Caroline	72 (3)
		But I'd come in, I'd hear something, come in, television's still on, light' still on, perhaps that door might be open. You know this is about 3 o'clock in the morning!	Caroline	118-119 (5)
		I got all his clothes ready, he wouldn't know what to wear unless I got them out for him. Like today I had to get everything ready	Caroline	346-348 (13)
		And he said "where am I going?" and I said "you're going to the Doctors",	Caroline	352-355 (13)

		"but where is it?" he's been umpteen times. I've really got to curb my patience with, and I've really got to treat him, like you would a geriatric I suppose		
		I worried all the time he was out	Caroline	358 (13)
		It's things like that, he needs me around for all the time	Caroline	377-378 (14)
		Whatever I do now I have to take into account that I have to make prevision for Nicholas, if I'm going for several hours have to make sure he's covered	Julia	121-123 (5)
		I've always had responsibility from a young age [pause] and that doesn't worry me. But it's very tiring and wearing. Because it's always there. And now I seem to have not only responsibility for Nicholas [...]	Julia	129-132 (5)
		We have cough medicine, walking sticks, oxygen, everything else that he might have needed. Everybody had their own little job to do in case he collapsed or whatever	Janet	73-75 (3)
		If we go out it's like a major military operation to get up to get Gerry ready. I do sort of three things at once	Janet	144-145 (6)
		It's just a constant, you've got to remember remember remember. All the time	Janet	305-306 (11)
		Now, I think, right, is Gerry well enough to leave? Can I go to the hairdressers and be back in an hour? Everything is, when he's ill I can't leave him at all. Now we have the stair-lift it's a little bit better but when he was so weak I thought well if he falls between the armchair and the stair-lift and knocks himself out he could be dead when I get back. I have to think ahead all the time	Janet	189-193 (7)
		You're constantly clock-watching. It's lovely that there's someone there to look after him, but it you're stuck in traffic or there's a huge queue at Asda. I'm thinking "I've got fifteen minutes to get through here, load the car and get home"	Janet	195-197 (7)
		"Well if I go next Saturday we can't have so and so for lunch cause I won't be back in time" because I can't go till after the carer's been because they bath him and I think	Janet	212-214 (8)

		"well if they need me and I'm not here what do they do?"		
		I'm always organised and I always try to plan ahead. In some things you can't with an illness, but in other things you can plan a week or so ahead	Janet	220-221 (8)
		I think if he trips, knocks himself out, I shall never forgive myself	Janet	279-280 (10)
		You've just got to think ahead the whole time	Janet	321 (12)
		I always say to him "just call out and let me know, otherwise I won't know if you're okay" and then if he's more than fifteen minutes I'll shout down and say "are you alright?"	Janet	379-381 (14)
		When we went [abroad] it took me and hour and a half to work out all his medications for six weeks	Janet	590-591 (21)
	Exhaustion	It's wearing, it's very wearing	Caroline	72 (3)
		And you say to the Lord "well I'm tired now, I've had enough"	Caroline	279-280 (10)
		Sometimes when you are exhausted you don't even want to answer the telephone	Caroline	465 (17)
		I'm a bit physically tired	Caroline	526 (18)
		Had to ring everybody up, all our relatives and our dear friends. That was awful, I could of done with one of these [Dictaphone] and switched it on cause I was exhausted	Sylvia	437-439 (16)
		When I got home I was *absolutely exhausted*. I was so tired. I thought "well that's the end of that, I'm not doing that again"	Sylvia	94-95 (4)
		They knew how tired I was	Sylvia	293 (11)
		It's very tiring and wearing	Julia	130-131 (5)
		I don't do as much as I should do because everything is so tiring to sort out and do	Julia	159-160 (6)
		I think one of the other overwhelming things is the tiredness that comes into everything. Perpetually you're tired, which isn't good	Julia	326-328 (12)
		It's a physical and emotional, mental type-tiredness really. I don't relax, I haven't found the art of relaxing and I don't think I will	Julia	330-331 (12)
		The actual getting him here is exhausting. I come here and I bring him and someone will say to me "would you like a coffee?" and I say "ooh yes please". And I'll sit down	Janet	152-154 (6)

		and I'll think "I could just go to sleep now"		
		I just feel that I get up in the morning and it's "oh god here we go again"	Janet	217 (8)
		I think the best time of day for me is actually when I get into bed because I can switch off, I haven't got to think about what Gerry might need. I can just empty my mind, read my book, or if I'm really shattered, which is some nights, I just go straight to sleep	Janet	261-264 (10)
		By two o'clock in the afternoon I'm absolutely, I'm ready to go and have about a three hour kip, which I don't	Janet	304-305 (11)
		But everything is regimented by the clock really, and I find it really irritating sometimes cause you can't go slow, you can't switch off, and you can't unwind basically. Just got to keep on at the same hell for leather pace at the same time, and that in itself is tiring	Janet	332-334 (12)
		I haven't done the crossword for months, I'm always too shattered to concentrate	Janet	440-441 (16)
		I just burst into floods of tears, and I'm not one given to tears and dramatics and what have you. I said "I just cannot cope" I said "I need a break". It was twenty four seven then I was hardly getting any sleep at night, Gerry was needing me *all* day	Janet	480-482 (17)
	Being an older woman and a carer	It's bad enough an 80 year old looking after herself without thinking for another person	Caroline	73-74 (3)
		But it's hard trying to work out everything, you know, for him as well as for myself	Caroline	439-440 (16)
		For four days James and I literally had to man-handle him out of bed, to the bathroom, sit him on the loo, but that was even difficult	Janet	100-101 (4)
		My husband got quite a shock when I ended up suddenly in the [local hospital]	Valerie	148-149 (6)
		Everything has a knock-on effect. I had the arthritis so you have the steroids and then the steroids push you towards the diabetes	Valerie	268-269 (10)
		I suppose if I was that much younger I wouldn't find everything quite so arduous. But I'm not	Julia	356-357 (13)
		I had an angina attack	Sylvia	142 (5)

		I've had a lot of terrible illnesses but I seem to have through them alright	Sylvia	314-315 (11)
		We're not fit enough either of us to go on a holiday	Sylvia	391-392 (14)
		There's this almighty crash and he's behind me on the floor...I just couldn't lift him	Emma	61-62 (3)
		I have difficulty, I mean great difficulty in trying to get him up...there is no way that I could lift him	Emma	108-110 (4)
		"Am I going to be able to cope if he get's worse?"…not my mind but physically more	Emma	145-146 (6)
		And yes it will be difficult for me more, sort of trying to shift him from one place to another	Emma	228 (8)
Coping	Problem solving	"I'll probably get a lodger"	Valerie	230 (9)
		All problems, realistically, can be looked at and you endeavour to solve them	Valerie	231-232 (9)
		Have the gardener, have the cleaner, and if I'm lonely you never know my granddaughter [...] may suddenly decide that she'll come and attend University here	Valerie	232-234 (9)
		The mobile phone, and one with extra bigger letters. And then you turn it over and whatever emergency numbers you've got programmed in, they'll ring	Valerie	259-260 (10)
		And then I thought "I'll do something about this"	Valerie	365 (14)
		Then I'd have put the dog into kennels and I would have booked myself into a hotel near the hospital, rather than running up and down the motorway everyday	Valerie	462-464 (17)
		He's on about some relaxation exercises that you can do and I do try them and they do work	Valerie	470-471 (17)
		"Perhaps it's becoming too much of an effort for us to go visiting, its better if they come and visit us if they can"	Emma	207-208 (8)
		I probably [laughing] would phone the fire brigade	Emma	112 (4)
		The last time he and I went on holiday [...] it wasn't very good because he became so ill. So now, last August we had a week away with all the family and this is what we're doing this year, because it works out	Julia	264-267 (10)

	Carrying on	We've always kept cheerful and kept going	Sylvia	441 (16)
		We've got to cope with it...and have to do the best I can	Sylvia	495 (18)
		It hasn't been all sunshine and flowers not at all. But, I've managed to get through and I'm certain a lot of people just don't	Sylvia	531-532 (19)
		I do feel sorry for myself sometimes but not, it doesn't last for long, I say "oh for goodness sakes snap out of it". Erm, all the things everybody, I go through and seem to try to get out of the other side	Sylvia	579-581 (20)
		It's been horrendous, horrendous. I can't tell you anymore. And how we've got through it, well obviously one has to, I don't know really. But we just did	Sylvia	105-106 (4)
		And I think, like I've done with my life, "how did I get through it all?" how *did* I get through it?"	Sylvia	451-452 (16)
		At the time he said "okay fair enough, I could have cancer so we'll just get on with it". And life sort of went on more or less as it had before	Janet	54-56 (2)
		It's just even worse than it ever was. You know, but never mind, just got to get on with it haven't you	Janet	336-337 (12)
		Carrying on, you don't have an option. What do I do? Go to pieces?	Janet	359-360 (13)
		When he was diagnosed I said "mmm, so this going to be a bundle of laughs" you know, but neither of us sort of dwell on it, he's got it, we get on with it	Janet	435-436 (16)
		I'll just carry on until I'm on my knees again and then say "help" and he'll come in here for another ten days and I shall be up here every day except one [laughs]. And we're back to square one again. But this is how it's going to be	Janet	529-531 (19)
		It's hard, but you don't have any choice	Janet	234 (9)
		I'll just hopefully get on with it	Emma	156 (6)
		At the moment maybe I try to put a shield across, maybe I'm quite good at keeping it suppressed. Whether that's right or wrong I don't know	Emma	175-176 (7)
		Maybe I'm just pretending and think I'm stronger than I am	Emma	316 (12)
		Still we keep going, well I keep going	Julia	106 (4)

		We just sort of get on and do it	Julia	398 (14)
	Shared use of humour	We tend to make a joke of it, there's no point being morbid and miserable because it's bad enough the fact he's ill anyway, you know	Janet	140-141 (5)
		We're never very serious for very long, life's too short	Janet	450 (16)
		We do try to have a, a bit of a joke about things rather than the other way	Emma	186-187 (7)
		We're always quite open and we joke about things, that keeps us a bit more positive and keep going	Julia	396-397 (14)
	Shared religious beliefs	But I've always had that same strong faith [...] It's just there. And I *know* I can get very down but it's still there. Nobody, honestly, I don't think I *don't* think anything would take it away. And I think that is a lot to do with it	Sylvia	184-188 (7)
		And Mike feels the same, that we both have this very strong faith. We don't sort of talk about it, we just have it. And it's sustaining	Sylvia	204-205 (8)
		I have a very strong Christian faith, very strong	Sylvia	177 (7)
		Well we were both born Catholic you see	Caroline	323 (12)
		We've always had a deep faith among all our family	Caroline	325-326 (12)
		I just offer it to God. Because we believe in the Catholic faith that it's a journey, a journey through life	Caroline	442-443 (16)
	Being in the present moment Vs Escapism	Enjoy today and the book I'm reading	Valerie	175 (7)
		I'm now learning not to feel guilty about reading a book in the middle of the afternoon	Valerie	188-189 (7)
		There's lots and lots of nice things in this world. I mean look at these little birds	Valerie	471-472 (17)
		We're spending the time together, because who knows. We don't know. So we're spending time together as much as possible. We always have done but probably a little more now	Sylvia	380-382 (14)
		Our future is right now	Sylvia	387-388 (14)
		Our future is now. We neither of us dwell on the future	Sylvia	390 (14)
		We could go on a holiday but we've decided this year, as regards the future, to just play it, erm, well as we say a day at a time	Sylvia	404-405 (14)

		I have this dream that when I'm eventually on my own I'm going to [an Island] and I'm not coming back for about six weeks! [laughs] I want to do just what I would like to do. So it's a way of running away isn't it, in your mind. And all the time I think these thoughts I can cope	Julia	133-136 (5)
		And I daydream, but then I did that as a child [laughs] so I still carry it on	Julia	164-165 (6)
		But one day I shall go to [an Island] and I shall, stay there for about six weeks. I shall go to bed and only get up when I feel like it [laughs]. So these dreams you know, they keep me going	Julia	359-361 (13)
		I suppose I keep going because I keep looking towards the future. I like to be able to have something to look forward to	Julia	392-393 (14)
Coming to terms	Acceptance	But you can't change it, you can't, you can't go on *all* the time thinking "it's unfair"	Emma	164-165 (6)
		I've more come to terms with the situation and I'm probably less angry now	Valerie	284-285 (11)
		You simmer down with the anger, the anger becomes less as the understanding becomes greater	Valerie	293-294 (11)
		There has been a gradual shift	Valerie	296 (11)
		An acceptance of the situation, I think when I was bloomin angry I was fighting against it	Valerie	352-353 (13)
		I've been through all sorts of stages on this, it's like a journey that you go on	Valerie	358-359 (13)
	Illness more acceptable in older people	And I think to myself "and I'm not even seeing the children with cancer and with the awful things that they've got"... When I see children who are dying of hunger I can't, I think "how can I ever grumble about any mortal thing?"	Sylvia	487-490 (17)
		To get three it was a blow, a real blow. I can't say that we were, we've never been devastated	Sylvia	439-440 (16)
		I mean you hear of young people dying, like that footballer the other week died of cancer didn't he, 48 or something like that. Another one has got leukaemia. And they're young people, they haven't even lived their life, well we've been there done that you know, we've done everything	Caroline	498-502 (18)

		We always say [sighs] “at least we’ve had a good life and it would be awful if it was children”	Emma	163 (6)
		The boy of fifteen’s got all of his life before him	Valerie	457 (17)
		I get very upset when I see children suffering from cancer ,and young people	Valerie	286 (11)
		Our lives are drawing to a close, whether we like it or not	Valerie	106 (4)
		We’re mindful of the fact that everybody’s got to die	Valerie	155-156 (6)
	Having lived a good life	So we’re very happy and very, no happy’s not the right word. We’re very contented. Happiness is a by-product of contentment	Sylvia	360-361 (13)
		You can have happy things, but you can also have a *deep* contentment, which I have. That’s probably what we were trying to get at earlier on. It’s a deep *contentment* that I’ve always had	Sylvia	365-367 (13)
		So I’m very contented and always have been, with *my lot*	Sylvia	372-373 (13)
		I just think that I am extremely fortunate	Sylvia	492 (17)
		And go on being thankful for everything I’ve got. Because I’ve got a jolly lot	Sylvia	496 (18)
		So, what could be better? I’ve a lot going for me. I don’t feel that I have had a terrible time, not a terrible time, I don’t feel as though I’ve had a bad pack of cards dealt to me at all	Sylvia	510-512 (18)
		[Speaking about Daughter] She’s always been a caring, loving person. So it must be in the genes mustn’t it, my mother was the same. I think it’s in the genes	Sylvia	322-323 (12)
		We were counting our blessings the other night because we’ve got such marvellous family and because we’ve moved so many times	Caroline	200-201 (7)
		Both had a pretty exciting life	Emma	33-34 (2)
		Brought up two children, so they’re great	Emma	34-35 (2)
		We have children that are reliable. And that must stem from the parents I would assume, as they’re being brought up	Julia	367-369 (13)
		We’ve had our lives and we’ve had a jolly good life	Valerie	287 (11)
		We’ve got two [children] that are not on drugs and not in prison and have	Valerie	288-289 (11)

		got lovely [partners] and good educations and so on		
	Dying and death	But it's not nice and I just hope one day whenever it is he'll just hopefully go to bed and go to sleep and that'll be it, because I would hate him to have a choking fit, or a coughing session which would exhaust him and he could probably get another mini-stroke and then it would be 999 and then it would be [local hospital] and he would hate it in there, cause they don't bring you in here [Hospice] when you're critically ill they take you straight up to the hospital, you know. So I just hope it'll be quick, whatever it is, you know, it's going to be whatever it is but that's how I would like it to be, for his sake more than anybody else's you know	Janet	669-675 (24)
		But hopefully we assume, he assumes, it's going to come quite fast the next part as well	Emma	225 (8)
	Anticipating widowhood	I really don't want to be a widow	Valerie	226 (9)
		Well it prays on my mind because, financially, everyway, I'm not prepared	Caroline	496 (18)
		But I can't imagine Charles not being there, you know, after so many years of marriage. I don't think I'll survive afterwards because I lived so so much, erm, in his care	Caroline	515-517 (18)
		I mean it won't exactly be a wonderful day for me, I won't be putting the flags up and saying "hip hip hooray" or anything like that. But I'm not going to fall the pieces, because... in a way it'll be a relief because he's not going to be like this anymore, do you know what I mean, it's, he's been ill, he's not got better, he's gone and that's it. It sounds very harsh, but probably it's the best way to think about things I think really. That's how I cope with it anyway. It's got to happen	Janet	537-541 (19)
		I know you must get some couples that are very very close and one doesn't know how they're going to exist without the other. But I'm not that way inclined	Julia	148-150 (6)
		So, no, I don't have fears, I have hopes of what I can do when	Julia	99-101 (4)

		Nicholas dies. And erm one thing I will move, which in my mind is some form of comfort for me		
	Own mortality	Well I might go first I don’t know	Caroline	314 (11)
		Now what if I die before Charles, I could die before Charles, he would be in a mess then wouldn’t he	Caroline	514-515 (18)
		And, don’t forget as I said, Mike’s not bound to be the first one to go	Sylvia	503-504 (18)
		My husband got quite a shock when I ended up suddenly in the [local hospital] to do with my heart problems last summer and he suddenly panicked and said “in the event that I’m dealing with your funeral and not you dealing with mine, I wouldn’t have a clue how to do it”	Valerie	148-151 (6)
		So part of me looks forward to, perhaps, the future. But I have to remember that I’m also the same age as Nicholas and we’re, what [...] this year. Which is quite old really	Julia	72-74 (3)

Appendix I

Table of Themes

Super-ordinate themes	Emergent themes
Holding uncertainty	The uncertain course of the illness
	Uncertainty about own and others' emotions/coping
	Tolerating uncertainty
Living alongside dying	Witnessing husband's physical frailty and suffering
	Witnessing the progression of the illness
Enduring partnership	Spending a lifetime together
	In good times and in bad, in sickness and in health
	Shared, unspoken, understandings
	Love and closeness
Attunement Vs Alienation	Empathic understanding
	Mutual protectiveness
	Disconnection (and re-connection)
	Internal Vs External attributions about behaviour
Preserving Vs Relinquishing	Relinquishing aspects of life together
	Preserving aspects of life together
Connectedness Vs Isolation	Imprisoned by illness
	Disconnected from others
	Connected with others
	Reluctance to burden others
	Relating to Vs Different from others
	Society's aversion to illness and dying
Self as a Carer	Congruent or incongruent with self-concept
	Husband's needs come first

	Taking on aspects of husband's role
	From partnering to parenting
	Vigilance and preparedness
	Exhaustion
	Being an older woman and a carer
Coping	Problem solving
	Carrying on
	Shared use of humour
	Shared religious beliefs
	Being in the present moment Vs Escapism
Coming to terms	Acceptance
	Illness more acceptable in older people
	Having lived a good life
	Dying and death
	Anticipating widowhood
	Own mortality

Appendix J

Letter of Favourable Opinion from NHS Local Research Ethics Committee

NHS
National Research Ethics Service
NRES Committee South West - Central Bristol
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol BS1 2NT
Email: ubh-tr.SouthWest3@nhs.net

Telephone: 0117 342 1335
Facsimile: 0117 342 0445

29 November 2011

Miss Anna Jepson
Trainee Clinical Psychologist
University of Southampton
34 Bassett Crescent East
Southampton
SO16 7PB

Dear Miss Jepson

Study title:	**The Experience of Living with a Husband or Partner who has a Life-Limiting Illness**
REC reference:	**11/SW/0313**

The Research Ethics Committee reviewed the above application at the meeting held on 25 November 2011. Thank you for attending to discuss the study.

Issues discussed

1. Members queried what support mechanism was in place should carers being interviewed at home become distressed.
   It was acknowledged that conversation relating to the research could be distressing. It was envisaged that participants would pass through the intensive part of the conversation. However, follow up from the psychology services would be offered if needed.
2. Why were only women carers being included in the study?
   It was proposed to use IPA methodology. It was aimed to undertake a small qualitative study where subjects were similar in age and gender. It was appreciated that this was not a representative sample and results could not be generalised.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Appendix K

Letter of Favourable Opinion from Hospice Ethics Committee

Our Ref [redacted]

21 December 2011

Miss A Jepson
[redacted]

Dear Anna

Thank you for submitting your research proposal to the Ethics Executive Group.

The Members of the EEG support the proposal and offer their full permission to conduct the research. They accept the research on the proviso that you can reassure the EEG that the patient knows that their spouse/partner has volunteered for this research.

Yours sincerely

[redacted]

Chief Executive

Appendix L

Reflective Commentary: Extracts from Research Journal

Interview with "Emma"

I noticed that I was wary of pushing for too much detail during the interview, about the future and about times at which it is harder for Emma to manage. This wariness could be related to queries raised during the process of gaining ethical approval about whether the interviews would cause participants' to feel distressed. I had also been aware that Emma's coping style seemed to be "getting on with things" and I had wondered whether being pressed to reflect on her experiences and feelings could be unhelpful or undermine her coping strategies. I felt touched by the evident closeness between Emma and her husband and the protectiveness she described towards him. I think that in future interviews shying away from asking potentially emotive questions due to my own anxieties could be unhelpful as I may miss rich information as a result, although I do think it is important to be mindful of participants' coping styles. I need to trust my own judgement and explore difficult subjects tentatively.

Interview with "Sylvia"

Possible themes arose during this interview around the idea that having lived a full life makes the prospect of death more acceptable. The role of religion and spirituality emerged for the first time as a major coping mechanism and I wonder if this will be the case for any other participants. I noticed how much I enjoyed the interview and that I felt a lot more relaxed as an interviewer. This was my fourth interview and I think that I am becoming more confident, and that the interview flowed more naturally as a result. I wondered about how Sylvia related to me as an interviewer, being a younger woman. I had a sense that Sylvia was confiding some of her experiences to me, not only for the purposes of my research but also because she wanted to share these on a more personal level, for instance when she was speaking about the importance of love.

General Reflections on Interviews 1-4

In general participants were less distressed and tearful than I had been expecting. The greater acceptance of illness and death which seemed to be present could be related to participant's age (although one woman interviewed was only 65 years old); this could also indicate that these women are at a similar point to one another on their journey through this process (perhaps the interviews would have a different tone if I spoke to people very soon after their husband had been diagnosed); or be due to the self-selection of the sample (women who chose to opt in to the research might share some common characteristics of resilience or stoicism).

I have had feedback from some of the interviews that participants have enjoyed them or found them helpful or interesting. This has been reassuring for me as a researcher, and also fits with the existing literature around people's experiences of participating in qualitative research. I am curious that some people I have spoken to about the research find it such a challenging idea that participants could experience the interviews as helpful. This could be related to narratives about illness in society, or an idea that it is harmful to discuss emotive subjects. This also makes me think about how some participants have spoken about friends avoiding them or appearing uncomfortable discussing illness.

Appendix M

Case study: Valerie

Valerie spoke about the length of her marriage and how well she and her husband had come to know one another over the years; weathering challenges as well as remaining best friends, this linked to the theme *enduring partnership*.

Valerie reflected on her closeness and the sense of attunement that she had with her husband, she also spoke about feeling a period of adjustment when her husband had returned home after a hospitalisation, which linked to the theme of a*ttunement Vs alienation*. Valerie spoke about how she had taken practical steps to manage this by making time to engage in activities that she enjoyed; actively problem solving and finding solutions formed an important part of Valerie's narrative and linked to the theme of *coping*.

Valerie conveyed a sense of the journey that she had been on since her husband's diagnosis, with her feelings gradually mellowing from anger into more of an acceptance over time as her understanding had increased; this process linked to the theme *coming to terms.* Valerie also identified that some good had come out of the bad, for instance she and her husband had forged some new friendships as a result of his illness.

Valerie touched upon the unpredictable course of her husband's illness and spoke about having to wait and see in reference to the future, this related to the theme *holding uncertainty*. She also spoke poignantly about bearing witness to the progression of her husband's illness and his suffering and this linked to the theme *living alongside dying*.

Valerie shared the very different reactions that she and her husband had encountered from their friends and acquaintances; with some people appearing to feel uncomfortable and awkward and others being extremely supportive and helpful, Valerie also spoke about how some fractured friendships had been mended. These experiences linked to the theme *connectedness Vs isolation*.

Valerie spoke about finding it upsetting when she encountered young people with cancer and there was a sense of illness being more acceptable to her because she and her husband had lived long and full lives. Valerie expressed that she did not want to become a widow but was philosophical about the inevitability of ageing and death and this linked again to the theme *coming to terms.*