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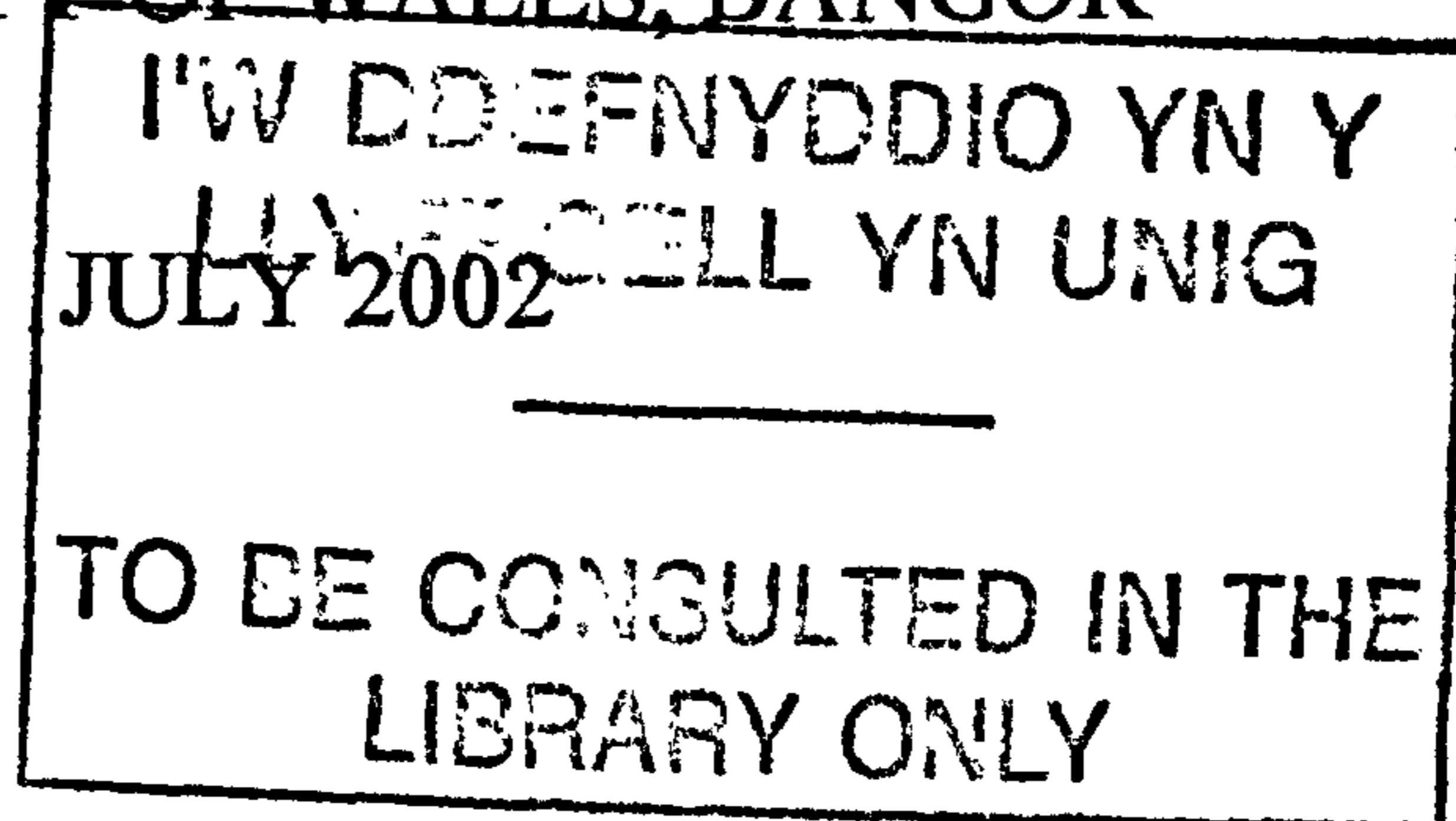
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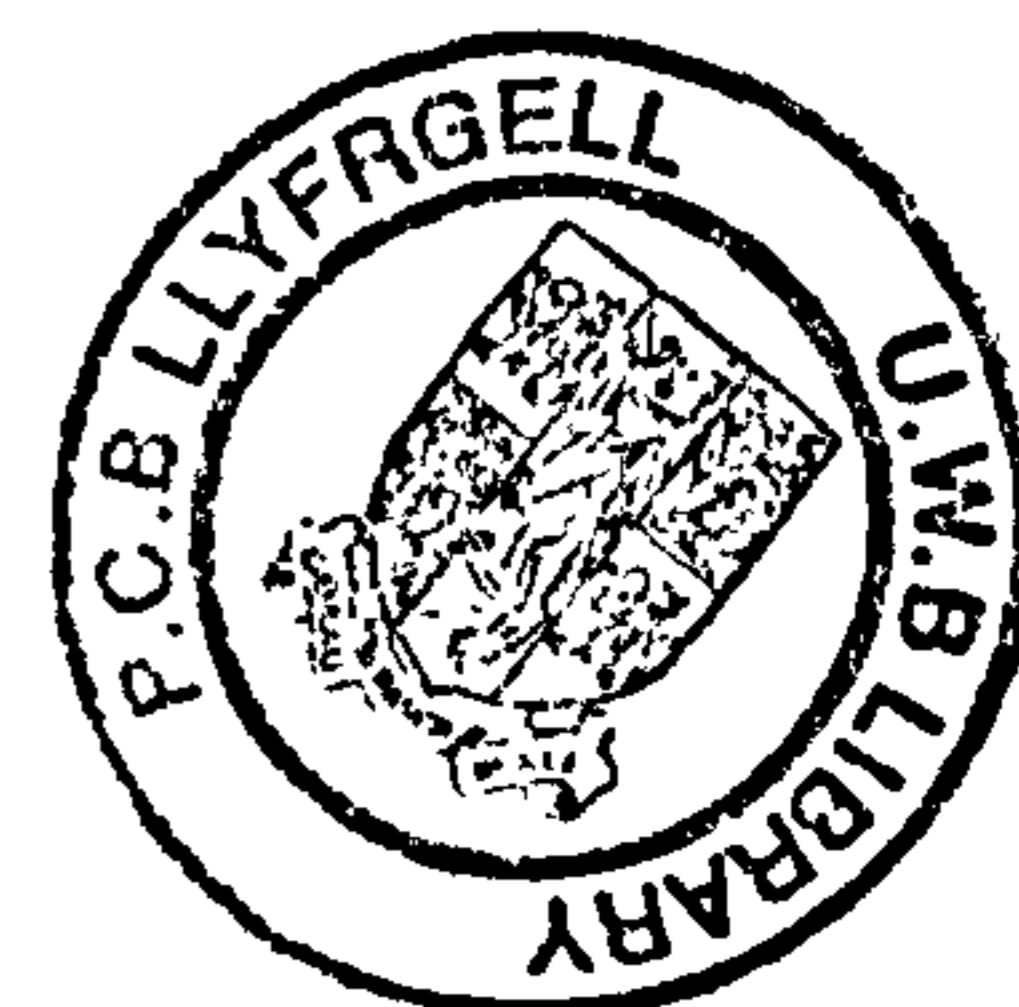
LIVES IN TRANSITION: CAREGIVING AND
BEREAVEMENT ADJUSTMENT AMONG SPOUSAL
DEMENTIA CAREGIVERS: A GROUNDED THEORY
STUDY

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**Thesis submitted in partial fulfilment of the requirements of
the degree of Doctorate in Clinical Psychology (D.Clin.Psy)**



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Appendix 1: Letter of Ethical Approval from School of Psychology Research Ethics Committee

Line of text on Appendix page 6 (Appendix 2: Participant Information Sheets)

Appendix 5: Notes for Contributors: *Aging & Mental Health*

Appendix 6: Notes for Contributors: *Dementia: The International Journal of Social Research and Practice*

Readers may consult the original thesis if they wish to see this material.

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Paul A. Waring

July 2002

Lives In Transition: Caregiving And Bereavement Experiences Among Spousal Dementia Caregivers: A Grounded Theory Study

This large scale research project examined caregiving and bereavement adjustment among spousal dementia caregivers. The thesis begins by outlining a range of theoretical models of stress and coping, depression, and anticipatory grief that have been proposed to explain dementia caregiving and bereavement adjustment. This is followed by a critical evaluation of the existing research literature on bereavement outcomes and predictors of caregiving and bereavement adjustment among spousal dementia caregivers. To date, few theoretical models have conceptualised caregiving and bereavement as a single, chronic process. The available evidence suggests that whilst spousal dementia caregivers typically experience a long and exhausting caregiving career, they experience relatively few bereavement adjustment difficulties. This has been attributed to mediating factors such as the end of caregiving strain, anticipatory grief, and social support. However, our knowledge about the process of caregiving and bereavement adjustment among spousal dementia caregivers and the transitional experiences that underpin such adjustment are poorly described in the literature.

The grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was employed to investigate the caregiving and bereavement experiences of five participant spousal dementia caregivers. The aim of the study was to develop a theoretical understanding of the process of caregiving and bereavement adjustment. A model incorporating five transitions of participants' caregiving and bereavement experiences is proposed. In each transition a number of key attributes are described.

These attributes emerged from analysis of participants' interview data about caregiving and bereavement experiences. A key finding from this study is that two participants reported they were still having difficulty in coming to terms with negative experiences of professional support during caregiving. The overall study findings are discussed in relation to previous research findings regarding dementia caregiving and bereavement adjustment. Finally, the clinical healthcare implications and potential for future research are outlined.

Part A

School Of Psychology Research Ethics Committee Proposal

Ethical approval to carry out this research study was granted by the Research Ethics Committee, School of Psychology, University of Wales, Bangor on 29 June 2001 (Appendix 1).

School Of Psychology Research Ethics Committee Proposal

1. Title of Project

Lives in Transition: Caregiving and Bereavement Experiences Among Spousal Dementia Caregivers – A Grounded Theory Study

2. Name of Investigators

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3. The Potential Value of Addressing This Issue

The retrospective accounts of bereaved older adult spouse carers of people with dementia have the potential to increase our understanding about adjustment processes during both the caregiving phase and the first two or more years following bereavement.

In seeking to learn about caregiving and bereavement experiences within this population, it is hoped to identify some of the difficulties that may be encountered during the caregiving and bereavement phases and to establish how factors such as

personal characteristics, coping strategies, social support and healthcare services impact on psychological adjustment.

4. Background to the Study

The death of a spouse has been reported to be one of the most stressful events that can be experienced in adulthood (Holmes & Rahe, 1967). Furthermore, spousal bereavement in older adults represents one of the most serious threats to physical health and general well-being (Osterweis et al., 1984; W. Stroebe & Stroebe, 1987).

The impact of bereavement is generally considered to increase the risk of mortality of a surviving spouse. Several studies have reported higher mortality rates amongst bereaved spouses compared to married people of the same age (Sidell, 1993), and the greatest risk of dying occurs in the first months after the bereavement (M.S. Stroebe & Stroebe, 1993). Parkes (1996) reported that mortality rates among widowers were 40% higher than for married men of the same age. Similarly, mortality rates among widows have been found to increase significantly but only during the first three months after spousal bereavement (Mellstrom et al., 1982). However, among bereaved spouses of patients with dementia, Ryan (1992) found mortality rates were significantly *lower* than the mortality rates of married and widowed older adults.

Living with and caring for a spouse who suffers a long and protracted illness may increase the difficulties experienced in the bereavement process (Gerber et al., 1975). Longer-term caregiving can be an exhausting role that places strain on the mental, physical and emotional well-being of the carer (Bass & Bowman, 1990; Gallagher et al., 1989a).

Mullan (1992) draws our attention to the numerous direct and indirect losses experienced by caregivers witnessing the deteriorating health of a loved one. Whilst the death of one's spouse represents the ultimate loss, a number of additional 'nondeath' losses are encountered during caregiving (Collins et al., 1993; Theut et al., 1991), which contribute to the experience of 'chronic sorrow' (Lindgren et al., 1999).

The burden of family caregiving has been found to manifest in significant levels of depression, burnout, poorer levels of health, and decreased life satisfaction (Cohen & Eisdorfer, 1988; Gallagher et al., 1989b; Lindgren, 1990, 1993). In many cases, the strain of caregiving can reach a point where spouses have to be moved into hospital or alternative care accommodation in the final period of their lives. As a consequence, surviving spouses may experience a 'sense of failure' (Sidell, 1993), feelings of guilt (Parkes, 1986; Sidell, 1993), and may reproach themselves for their actions, wishing they had done things differently (Bowling & Cartwright, 1982). In addition to the experience of depression following the death of a relative, caregivers may experience a sense of guilt with frequent ruminations about their efficacy as a carer (Bodnar & Kiecolt-Glaser, 1994). This group of older adults, whose caring is over, seldom receive healthcare services (Davies, 1999).

Bass and Bowman (1990) investigated the transition from caregiving to bereavement among spousal and family caregivers. They found that family members appraisals of greater strain during the caregiving process was predictive of greater strain during bereavement. Furthermore, Bass & Noelker (1987) found that appraisals of greater strain during caregiving predicted higher levels of long-term community

service use during bereavement.

The caregiving and bereavement adjustment experienced by caregivers of people with dementia may be more complicated than other forms of bereavement (Wasow & Coons, 1987). For instance, caregivers of spouses with dementia may face difficulties in coping with 'dual dying' (Jones & Martinson, 1992), a process that involves 'acute grief' during active caregiving and re-stimulation of this phenomenon following the person's death (Almberg et al., 2000).

Mullan (1992) proposes that the bereavement experiences of Alzheimer's caregivers may be qualitatively different from other bereaved caregivers or non-caregivers and, furthermore, dementia caregiving may also have *positive effects* on bereavement adjustment. The rationale underlying this proposition is that caregiving for a person with dementia, often over many years, "creates opportunities for emotional closeness and also for anticipating and preparing for the impaired person's death" (Mullan, 1992; p.675). The relief from the burden of caregiving following the death of the person with dementia may also have positive effects on bereavement adjustment (Almberg et al., 2000).

Troll et al. (1979) proposed that part of the grieving process takes place during the later or terminal stages of an illness, referred to as anticipatory grief (Aldrich, 1974; Fulton & Fulton, 1971; Lindemann, 1944). However, in a later review of the research literature concerning the concept of anticipatory grief, Sweeting and Gilhooly (1990) found conflicting evidence about whether or not it actually forms part of the process of bereavement adjustment.

In a qualitative study, Jones and Martinson (1992) analysed the caregiving and bereavement experiences of family members who had been Alzheimer's caregivers for between 3-10 years and bereaved for 1-20 months. These caregivers were said to face 'dual-dying', because the grief experienced during the caregiving phase became reactivated during bereavement. Jones and Martinson argue that the study findings "support the need for professional intervention during the caregiving phase which may also be a time of intense bereavement" (p.172).

Mullan (1992) studied the short-term bereavement adaptation amongst caregivers of spouses or parents with a progressive dementia and described the first year of bereavement as a time of transition. During this transition period, depression levels declined soon after the death, whilst 'overload', and indicator of distress, fell dramatically and a sense of mastery increased. Almberg et al. (2000) obtained qualitative data regarding the experiences of caregivers of a spouse or family member with dementia and the first six months of bereavement. They reported that the availability of social support, the continued support of family and/or friends, positive memories, the perception of caregiving as a burden, and the possibility of saying goodbye were key factors which linked the stages of caregiving and bereavement.

Recently, Keady (1999) outlined a five stage temporal model to explain the experiences of carers of people with dementia. In the final stage of this model, carers enter 'a new beginning' at the end of their caregiving career. However, as yet, our understanding of the transitions and experiences of carers of people with dementia involved in this stage are poorly understood and described in the literature. This study, therefore, aims to address this issue by conducting an exploratory study of the

transition from the role of caregiver to being a surviving spouse of a person with dementia during the first two years or more following bereavement.

Specifically, this study seeks to develop a grounded theory account of this process of transition by addressing the following research questions: (1) what are the experiences of being a carer of a spouse with dementia and the experiences of being a widow or widower?; (2) what factors are involved in the process of psychological adjustment during the caregiving phase and bereavement phase?; (3) what is the role of social support and personal characteristics in the process of psychological adjustment during caregiving and bereavement?; (4) what role do healthcare services play in the process of psychological adjustment?; (5) what are the major difficulties encountered in the caregiving and bereavement phases?

5. The Hypotheses

This study employs qualitative methodology. Qualitative research “begins with an area of study and allows the theory to emerge from the data” (Strauss & Corbin, 1998; p.12) rather than beginning the research with a preconceived theory in mind. This study seeks to generate a theory of psychological adjustment prior to and following the death of a spouse with dementia. As stated above, the study aims to gain an understanding of:

- ❖ the experience of being a carer of a spouse with dementia and the experience of being a widow or widower
- ❖ the process of psychological adjustment during the caregiving phase and after the death of the spouse with dementia

- ❖ the role of social support and personal characteristics in the process of psychological adjustment during caregiving and bereavement
- ❖ the role that healthcare services play in the process of psychological adjustment
- ❖ major difficulties encountered in caregiving and bereavement adjustment

6. Recruitment of Participants

Inclusion Criteria

Participation in this study will be on a voluntary basis and participants will be purposively sampled by the main researcher. The inclusion criteria for participants in the study are as follows:

- ❖ female and male bereaved spouses age 65 years and over
- ❖ spouse formally diagnosed with dementia before their death
- ❖ bereaved for at least 18, but preferably 24, months

Exclusion Criteria

- ❖ bereaved spouses with a diagnosed dementia that clearly affects their ability to contribute to this study in a meaningful way

Participant Recruitment

Participants will be recruited via two methods. Firstly, from Alzheimer's Society Carer Support Groups within the Bangor and Chester branch regions. Outline written approval has been received from both the Bangor and Chester branches to circulate information about this study at Carer Support Group meetings. The

Alzheimer's branches will inform the researcher of the names of their members who express an interest in taking part in this study.

The second method of recruitment into the study will be via the Alzheimer's Society Regional Newsletter. This is distributed by mail to the homes of Alzheimer's Society members throughout the North West region. Outline approval has been received to include information about this study in newsletters to Alzheimer's Society support groups in the North West region. Members who express an interest in participating in the study will be asked to inform their local branch or the main researcher in this study via the School of Psychology in Bangor.

Once Alzheimer's Society members' expression of interest in participating in the study has been received, they will be sent information sheets (Appendix 2). They will also be sent a 'Research Consent Form' (Appendix 3) which they will be asked to complete and return in a stamped addressed envelope if they wish to participate. A further 'Audio Tape Recording Consent Form' (Appendix 4) will be given to participants to complete prior to commencement of the interview.

7. Research Design

This is an exploratory study into a relatively poorly described area of research. On this basis grounded theory (Glaser & Strauss, 1967), a well known qualitative research methodology, was selected because it places emphasis on understanding the multiplicities, variations and complexities of individual's personal experiences. Creswell (1998) states that "the intent of a grounded theory study is to generate or discover a theory, an abstract analytical schema of a phenomenon, that relates to a

particular situation. This situation is one in which individuals interact, take actions, or engage in a process in response to a phenomenon” (pp.55-56).

Strauss and Corbin (1990) propose that the “grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon” (p.24). In grounded theory it is important that the researcher develops a theory rather than providing a ‘mere description’ of the phenomenon in question. In this way grounded theory can serve two important roles. Firstly, in clinical practice terms, it can increase psychological knowledge about a phenomenon. Secondly, it can contribute to further research about the phenomenon in question by generating hypotheses and theories which may then be subjected to subsequent objective testing (Burt & Oaksford, 1999).

Using the framework proposed by Pidgeon and Henwood (1996), the collection of data in this study will involve conducting and tape-recording interviews with participants. These interviews will be transcribed verbatim and initial data analysis will involve inspection and open coding of the text on a line-by-line basis. The method of constant comparison (Glaser & Strauss, 1967) requires the researcher to continually examine the data and systematically compare it to emerging categories. Categories and concepts of importance that emerge during initial data analysis will be incorporated into an indexing system, and will be supplemented by memo-writing.

Theoretical sampling will be employed as a means to fill out categories, to discover variations between them and to identify gaps between them. On this basis, participants in this study will be ‘theoretically chosen’ for their potential for

generating new theory rather than for being representative of this population. The number of visits to the field “depends on whether the categories of information become saturated and whether the theory is elaborated in all of its complexity” (Creswell, 1998; p.57). As such, it is difficult to estimate the number of participants in this study. However, due to restrictions on the time available to collect and analyse the data, it is proposed that the number of participants is likely to be around one dozen or less.

Following initial data analysis, further analysis involving axial coding will seek to refine the indexing system. This will attempt to link together relevant categories, and to establish key concepts that can be incorporated into a meaningful framework or grounded theory. The grounded theory approach, therefore, enables the generation of theoretical outcomes from initial unstructured data (Strauss & Corbin, 1990).

8. Procedures Employed

A semi-structured interview format (e.g. Barker et al., 1994) will be used to conduct interviews with bereaved spouses of persons with dementia. Interviews will be recorded onto an audiocassette for later transcription and data analysis. It is anticipated that interviews will last between sixty to ninety minutes.

9. Measures employed

This study does not propose to employ any formal measures.

10. Qualifications of the Investigators to use the Measures

Not applicable. This study does not propose to employ any formal measures.

11. Venue for Investigation

It is anticipated that interviews with participants will normally take place in their own home but they will be given the choice of conducting the interview at an Alzheimer's Society venue, providing that the necessary arrangements can be made.

12. The Duration of the Study

The proposed timetable for this study is as follows:

May 2001: Application to School of Psychology Research Ethics Committee

Oct 2001: Commencement of data collection and analysis

Mar 2002: Completion of data collection and analysis

May 2002: Completion of research project write up

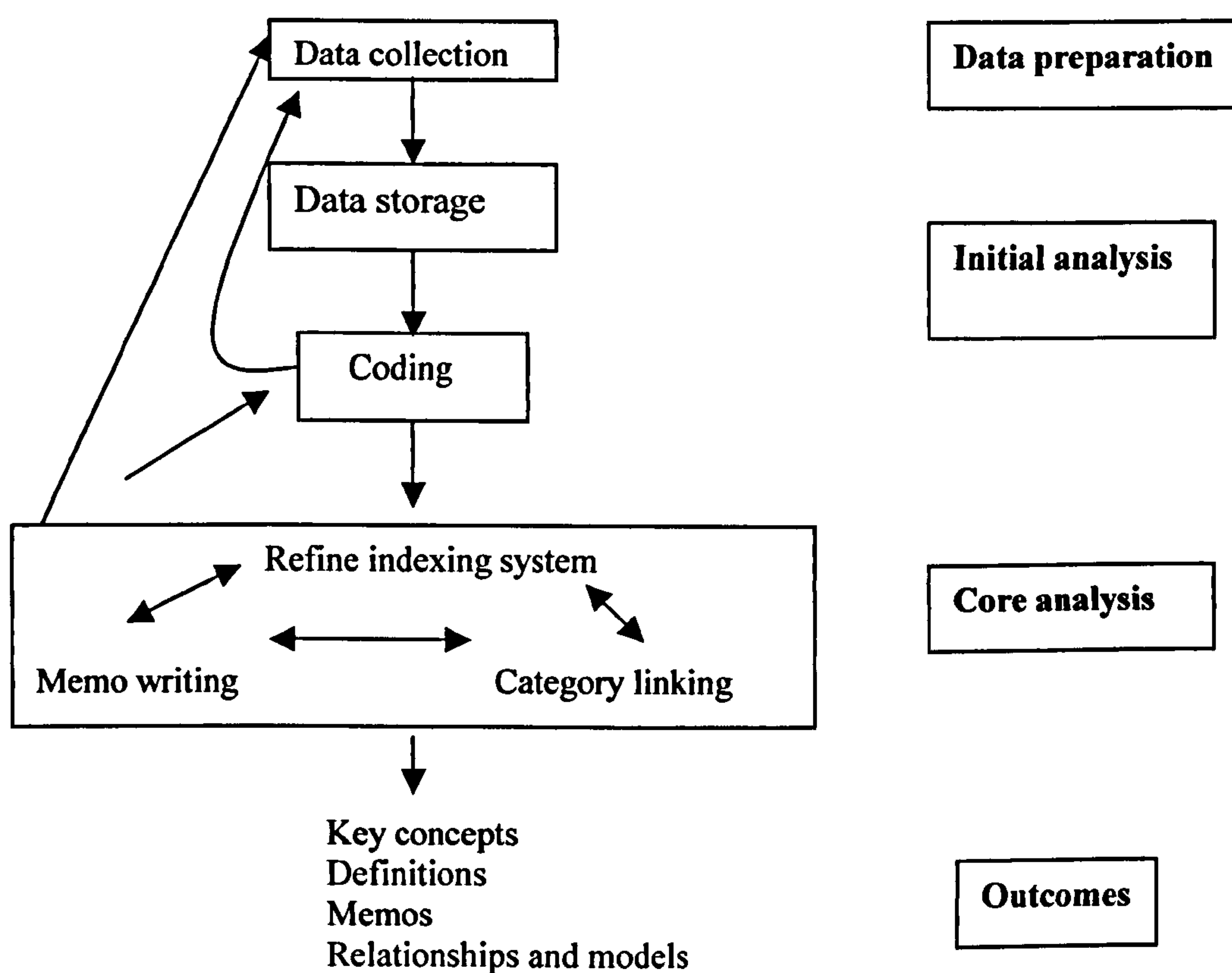
13. Data Analysis

The tape-recorded interviews with participants will form the data in this study. Each interview will be transcribed verbatim in accordance with the grounded theory approach. Data analysis will begin soon after the first interview has been completed.

Data analysis in this study will follow Pidgeon and Henwood's (1996) proposed framework (fig. 1) which summarises the process in grounded theory of moving from the collection of unstructured data to the generation of theoretical outcomes.

During initial data analysis, the text of each interview will be inspected and coded on a line-by-line basis to answer the question as posed by Pidgeon and Henwood (1996), “what categories, concepts, or labels do I need to account for what is of importance to me in this paragraph?” (p.92). An indexing system will document emerging categories and the specific instances of such categories that emerge during interviews, thereby enabling the generation of multiple examples of categories both within and between participants.

Figure 1. Grounded theory approach (Pidgeon & Henwood, 1996; p.88).



The coding process will be iterative, in that as new categories emerge from subsequent interviews, previous transcripts will be examined for further examples of the category in question. As categories become more developed or ‘saturated’, sub-categories may be established. The potential links with other categories will be

explored and theoretical memos and field notes will be used to refine the indexing system and assist theory development. Core concepts derived from the indexing system will reflect the extent to which identified categories or themes apply to participants. This process will be continued until no further concepts develop and a point of saturation is reached. The final stage of data analysis involves the linking together of conceptual categories into a meaningful framework.

14. Potential Hazards to Participants / Investigators

No potential hazards to participants or investigators are anticipated.

15. Potential Offence / Distress to Participants

The researcher is aware of the sensitive nature of this research. Every effort will be made to minimise participants' distress. It will be made clear that participants may end the interview at any stage. If it becomes apparent that a participant requires psychological intervention, then relevant information will be given on how to access psychological services.

16. Procedures to Ensure Confidentiality

Participants will be assured that confidentiality will be respected at all times throughout the study. They will be informed that the interview will be recorded and the audio-taped interviews will be kept for the purposes of transcription and supervision, and will be erased by the researcher after data analysis has been completed.

17. How Consent is to be Obtained

Written consent to participate in the study will be obtained in all cases using the attached 'Research Consent Form' (Appendix 3). Written consent to tape-record the interview will be obtained in all cases using the attached 'Audio Tape Recording Consent Form' (Appendix 4).

18. Information for Participants

Participants in this study will be given a copy of the attached information sheets (Appendix 2). Every effort will be made to ensure that participants fully understand the purpose of the research and have the opportunity to ask questions prior to taking part.

19. Approval of Relevant Professionals

This is not required for the purposes of this study.

20. Payment to: Participants, Investigators, Departments/Institutions

It is not anticipated that payment will be made to any of the above during the course of this study.

21. Equipment Required and Availability

Tape recorder and audiocassettes to be provided by the researcher.

22. Arrangements to Give Feedback to Participants

The information sheets (Appendix 2) inform participants that they will be contacted at a later date to discuss the findings of this research study.

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Part B

Literature Review

Aging & Mental Health (Notes for Contributors – Appendix 5)

Abbreviated title: Spousal dementia caregiving and bereavement adjustment

Caregiving And Bereavement Adjustment Among Spouses of People with Dementia: A Literature Review

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Caregiving And Bereavement Adjustment Among Spouses of People with Dementia: A Literature Review

Abstract

This paper reviews the existing literature on family and spousal dementia caregiving and bereavement adjustment. A number of proposed theoretical models that seek to explain caregiving and bereavement adjustment are described and the evidence from a number of research studies that have investigated the caregiving and bereavement experiences of spousal dementia caregivers is evaluated. Examination of the existing research literature suggests that caregiving for a spouse with dementia is characterised by a number of primary stressors related to caregiving strain and secondary stressors, including multiple dementia-related losses, which exacerbate the caregiving experience. Researchers investigating bereavement adjustment have reported that the death of a spouse with dementia has relatively few long-term negative consequences. This has been attributed primarily to relief from the burden of caregiving, social support, and the beneficial effects of anticipatory grief. There is a growing consensus among researchers that caregiving and bereavement are part of a single, chronic process, whereby in each individual case adjustment is mediated by a complex interaction between a range of individual and situational factors. Of these, social and professional support and appraisals of caregiving have been proposed as key factors that link both caregiving and bereavement adjustment transitions.

Caregiving And Bereavement Adjustment Among Spouses of People with Dementia: A Literature Review

Caregivers of a spouse with dementia typically face an ambiguous and constantly changing caregiving situation, together with a number of unanswered questions and uncertainty about their spouse's condition, their role as a caregiver and the future (Ingebretsen & Solem, 1997). Furthermore, dementia caregiving for a family member, including a spouse, may be unique and distinctly different from other forms of caregiving (Brody, 1988) because of the nature of the disease, the intensive and often long-term care involved, and the ultimate death of the person with common reactions such as sadness, grief and depression (Almberg et al., 2000; Collins et al., 1993).

Bass et al. (1991) assert that caregiving and bereavement should be considered as a single, chronic process that encompasses the caregiving situation, the death of the person, and bereavement adjustment. This paper will begin by outlining some of the theoretical models that have been proposed to account for caregiving and bereavement. The paper will then review evidence from a number of research studies that have investigated the process of psychological adjustment experienced by spousal dementia caregivers during caregiving and bereavement.

Theoretical models of caregiving and bereavement

Caregiving models

The experience of caregiving has most often been conceptualised within the stress and coping paradigm. According to Pearlin et al. (1990) caregiving adjustment may be influenced by a range of factors including the characteristics and context of

the stressor, coping resources, social support, concurrent stressors and individual resources. An extension of the stress and coping model (Haley et al., 1987) emphasises how caregivers' subjective appraisals about their caregiving burden can influence outcomes, such as depression. Another model (Schulz et al., 1988; 1989) focuses on interactions between categories of stress-related variables including objective conditions, individual perceptions, short-term responses to stress, enduring outcomes and conditioning variables such as social support and perceived control.

Researchers working within the stress and coping paradigm have typically viewed the caregiving situation as a primary stressor that may give rise to a host of parallel, secondary stressors (Mullan, 1992). Dementia caregiving has been referred to as a "36-hour day" (Mace & Rabins, 1991). The emotional and physical health effects of caregiving for a physically or cognitively impaired family member have been described in terms of depression, burnout, poorer levels of health, decreased life satisfaction, and detrimental effects on kin relationships and social activities (Cohen & Eisdorfer; 1988; Gallagher et al., 1989a; Gallagher et al., 1989b; George & Gwyther, 1986; Grafstrom et al., 1992; Lindgren, 1990, 1993; Vitaliano et al., 1991).

Caregivers often face a number of secondary stressors, in terms of dementia-related losses, as they witness the deteriorating health of a loved one with dementia (Bull, 1998; Collins et al., 1993; Mullan, 1992; Theut et al., 1991) including loss of familiarity, intimacy, and spousal role (Collins et al., 1993; Rudd et al., 1999) together with a loss of hope of recovery and future together (Lindgren et al., 1999). As a result, caregivers may experience a reduced sense of self, ambivalence, and guilt (Mullan, 1992).

Witnessing the gradual loss of a family member with dementia, and coping with unpredictable and uncharacteristic behaviours and aggressive outbursts has been

suggested to be especially distressing (Mullan, 1992). Eventually, the strain of caregiving may reach a point where the care recipient has to be moved from their home into nursing home care. Caregivers of spouses with dementia who enter nursing home care have been found to experience greater strain and impaired health status, together with higher levels of anxiety, sadness, anger and guilt (Brown et al., 1992; Rudd et al., 1999), and grief about the loss of the spouse's physical presence from the home (Rudd et al., 1999).

Faced with these potential loss experiences, family and spousal dementia caregivers may begin to grieve long before the death of the person with dementia (Almberg et al., 2000; Collins et al., 1993; Lindgren et al., 1999; Mullan, 1992; Theut et al., 1991). Furthermore, in the latter stages before the death, caregivers often continue to care for the 'body' whilst experiencing partial bereavement (Troll et al., 1979). This phenomenon has been described by Lindgren et al. (1999) as "residing in the land of the living death" (p.535) and by Kapust and Weintraub (1984) as "the funeral that never ends" (p.462).

The concept of 'chronic sorrow' (Lindgren, 1996), defined as resurgent feelings of sorrow triggered by new losses and remembrances of previous losses within a chronic illness trajectory (Burke, 1989; Lindgren et al., 1992), has been proposed to measure family dementia caregivers pre-death grief experiences. Chronic sorrow has been found to be a frequent emotional response among family caregivers of people with Parkinson's disease (Lindgren, 1996) and Alzheimer's disease (Lindgren et al., 1999; Mayer 2001). However, caregivers' nondeath grief has been found to relate more closely to secondary losses, such as loss of future and changes in the trajectory of their lives, than to primary losses such as the degenerative changes in the family member with dementia (Lindgren et al., 1999).

The concept of 'anticipatory grief', originally identified by Lindemann (1944), involves a "process of slowly experiencing the phases of normal post-death grief in the face of a potential loss of a significant person" (Theut et al., 1991, p.114). Rando (1986) further defines anticipatory grief as a person's growing awareness of the impending loss of a relative and the reaction to associated losses in the past, present, and still to come. Anticipatory grief has been proposed to be a unifying response that encompasses such reactions as anger, guilt, anxiety, and sadness in response to spousal dementia caregiving (Theut et al., 1991).

Almberg et al. (1997) investigated how family and spousal caregivers cope with the burden of dementia caregiving and burnout. Burnout has been defined as the subjective experience of a state of physical, emotional and mental exhaustion, often characterised by a combination of high expectation and chronic strain (Maslach, 1982; Pines & Aronson, 1988). Almberg and her colleagues found that caregivers who reported burnout were far more likely to employ emotion-focused coping strategies (e.g. grieving, worrying, and self-accusation), whilst caregivers without burnout were found more frequently to employ problem-focused strategies (e.g. confronting the problem, seeking information and seeking social support). Almberg et al. (1997) concluded that problem-focused strategies, used either alone or in combination with an emotion-focused strategy such as acceptance, were more effective in the coping process than primarily emotion-focused strategies.

Bereavement models

In a review of the literature, Schulz et al. (1997) highlight the need to extend models of caregiving and bereavement to facilitate an understanding of the process of bereavement adjustment following caregiving. However, research has begun to focus on factors that may influence adjustment to loss, including personality and prior

health, and situational factors such as antecedent stressful events, the relationship with the family member, cause of death and circumstances after the loss (M.S. Stroebe & Stroebe; 1985; W. Stroebe & Stroebe, 1987).

Stress and coping models conceptualise bereavement as a stressful life event that challenges individuals' coping resources (Holmes & Rahe, 1967; Lazarus & Folkman, 1984; Reich et al., 1989; M.S. Stroebe & Stroebe, 1985; W. Stroebe & Stroebe, 1987). Such models explain bereavement adjustment in terms of a complex interaction between individual and situational factors, mediated by the social and personal resources of the bereaved person.

Depression models of bereavement have tended to focus on emotional reactions to the death of a loved one. Examples include Freud's (1917) psychoanalytic and Bowlby's (1980) attachment models, and models that conceptualise bereavement adjustment in terms of either 'pathological' or 'normal' grief reactions (Parkes, 1970; Parkes & Weiss, 1983). According to Parkes (1972), the experience of grief following spousal bereavement is characterised by an awareness of a discrepancy between the world that 'is' and the world that 'should be'. As a result of the loss of a loved one a person's internal model of, and assumptions about, the world must change, and this potentially dangerous life event has been termed a 'psychosocial transition' (Parkes, 1972).

A number of researchers have suggested that identity change is a key component of psychological adjustment following spousal bereavement (Bowlby, 1980; Glick et al., 1974; Weizman & Kamm, 1985). Gut (1974) has argued that successful resolution of the mourning process involves a recognition and acceptance of the finality of the loss, together with a reorientation and reintegration of the bereaved spouse's personality. Saunders (1981) suggests that the bereavement process

is not complete until the surviving spouse develops an 'uncoupled identity'.

Models of caregiving and bereavement

Keady (1999) proposes that at the end of their caregiving career, caregivers of people with dementia enter a final phase or 'a new beginning'. However, as yet, our understanding of the transitional experiences of bereaved family and spousal dementia caregivers is limited (Aneshensel et al., 1995; Schulz & Williamson, 1997).

Stress and coping models of caregiving and bereavement suggest that caregiving may deplete one's coping, or stress-buffering, resources in response to cumulative stressors and, furthermore, long-term exposure to chronically stressful caregiving situations may lead to more difficult adjustment by depleting social support resources and reducing perceptions of control (Pearlin et al., 1989). As such, the amount of time as a caregiver and the amount of support received are likely to be important predictors of adjustment and health outcomes (Schulz et al., 1997). A further prediction of these models appears to be that the death of a family member may increase stress-buffering resources, in terms of enhanced mental and physical health, through the elimination of a major stressor (Norris & Murrell, 1987).

Depression models (Bowlby, 1980; Freud, 1917; Parkes, 1970; Parkes & Weiss, 1983) predict that long-term caregiving may increase bereavement adjustment difficulties. Such models focus on emotional reactions and the role of attachment, guilt, resentment, relationship conflicts, and family dynamics as predictors of poor bereavement outcomes (Schulz et al., 1997).

Anticipatory grief models (Atchley et al., 1974; Fulton & Gottesman, 1980; Weisman, 1974) predict that caregiving, particularly in the long-term, enables caregivers to prepare for the loss of the person, and is likely to have a more beneficial effect on bereavement adjustment than if a death is sudden. Grief experienced prior to

the death may help caregivers to resolve difficult interpersonal relationships and assist the process of detachment from the dying person (Rando, 1986). However, dementia caregivers' adjustment may also become complicated by 'disenfranchised' grief (Doka, 1989), whereby they may not receive the potentially stress-buffering effects of support that might normally be afforded to bereaved persons (Rudd et al., 1999).

A number of stage models have sought to explain bereavement adjustment following dementia caregiving. For example, Teusink and Mahler (1984) modified Kubler-Ross' (1969) stages of dying model in an attempt to explain family dementia caregivers' bereavement adjustment. Rando (1984) developed a 3-phase model to explain the grieving process following dementia caregiving in terms of avoidance, confrontation and re-establishment. However, a study involving spousal dementia caregivers found no identifiable patterns of coping or stages of recovery following bereavement (Wasow & Coons, 1987). Following a number of criticisms of stage models (e.g. Kastenbaum, 1991; Wortman & Silver, 1989), newer models such as Worden's (1991) task-based model have been suggested to understand bereavement adjustment (Rudd et al., 1999).

Jones and Martinson (1992) investigated the caregiving and bereavement experiences of family and spousal dementia caregivers and proposed a two-stage model of intense bereavement. In the first stage during caregiving, characterised by diagnosis and deterioration, powerlessness and agonizing losses, an 'empty space' develops and caregivers begin the process of detachment from the person with dementia 'inch by inch'. The second stage characterises bereavement in terms of the loss of the physical person and caregivers' grief reactions, an enlargement of 'empty space', and a process of complex relief.

Another qualitative study (Almberg et al., 2000) involving family and spousal dementia caregivers identified a number of key factors that link the process of caregiving and bereavement adjustment. These include the availability of social support, the continued support of family or friends, positive memories, the perception of caregiving as a burden, and the possibility of saying goodbye.

The studies by Jones and Martinson (1992) and Almberg et al. (2000) illustrate the potential of qualitative research to increase our understanding of the personal meanings that bereaved caregivers attach to their experiences and the influence that this might have on psychological adjustment. The following section will review evidence from both qualitative and quantitative research studies regarding bereavement outcomes following dementia caregiving.

Bereavement outcomes

The death of a family member following dementia caregiving has been proposed to represent the most difficult transition that caregivers have to face (Aneshensel et al., 1995). Schulz et al. (1997) point out that traditional bereavement research has focused on the emotional or physical health consequences of death of a loved one, such as major depressive episode (Brown & Harris, 1989; Clayton, 1990), anxiety (Jacobs et al., 1990; Parkes & Weiss, 1983), compromised immune functioning (Irwin et al., 1987), and physical health problems (Reissman & Gerstel, 1985). The impact of the death experienced by caregivers of a mentally or physically impaired relative has been reported in terms of depression (Bodnar & Kiecolt-Glaser, 1994; Collins et al., 1994), social and emotional difficulties (Bass et al., 1991; Collins et al., 1993), feelings of guilt, especially about decisions to put a spouse into nursing

care (Bodnar & Kiecolt-Glaser, 1994; Parkes, 1996; Sidell, 1993), and ruminations about caregiver efficacy (Bowling & Cartwright, 1982; Sidell, 1993).

In a study involving family dementia caregivers, Aneshensel et al. (1995) noted a number of common reactions but also considerable individual variation in the amount of grief, ways of grieving, and the factors contributing to grief experiences. Aneshensel and her colleagues observed that pre-death influences such as role overload, depression, guilt, and loss of self increased some aspects of grief. In contrast, factors such as a sense of mastery, a developed sense of loss of the care recipient, and a difficult past relationship with the patient appeared to protect against grief.

In a review of the empirical studies that have focused on bereavement outcomes following family and spousal dementia caregiving, Schulz et al. (1997) found some evidence of short-term negative affect following the death of the care recipient. However, they also reported a preponderance of research findings suggesting that bereaved caregivers appear to have relatively few difficulties in adjusting to the death of the person. Additionally, a number of positive outcomes following the death have been reported including relief from the burden of caregiving and increased quality of life. Schulz and his colleagues describe three factors that may contribute to the presence of either positive or negative bereavement outcomes following dementia caregiving. First, caregivers may view the death as an end to the care recipient's suffering as well as the end of the strain of caregiving. Second, the predictability of the death enables the caregiver to grieve prior to the death. Third, family caregiving support systems that provide aid and relief during caregiving are likely to already be in place when the death occurs.

Evidence from a number of studies appears to support stress and coping model predictions that the death of the care recipient will be experienced as relief from the stresses of caregiving, leading to enhanced well-being (Collins et al., 1993; George & Gwyther, 1984; Norris & Murrell, 1987). Although there is a dearth of research evidence about gender differences in terms of the impact of spousal bereavement following dementia caregiving, a study involving family and spousal dementia caregivers (Collins et al., 1994) reported a post-bereavement decrease in depression among female caregivers and an increase among males caregivers.

In a study involving 82 bereaved caregivers of relatives with Alzheimer's disease, including 57 spouses, Collins et al. (1993) found that the majority of caregivers reported feelings of relief in the immediate post-death period. Jones and Martinson (1992) reported that 77% of family dementia caregivers felt the death of the relative was a relief and that they were ready to let go. However, this relief was found to be complex and experienced in terms of sorrowful relief, guilty relief, and grateful relief. Another study (Almberg et al., 2000) reported that family dementia caregivers who appraised their caregiving experiences in positive terms were more likely to report feelings of relief following the death.

A number of key predictors of bereavement adjustment following dementia caregiving will now be discussed. These factors include caregiving strain, anticipatory grief, time since bereavement, the relationship with the person with dementia, social support, and professional support.

Caregiving strain

Some bereavement outcome research studies involving family and spousal dementia caregivers have reported that greater caregiving strain is predictive of fewer bereavement adjustment difficulties (George & Gwyther, 1984; Norris & Murrell,

1987). However, contrary to this finding, Bass & Bowman (1990) investigated caregiving and bereavement transitions among 73 caregivers, including 18 spouses, of chronically disabled relatives, and found that family members who perceived greater caregiving strain experienced greater bereavement adjustment difficulties.

Bass and Bowman's proposed explanations for their findings may help to explain caregiving and bereavement adjustment among spousal dementia caregivers in terms of a complex interaction between situational and individual factors. Firstly, consistent with stress and coping model predictions, the 'cascade effect' of multiple stressors experienced during caregiving may exhaust the individual and increase their vulnerability to negative consequences and coping difficulties. This, in turn, may decrease their resources to cope with bereavement, thereby causing greater strain. Second, unlike caregivers with a 'hardy personality' (Kobasa, 1979), other caregivers may perceive less mastery or control, lower self-esteem and a less positive attitude towards challenge and change, which may heighten their perceptions of stress and result in greater bereavement adjustment difficulties. Finally, contrary to anticipatory grief model predictions, longer-term stressful caregiving may hinder preparations for death and contribute to more difficult bereavement adjustments.

Anticipatory grief

Although tacit attempts have been made to relate caregiving experiences to bereavement adjustment in terms of anticipatory grief, a comprehensive review of the available research literature (Sweeting & Gilhooly, 1990) has found conflicting evidence about the relationship between anticipatory grief and bereavement adjustment. Whilst a number of studies have reported that advanced warning of death is positively associated with good bereavement outcomes (Atchley et al., 1974; Ball, 1977; Lundin, 1984; Parkes & Weiss, 1983; Weisman, 1974), other studies have

found no such association (Bowling & Cartwright, 1982; Clayton et al., 1973; Gerber et al., 1975; Hill et al., 1988; Jacobs et al., 1986; Sanders et al., 1979).

Rando (1983) reported an association between extended terminal illness and poor bereavement outcomes. Moreover, it has been proposed that long-term, stressful caregiving may increase bereavement adjustment difficulties (Gerber et al., 1975), increase the commitment and closeness to the dying person, and isolate the caregiver from other associations (Bass & Bowman, 1990; Collins et al., 1993; Tebb & Jivanjee, 2000). As a result, caregivers may be too stressed and immersed in the caregiving role to anticipate and prepare for the death (Rosenblatt, 1983; Sanders, 1982). Furthermore, Liken and Collins (1993) assert that pre-death grief does not substitute for post-death grief.

In a qualitative study investigating the bereavement experiences of family and spousal dementia caregivers, Jones and Martinson (1992) concluded that whilst caregivers' grief experiences may have been anticipatory in nature, this might have equally been "acute grief related to the immediate and permanent loss of a relative's human abilities and personhood while still living" (p.175). Jones and Martinson proposed the concept of 'dual dying' to explain a first stage of acute grief during caregiving, experienced in terms of agonizing emotional dissonance and detrimental effects on caregivers' health, and a second stage of acute grief which begins after the death and is characterized by feelings of complex relief, guilt resolution and, ultimately, recovery.

The reasons for the absence of the purported benefits of anticipatory grief as reported by some research studies involving dementia caregivers have not been fully established. However, one possible explanation is Worden's (1992) proposal that the grieving process becomes complicated when a loss is 'ambiguous', or is not able to be

clearly identified and confirmed. This has been suggested to reflect family dementia caregivers' loss experiences (Bull, 1998), the adjustment to which may be complicated by disenfranchised grief (Doka, 1989), meaning that caregivers' pre-death grief may not be fully acknowledged and the potentially stress-buffering effects of support are not received.

Time since bereavement

Researchers investigating bereavement in the general population have found that, for some, the grieving process may be a short-lived experience whilst, for others, it may last many years (Wortman & Silver, 1990). The period of adjustment among bereaved spouses has been reported to be around 30 months, although there may often be residual grief (Thompson et al., 1991). Parkes and Weiss (1983) found that 40% of bereaved widows and widowers showed moderate to severe anxiety and depressive symptomology 2-4 years after the loss.

A number of researchers have proposed that dementia caregivers' bereavement experiences may be similar to those of non-caregivers (Bass & Bowman, 1990, Bodnar & Kiecolt-Glaser, 1994; Mullan, 1992) although some specific differences have been reported (Almberg et al., 2000; Bass & Bowman, 1990; Mullan, 1992; Wasow & Coons, 1987). Aneshensel et al. (1995) noted that family dementia caregivers' grief reactions were still present up to 3 years after the death and, additionally, some consistency was observed between patterns of adjustment during caregiving and bereavement, in that surviving caregivers were observed to do as well during bereavement as they had been doing during caregiving.

Mullan (1992) examined short-term bereavement adjustment amongst 74 family caregivers, including 47 spouses, of people with Alzheimer's disease and described the first year of bereavement as a time of transition. During this period,

depression levels were found to decline soon after death, whilst 'overload', an indicator of distress, fell dramatically and a sense of mastery increased. The findings from this study were supported by evidence from subsequent studies (Aneshensel et al., 1995; Skaff et al., 1996). Mullan attributed the observed changes to 'psychological preparation' that had taken place among caregivers in response to losses prior to the death of family members with dementia but concluded that this was not identical with the concept of anticipatory grief.

The relationship with the care recipient

Whilst depression models (e.g. Bowlby, 1980) predict that deeply ambivalent relationships are likely to complicate bereavement adjustment by creating difficulties in parting psychologically from a person to whom one is bound contentiously, Aneshensel et al. (1995) reported evidence that dementia caregivers who reported difficult past relationships actually experienced less grief at the time of death. Collins et al. (1993) reported that, contrary to predictions made by anticipatory grief models, caregivers in their study were unable to resolve aspects of their relationship with the dying person because of the dementing illness and the fact that most caregivers maintained a strong emotional attachment to the dying family member.

In their review of the literature, Schulz et al. (1997) reported that findings from studies investigating caregiver-patient relationships have found greater negative effects of bereavement among bereaved spouses than among adult children who lost their parents. However, Schulz and his colleagues point out that many studies within depression models of bereavement have typically not gathered data on the levels of happiness or marital/relationship satisfaction prior to the onset of the dementing process and, as caregivers' accounts tend to be retrospective, there is potential for bias when recalling events from memory.

Social support

A number of researchers have suggested that a lack of social support may exert an important influence on bereavement outcomes (e.g. Osterweis et al., 1984; W. Stroebe & Stroebe, 1987). Schulz et al. (1997) contend that multiple losses experienced during caregiving may increase the need for social support. Social support has the potential to relieve emotional strain during caregiving, to have an impact on the level of grief that is experienced (Almberg et al., 2000), and to help lessen distress during bereavement (Bass et al., 1991).

Social support received during caregiving has been found to exert an important influence on both pre- and post-death adjustment (Almberg et al., 2000; Collins et al., 1993). Furthermore, Almberg et al. (2000) noted a relationship between factors linking pre- and post-death adjustment, including social support, coping-mastery and positive interpretations of caregiving. Collins et al. (1993) found that, compared to caregivers who reported good family and social support, socially isolated caregivers were less likely to experience feelings of relief at the death and were more likely to report persistent negative post-bereavement emotions.

Professional support

A number of researchers have highlighted the contribution that professional support may have on caregiving and bereavement adjustment, and the importance of matching professional healthcare services to caregivers needs (Bass & Bowman, 1990; Collins et al., 1993; Jones & Miesen, 1992; Parkes, 1993; Rudd et al., 1993). Jones and Martinson (1992) suggested that their study findings “support the need for professional intervention during the caregiving phase, which may also be a time of intense bereavement” (p.172). However, one difficulty is that pre-death losses that cause caregivers to grieve are often hard to recognize, and this may restrict the

planning of healthcare interventions to facilitate pre-death grief (Liken & Collins, 1993).

Methodological considerations

Aneshensel et al. (1995) point out that many research studies have focused on a limited range of outcomes, such as grief and associated psychopathology (e.g. depression). In addition, relatively few prospective studies have been conducted into caregivers' experiences prior to the death (e.g. Bass & Bowman, 1990; Bodnar & Kiecolt-Glaser, 1994; Norris & Murrell, 1987) and the transition from caregiving to bereavement has often been secondary to the main study objective (Aneshensel et al., 1995; Bass & Bowman, 1990).

To date, the bereavement experiences of caregivers of a spouse with dementia have received relatively little research attention. A number of studies (Almberg et al., 2000; Aneshensel et al., 1995; Collins et al., 1993; Jones & Martinson, 1992; Mullan, 1992) have investigated psychological adjustment following caregiving and bereavement among family caregivers but relatively few studies have focused exclusively on the experiences of spousal dementia caregivers.

Finally, few research studies have investigated psychological adjustment beyond the first year post-bereavement, although it has been asserted (Collins et al., 1993) that "even years after the death of a spouse or family member with dementia, former caregivers may still be attempting to develop a retrospective understanding of their caregiving experiences" (p.251).

Conclusions

The research evidence regarding family and spousal dementia caregiving suggests that it is a demanding and potentially exhausting experience, due to the burden of providing care and the effects of multiple dementia-related losses and associated grief reactions. However, a number of studies have reported that the negative effects experienced following bereavement tend to be short-lived and caregivers appear to experience relatively few difficulties in terms of bereavement adjustment after the death of a spouse with dementia. A number of factors have been proposed to explain these findings, such as feelings of relief that the burden of caregiving has ended, social support, and the predictability of the death that provides opportunities to grieve in advance. However, research evidence regarding the concept of anticipatory grief and its purported beneficial effects on bereavement adjustment is by no means definitive. One explanation for this might be the complexity and uniqueness of loss and grief experiences among caregivers of family members with dementia (Almberg et al., 2000; Bull, 1998; Collins et al., 1993; Wasow & Coons, 1987).

Finally, the small number of qualitative research studies conducted to date (e.g. Almberg et al., 2000; Jones & Martinson, 1992) have contributed to our understanding of bereavement adjustment among spousal caregivers by investigating not only the transitions experienced by caregivers but also the personal meanings they attach to caregiving and bereavement. However, the process of caregiving and bereavement adjustment in this population is, as yet, not clearly described in the research literature. In order to broaden our understanding of caregiving and bereavement adjustment among spousal dementia caregivers, and to develop and

deliver adequate services to meet the potential healthcare needs of this population, further investigation is clearly warranted.

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Part C

Research Paper

Dementia: The International Journal of Social Research and Practice

(Notes for Contributors – Appendix 6)

Abbreviated title: Spousal dementia caregiving and bereavement adjustment transitions

**Lives In Transition: Caregiving And Bereavement Adjustment
Among Spousal Dementia Caregivers: A Grounded Theory Study**

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Lives In Transition: Caregiving And Bereavement Adjustment Among Spousal Dementia Caregivers: A Grounded Theory Study

Abstract

This study employed the qualitative methodology of grounded theory to investigate caregiving and bereavement adjustment among five older adult bereaved caregivers of a spouse with dementia. Semi-structured interviews were conducted with participants about their caregiving and bereavement experiences. A number of key attributes that emerged from core analysis of participants' transcribed interview data were incorporated into a model of caregiving and bereavement adjustment transitions. Two participants' accounts indicate that their psychological adjustment during caregiving and bereavement was influenced by ruminations about their perceived negative experiences with healthcare professionals during caregiving. Professional support and social support emerged as key factors linking caregiving and bereavement adjustment transitions. The study findings support the importance of delivering appropriate professional healthcare services to reduce the exhausting burden of spousal dementia caregiving.

Keywords Alzheimer's disease (AD); bereavement; psychological adjustment; spousal dementia caregiving; transitions

Lives In Transition: Caregiving And Bereavement Adjustment Among Spousal Dementia Caregivers: A Grounded Theory Study

Introduction

The experience of caregiving

Caregiving for a person with dementia may be unique compared to other forms of caregiving due to the nature of the disease and the intensive care necessary, often over long periods of time (Almberg et al., 2000). Dementia caregivers have been reported to experience depression, burnout, poorer levels of health, and decreased life satisfaction (Cohen & Eisdorfer, 1988; Gallagher et al., 1989; Lindgren, 1990, 1993).

Bereavement may begin long before the death occurs (Almberg et al., 2000), and caregivers' grief is often compounded by multiple dementia-related losses (Bull, 1998; Collins et al., 1993; Mullan, 1992). The reactions of Alzheimer's disease (AD) and Parkinson's disease caregivers to new losses and remembrances of previous losses within a chronic illness trajectory have been reported in terms of 'chronic sorrow' (Lindgren, 1996; Lindgren et al., 1999; Mayer 2001).

Caregivers' reactions to grief and loss experiences have also been conceptualized as anticipatory grief, that entails "not only grief over future losses but over past and present ones as well" (Rando, 1986; p.34). Anticipatory grief has been suggested to exert a beneficial influence on AD caregivers' bereavement adjustment (Atchley et al., 1974; Lundin, 1984; Weisman, 1974) by, for example, enabling caregivers to finalise relationships with a dying spouse, resolve pre-existing marital conflicts, and make funeral plans (Fulton & Gottesman, 1980; Rando, 1986). However, other studies have failed to report a positive association between anticipatory grief and bereavement outcomes (Hill et al., 1988; Sanders et al., 1979). Long-term, stressful

caregiving has been suggested to hinder caregivers' preparations for death (Gerber et al., 1975; Rosenblatt, 1983; Sanders, 1982) by increasing commitment and closeness to the dying person and socially isolating the caregiver (Bass & Bowman, 1990).

Although the bereavement experiences of dementia caregivers appear to parallel those of other caregivers and non-caregivers (Aneshensel et al., 1995; Bass & Bowman, 1990; Bodnar & Kiecolt-Glaser, 1994; Mullan, 1992), there may also be some unique differences (Bass & Bowman, 1990; Mullan, 1992; Wasow & Coons, 1987). In addition to a range of possible negative physical health effects, bereaved spousal caregivers may experience a 'sense of failure', guilt feelings (Parkes, 1996; Sidell, 1993), and ruminations about nursing care decisions and caregiving efficacy (Bodnar & Kiecolt-Glaser, 1994; Bowling & Cartwright, 1982). Despite this, the process of bereavement adjustment may be assisted by the cessation of caregiving strain (Almberg et al., 2000; Schulz et al., 1997) and by opportunities that caregiving provides to develop emotional closeness and prepare for the death of the care recipient (Mullan, 1992).

The process of caregiving and bereavement adjustment

Keady (1999) proposes that caregivers enter a final phase or 'a new beginning' at the end of a caregiving career, and a number of researchers (e.g. Almberg et al., 2000; Jones & Martinson, 1992; Mullan, 1992) have investigated the link between caregiving and bereavement adjustment in family dementia caregivers. Almberg et al. (2000) identified a number of factors linking caregiving and bereavement adjustment, including the availability of social support, the continued support of family and friends, positive memories, the perception of caregiving as a burden, and the possibility of saying goodbye. Almberg and her colleagues found that positive appraisals of caregiving predicted better post-death adjustment, whilst social support and

professional support received during caregiving were suggested to link both caregiving and bereavement adjustment. Another study (Collins et al., 1993) noted that socially isolated (i.e. less socially supported) caregivers reported less relief and more persistent negative post-bereavement emotions.

The first year of bereavement has been described as a time of transition during which caregivers' levels of depression and 'overload', an indicator of distress, decrease, whilst a sense of mastery increases (Aneshensel et al., 1995; Mullan, 1992). However, as yet, these transitions among spousal dementia caregivers are poorly understood and described in the literature.

Although there are a number of qualitative research methods, the grounded theory approach (Glaser, 1978; Strauss & Corbin, 1990) was considered to be an appropriate methodology to derive a theoretical understanding of the attributes of caregiving and bereavement adjustment experienced by bereaved spousal dementia caregivers in this study, and the basic social process or processes (Glaser, 1978) that underpin such adjustment.

Method

Interviews

Participants were interviewed on two occasions by the main researcher. Initial semi-structured interviews (e.g. Barker et al., 1994) were conducted with participants using an interview guide comprising mainly open questions (Appendix 7). Follow-up interviews were conducted 3-4 months later to inform participants about the results of the study. Concerted attempts were made to establish rapport and convey empathy towards participants during initial and follow-up interviews, which lasted approximately ninety minutes and sixty minutes respectively. All participants chose to

be interviewed in their own home. In accordance with the grounded theory approach (Strauss & Corbin, 1990), field notes and theoretical memos were recorded as soon as possible after initial interviews.

Initial interviews were audiotaped and transcribed in full by the main researcher as soon as possible after the interview. During the transcription process, participants were assigned a study name (e.g. Mrs A) to maintain confidentiality and individual paragraphs were numbered to assist data analysis. Working closely with interview data during the transcription process was considered to enhance 'theoretical sensitivity' (Strauss & Corbin, 1990).

Participants

A total of five Alzheimer's Society carers' group members living in the North West of England volunteered to participate in the study after receiving information in an Alzheimer's Society North West regional newsletter. The study sample was therefore 'theoretically selected' on the basis of affiliation to an Alzheimer's Society carers group. A profile of participants is shown in Table 1. below.

Study procedure

Recipients of the Alzheimer's Society North West regional newsletter were invited to participate in the study. Respondents were sent information about the study (Appendix 2) together with a consent form (Appendix 3), which they were asked to sign and return to consent to participate in the study. On the day of the interview, written consent was sought from participants to tape-record the interview (Appendix 4) for later transcription. Participants' confidentiality and anonymity were assured. At the end of the initial interview, participants were invited to participate in a follow-up interview 3-4 months later to discuss the study findings.

Table 1. Participant Characteristics

| Participant | Age | Total time caregiving | Caregiving at home | Time spouse in nursing care | Age of spouse at death | Time since bereavement |
|-------------|-----|-----------------------|--------------------|-----------------------------|------------------------|------------------------|
| Mrs A | 65 | 9 years | 8.5 years | 4 months | 64 | 26 months |
| Mrs B | 79 | 12 years | 7 years | 5 years | 68 | 10 years |
| Mrs C | 70 | 10 years | 6 years | 4 years | 80 | 20 months |
| Mrs D | 68 | 8 years | 8 years | n/a | 67 | 18 months |
| Mr E | 72 | 10 years | 10 years | n/a | 72 | 7 months |

According to Charmaz (1995), the grounded theory approach anticipates and encourages the development of interview structures throughout the research project. Revisions were made to the original semi-structured interview protocol (Appendix 8) to incorporate additional questions that emerged following inspection of the first two participants' transcribed interviews. 'Credibility checks' (Elliott et al., 1999) have been proposed as a means to judge 'good' qualitative research. In an attempt to establish 'respondent validation' (Pidgeon, 1996), testimonial feedback was requested during follow-up interviews by inviting participants to comment, firstly, on the accuracy of a summary, provided by the main researcher, of their initial interview. Secondly, feedback was sought from participants about the ability of a proposed model of caregiving and bereavement adjustment, derived from analysis of participants' transcribed interview data, to encapsulate their personal caregiving and bereavement adjustment experiences.

Data analysis

The grounded theory framework of Pidgeon and Henwood (1996) was used to guide the analytic process. Open coding was used to inspect interview transcriptions on a 'paragraph-by-paragraph' basis to identify attributes of participants' caregiving and bereavement experiences (Appendix 9). These attributes were incorporated into an index system. The method of constant comparison was used to compare new interview data with earlier transcripts, thereby facilitating the emergence of attributes based on analysis of similarities and differences in individuals' experiences. The coding process was iterative, in that as new attributes emerged from subsequent interviews, previous transcripts were examined for further examples. During core analysis, the indexing system was refined to identify key attributes of participants' caregiving and

bereavement experiences. A reflexive journal (Strauss & Corbin, 1990) containing field notes and theoretical memos was used to assist theory development.

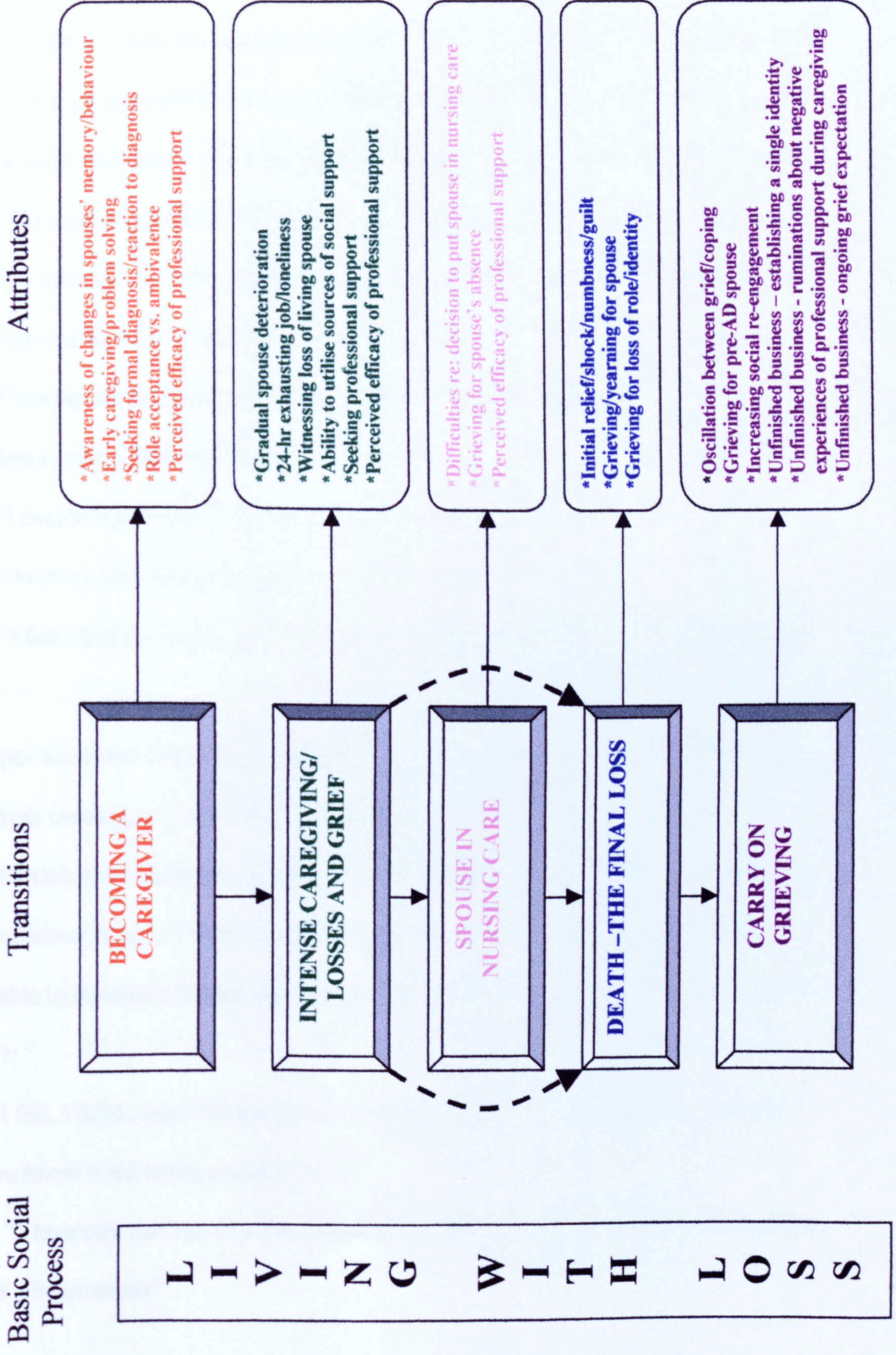
Results

A number of key attributes of caregiving and bereavement experiences that emerged from core analysis of participants' interview data were incorporated into a model of five caregiving and bereavement adjustment transitions (fig. 1). Attributes 'emerged' from the core analysis in the sense that they were derived from, or grounded in, participants' transcribed interview data. As such, an attribute may be conceptualised as a category of participants' reported experience during caregiving and bereavement. There appeared to be fairly distinct groups of attributes relating to different transitions and phases of the caregiving career relating to becoming a caregiver, more intense caregiving and, for some participants, caregiving after a spouse entered full-time nursing care. The post-death component appeared to fall into two distinct transitions and phases, relating to the immediate aftermath of the death and the longer-term adjustment, respectively. A story line (Appendix 10) was also constructed during core analysis, from which a basic social process (Glaser, 1978) was identified as 'living with loss'. This statement appears to capture the essence of participants' reported caregiving and bereavement experiences. The five transitions and key attributes within the proposed model will now be described (see also Appendix 11 for additional quotes).

Transition 1: Becoming a caregiver

During the early stages of caregiving, participants reported an increasing awareness of changes in their spouse, especially in terms of behaviour change and memory deterioration, and a gradual increase in the nature of their caregiving role:

Figure 1. Model of caregiving and bereavement transitions



Mrs A: “to start off with...you’re only here to sort of lighten things that are going wrong...but it goes worse as time goes on”

Mrs B: “we didn’t know he was ill to begin with...so he was very difficult to deal with”

Mrs C: “he’d get up early hours of the morning and say he was just going to take the dog for a walk..and then I’d have to persuade him that it was not the right time to go”

Mrs D: “I’d suddenly realise, ‘I’ll have to remind him to get shaved’...erm..or, gradually I realised I couldn’t rely on him to get clean underpants...or anything...I had to put them out for him.....so it was all very gradual”

Participants expressed different attitudes, from willing acceptance to ambivalence, about their role as caregiver:

Mrs D “I couldn’t have done anything else, I loved him so much”

Mr E: “I told my son, I’ve got the best job in the world”

Mrs B: “I felt I had no choice, the man said ‘for better or for worse’ so I had to get on with it”

Mrs C: (re: secret her husband revealed after onset of dementia about having syphilis before their marriage) “I was angry with him for ages”

Participants’ decisions to approach their GP to seek a diagnosis were influenced by deterioration in spouses’ functioning and a growing concern that this might be attributable to dementia. Caregivers reacted differently to their spouse being diagnosed with AD:

Mr E: “I felt, I think, once I knew (AD diagnosis)...alright, you’ve got something to do....you know what to do, get on with it”

Mrs D: “I honestly can tell you the diagnosis of AD was a big, worse shock than him dying of a heart attack”

Mrs B: “the doctor just said..erm... ‘afraid your husband’s got AD, there’s nothing I can...you can do about it, you’ll just have to go home and get on with it’...and that was all the help I got”

Mrs B: “it wasn’t so bad, once I had a diagnosis... because at least I knew it was an illness then... up ‘til then I thought it was our marriage or..it was me...”

Transition 2: Intense caregiving/losses and grief

All participants observed a gradual deterioration in their spouse’s memory, behaviour, and physical health, and a concomitant increase in their caregiving role. Many participants reported becoming physically and emotionally exhausted, and described caregiving as an intense ‘24-hour’ experience accompanied by feelings of grief and loneliness as they witnessed the demise of their beloved:

Mrs A: “I was just absolutely worn out, it was all night and all day....”

Mrs C: “it’s a 24-hour job, basically....you don’t think about anything else..... it was very tiring because you don’t get much sleep”

Mrs D: “the only thing I can liken it to is looking after a toddler at home...it’s very draining thinking for two people”

Mrs B: “he got me round the throat one night when I was putting him to bed... and he used to smash things....one day when I was doing the garden, he threw an axe at me, which... stopped a couple of inches from my foot”

Mrs D: “I used to wait until he went to bed and then I’d cry my heart out... I was grieving ‘cos he didn’t have a future.....it was as though he was dead in a way”

Mr E: “to me it was terrifically difficult...how do you go to bed with a woman you’ve loved for 50 years and you can’t touch her?”

Several participants reported distress about living with a spouse who, ultimately, was 'there but not there', in that they were unable to speak or recognise the caregiver:

Mrs C: "in a way it's watching someone you've known for 40 years suddenly disappear on you... the same, the outline's there..but the person's gone, or going rapidly"

Mrs C: "he got to the stage where he didn't speak,... didn't know who I was"

Mr E: "for the last 4 years, she never spoke... and she was totally immobile... but she was a very gentle soul"

Mr E: "it was so difficult sitting there night after night with someone with no conversation... it was as though she was there but not there, if you know what I mean"

Many participants reported how much sources of social support assisted the caregiving process:

Mrs A: "I've got marvellous family and friends... I don't know how I could have coped without them..really..."

Mrs C: "I always knew they (friends) were there if I needed them... sometimes I used to slip out for an hour after he'd gone to bed..you know, for respite"

Mrs D: "My family and friends meant everything to me... it was such a relief to have their support...but my sister stopped visiting the house because she felt uncomfortable with his behaviour... she couldn't cope around him"

However, some caregivers' ability to utilise social support appears to have been compromised by factors such as the attitude of people towards their spouses' condition and the demands of caregiving:

Mrs A: "emotionally, I was a wreck... we'd got really good friends and families, they've supported us... but at the end of the day, you're coping with it on your own... often you don't have time to see people or they're busy"

Mrs B: “I do have good family and friends, but... I mean all your friends dropped off, they couldn't cope with his behaviour... you were just at home with this stranger, really.....”

All participants sought professional support during this period, in the form of help with the spouse at home or respite care. Three participants (Mrs A, Mrs B, Mrs C) spouses eventually entered full-time nursing care:

Mrs C: “the specialist said to me, ‘you do know, you're looking for long-term, full-time care now, don't you?’ ... I said ‘I can't tell you how glad I am you said that’ ... because to make that decision yourself...because you can't cope any longer....it's really hard to do...”

Mrs B: “well it was just his behaviour was so impossible and...and he was so violent to me...I just couldn't cope with him anymore....I'd seen the GP, and his psychiatrist and ..erm.. I think he realised I was at the end of my tether with him...”

Mrs A and Mrs B reported some difficult experiences with healthcare professionals at this time:

Mrs A: “you see he went in, erm, into one of the respite homes... sometimes he had his bowels move 5 and 10 times before breakfast ..and of course they don't want people with diarrhoea like that, they've got to keep changing all the time, so when the time come they said you know, ‘we don't want him back, very sorry but er, we can't stimulate him and if.. we're not looking for people we can't stimulate, so he can't go any longer’ ..I couldn't believe it.....so we had to go for (full-time) nursing care”

Mrs B: “he had to be sectioned to go to hospital which was a horrible experience, I wouldn't wish that on anybody..he ran round the house with the two... ambulance men after him... the GP wouldn't come out....and in the end, erm... one of the other doctors came..and he came out and they got (husband) downstairs outside and he stood with

this big syringe..in full view of everybody..and injected (husband) and then he drove off...he didn't come in and see me or talk to the men, so the ambulance men didn't know what he (GP) had given him..and he'd thrown down the vial...it's the only way they knew what he'd actually given him to quieten him down...I mean, I thought it was horrendous the way they treated him..I mean, the animals in the zoo aren't treated like that, they're given a dart, aren't they?"

Transition 3: Spouse in nursing care

Several participants reported negative emotions regarding the decision to place their spouse in nursing care and an awareness of grieving for the spouse's absence from the marital home:

Mrs A: "If the respite had still been available, he could have been at home with me... I had no choice but to put him into the nursing home"

Mrs B: "it was a terrible decision to take but had to be done.... you felt you'd failed somehow.....but I couldn't go on any longer"

Mrs C: "it's a very difficult thing to do because you feel you're betraying them, letting them down, or being selfish, or something..... it's like a big hole or space at first... I really missed him not being at home, it felt awful"

Caregivers reported both positive and negative experiences of nursing home care:

Mrs C: "I was lucky because I got him in a place where the woman who was in charge..looked after them like a family, so I didn't have to worry"

Mrs B: "I went every second day... it was quite nice to visit there..it was funny, it was like your home, you couldn't wait to get there, which seems silly really"

Mrs A: "I don't think I'll ever get over it... them not treating him right in the (nursing) home...they didn't look after him properly... he didn't deserve that... it still upsets me"

Transition 4: Death - The final loss

All participants recalled short-lived feelings of relief after their spouse's death, before the onset of grief and yearning for the spouse, accompanied in some cases by emotions such as shock, numbness and guilt:

Mrs A: "at first you feel relieved but it doesn't last... probably a week or two, that's all... and all you're really doing then is missing him"

Mrs B: "it was such a sense of relief that his worry was over... that... his pain was finished"

Mrs D: "I had a kind of relief for 48 hours... then I didn't know what to do with myself... it's as if everything ended... I felt very guilty, I felt I had no right to be alive"

Mr E: "I think the big problem is that when she died... I was by myself... people had been coming 4 times a day... suddenly a terrific structure was taken away"

Several caregivers described the dual difficulties of grieving for the loss of their spouse and a loss of identity:

Mrs D: "I didn't know what to do with myself... I kept saying to myself 'what am I going to do for the rest of my life?' ... I didn't want to be a widow... I would have been quite happy to have died with him at that stage"

Mr E: "I felt empty... I'd lost my job, and how do you feel when you're made redundant?"

Transition 5: Carry on grieving

The final transition of participants' bereavement adjustment appears to be characterised by ongoing grief and an increasing perception of coping despite the death, during a process of re-building their lives in personal and social terms. Most participants recalled that the intensity of their grief began to diminish during the first year after the death of their spouse. During this time, often with persistent

encouragement from family and friends, they began to re-engage in home and social activities:

Mrs C: "it took a couple of months at least before I started to do things all the time...my friend pushed me... saying 'you've got to go (e.g. bowling)...you're *going* to do it'...."

Mrs A: "I couldn't make a meal, it took me all my time to brew a cup of tea some days....it's changed since the anniversary of (spouse's) death.... I talk to a lot more people and I keep trying to do useful things"

Mrs D: "I started getting back in very slowly, about 6 weeks after (spouse) died....after 18 months... (the grief) is just as deep but not as often... I'm coping fine most of the time...but 10% of the time I'm not coping at all"

Mrs B: "I suppose your life takes over and you get back to doing things...you don't think about things so much....but I still feel it sometimes....what it was like when he was there"

Several participants were aware of initially grieving for their spouse with AD and then, at a later stage, beginning to grieve for the spouse they remembered, or wanted to remember, before AD:

Mrs D: "I've dreamt a couple of times of (husband) as we were....before he had the Alzheimer's...I think something's just come into me consciousness now...it's as though I hadn't allowed myself to think about how he was before he had the Alzheimer's"

Mrs B: "well, I try to forget all the difficult times...it's such a long time ago when he was well...it's difficult to remember but I do try and remember the happy times we had"

Mr E, bereaved for only 7 months, appears to describe an earlier stage of adjustment where he is unable to grieve for his wife before her dementing illness began:

Mr E: "I've started to get photographs of her when she was normal but it's not registered...every time I think about her, I think about her in that chair"

This last statement by Mr E appears to be an example of 'unfinished business' following bereavement. Other examples of unfinished business appear to reflect some participants' difficulties in establishing a single identity following the death of their spouse:

Mrs A: "I would like to get to meet other people that I don't know...but I've got to get the ...courage to do it"

Mrs D: "I've got to start doing things on my own, going places on my own....I feel I've got to do something that's just me"

Mrs A and Mrs B also reported what appears to be unfinished business, in the form of ruminations about negative experiences with professional support during caregiving:

Mrs A: "I don't think I'll ever really get over it....like them not treating him right in the home and they weren't looking after him...."

Mrs B: "he's particularly hopeless our GP, I'm afraid...his whole attitude...telling me to go home and get on with it...then he wouldn't come out when they sectioned him...I still find that hard to believe..."

Finally, several study participants, bereaved for 18 months and longer, reported an expectation that their experience of grief would continue:

Mrs A: "I don't think I'll ever really get over the way they treated him...it still makes me upset....it's gonna take a long time to get over it"

Mrs B: “you’d think I’d be over it after 10 years, wouldn’t you?...but I’m afraid I’m not...I don’t see that the grief or bereavement ever goes away...I mean it becomes duller with time but...I mean the person’s gone and won’t come back.... but you never forget someone do you?”

Mrs D: “I think I will always be grieving for him, I don’t think I will ever stop grieving for him.....you’ve got to live with your grief, that’s the difficult thing”

Discussion

Participants in this study could be described as ‘caregiving experts’ with 8-12 years experience and, with the exception of Mr E, at least 18 months experience of spousal bereavement. These participants’ accounts enabled a rich picture to develop of their caregiving and bereavement experiences. However, a potential limitation of this study is the relatively small sample consisting exclusively of Alzheimer’s Society carers’ group members. It is acknowledged that participants who continue their affiliation with Alzheimer’s carers groups after the death of the spouse may possess characteristics that are not shared by other bereaved spousal dementia caregivers.

Although previous researchers have described caregiving and bereavement adjustment among family and spousal dementia caregivers, this study is distinctive because of its specific focus on bereaved spousal dementia caregivers. A theoretical model of caregiving and bereavement adjustment is proposed and participants were engaged in the analytic process to ensure that the model adequately encapsulated their personal experiences.

Participants’ accounts suggest that the transitions within the proposed model are not time-limited. For example, Mrs A and Mrs B, bereaved 26 months and 10 years respectively, reported an expectation that their grief would continue for the foreseeable

future. Several participants' accounts suggest that the final transition 'carry on grieving' may reflect the 'dual process of grieving' (Stroebe et al., 1994) which proposes that during the course of bereavement adjustment, people oscillate back and forth between grieving and the other demands of their lives.

The findings from this study provide support for previous research findings that describe family, including spousal, dementia caregiving as an agonizing, exhausting experience (Cohen & Eisdorfer, 1988; Gallagher et al., 1989; Lindgren, 1990, 1993), characterised by multiple losses (Bull, 1998; Mullan, 1992). All participants described a combination of caregiving exhaustion and intense sadness about slowly witnessing the loss of their spouse after, in some cases, 50 years of married life.

However, it was difficult to establish clearly whether participants' pre-death grief supported the predictions made by anticipatory grief models (Fulton & Fulton, 1971; Lindemann, 1944) or whether these experiences were "acute grief related to immediate and permanent loss of a relative's human abilities and personhood whilst living" (Jones & Martinson, 1992; p.175). Indeed, the recurrence of grief that results from losses experienced during caregiving may be better explained by the concept of chronic sorrow (Lindgren, 1996).

The findings from this study are consistent with previous research findings that social support and positive appraisals about caregiving experiences may be key factors linking caregiving and bereavement adjustment (Almberg et al., 2000). A key finding from this study is that the *negative* experiences of professional support during caregiving reported by Mrs A and Mrs B appears to continue to affect their psychological adjustment following bereavement, in the form of negative ruminations. Mrs A's negative experiences related, firstly, to being told that respite care was being withdrawn because care staff could no longer 'stimulate' her husband and, secondly, to

what she perceived as inadequate nursing home care during the final 4 months of her husband's life. Mrs B reported dissatisfaction with her GP regarding his attitude towards her husband's diagnosis of AD and the behaviour of a locum GP during the attempt to admit her husband into full-time nursing care.

To date, our understanding of the process of caregiving and bereavement adjustment among spousal dementia caregivers is limited. This understanding might be enhanced by future research involving spousal dementia caregivers recruited from memory clinics, or other clinical settings and by the use of prospective research designs. A prospective approach to investigating caregiving and bereavement experiences has the potential to increase our understanding of psychological adjustment among spousal dementia caregivers in two ways. Firstly, by helping to overcome problems associated with the validity of participants' accounts in retrospective research (Schultz et al., 1997) and, secondly, by enabling a more accurate assessment to be made of the impact of caregivers' pre-death losses, which are often hard to recognise (Liken & Collins, 1993). Increasing our understanding about the relationship between pre-death loss and grief and caregiving and bereavement adjustment also has the potential to assist the development of more appropriate healthcare services to meet the needs of spousal dementia caregivers.

Conclusions

A key finding from this study is that two participants reported having continuing difficulty in coming to terms, or adjusting to, what they perceived as negative experiences of professional support during their caregiving career. The accounts of these participants (Mrs A, Mrs B) appear to highlight the need for sensitive and responsive interactions (Bull, 1998) with caregivers, and supports previous

research recommendations about the need to plan and facilitate appropriate professional help for caregivers experiencing difficulty (Bull, 1998; Jones & Martinson, 1992; Jones & Miesen, 1992; Liken & Collins, 1993; Parkes, 1993). In the words of Almborg et al. (2000) "it is of utmost importance that policy-makers recognize and support those families who are able to make significant contributions to their relative's care" (p.88). Finally, this study concurs with Mullan's (1992) proposal that the development and provision of services that facilitate reflection on losses being experienced by dementia caregivers, may lessen the experience of distress after the death of the person with dementia.

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Part D

Critical Review

Critical Review of the Large Scale Research Project

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Critical Review of the Large Scale Research Project

Background to the study

After several months of indecision and consultations with my research supervisors, I decided to investigate the caregiving and bereavement experiences of bereaved spousal dementia caregivers for two main reasons. Firstly, an initial literature search revealed this to be a relatively under-researched area and, secondly, I have a long-standing interest in dementia together with some experience of work with, and personal knowledge of, bereaved caregivers of a spouse with dementia.

Why a qualitative rather than a quantitative approach?

In the past decade, qualitative research methods have become more commonplace in areas such as health services research (Mays & Pope, 2000). In this study qualitative research methodology, which usually begins with the intention to explore a particular area, collect data and generate ideas and hypotheses through inductive reasoning (Greenhalgh & Taylor, 1997), was considered to be appropriate to derive a coherent theoretical understanding of caregiving and bereavement adjustment among spousal dementia caregivers. By comparison, quantitative methodology, which usually begins with an idea or hypothesis that is systematically tested by measurement and the generation of data, was considered less appropriate.

Why grounded theory rather than another qualitative approach?

Although there are a variety of qualitative methods (Richardson, 1996), grounded theory was considered to be an appropriate methodology to investigate caregiving and bereavement adjustment among spousal dementia caregivers

because it uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon (Strauss & Corbin, 1990).

Another influence on the selection of the grounded theory approach was that caregiving and bereavement adjustment among spousal dementia caregivers is a relatively under-researched area. Elliott et al. (1999) recommend that where relatively little research has been undertaken, a discovery oriented qualitative approach such as grounded theory lends itself to understanding participants' perspectives and the process of defining phenomena in terms of experienced meanings and observed variations.

Summary of the research paper (Part C) findings

Following data analysis, a basic social process 'living with loss' was identified to summarise participants' experiences of caregiving and bereavement. A number of attributes of participants' experiences were incorporated into a model of five caregiving and bereavement adjustment transitions.

The study findings support previous research describing spousal dementia caregiving as an agonizing, exhausting experience, characterised by multiple losses and pre-death grief (Bull; 1998; Cohen & Eisdorfer, 1988; Gallagher et al., 1989; Jones & Martinson, 1992; Lindgren, 1990, 1993; Mullan, 1992). Although all participants reported grief experiences about their caregiving losses, it was nevertheless difficult to establish whether this grief was consistent with the concept of anticipatory grief (Fulton & Fulton, 1971; Lindemann, 1944) or whether, as Jones and Martinson (1992) suggested in their study, this was "acute grief related to immediate and permanent loss of a relative's human abilities and personhood whilst living" (p.175).

The proposed model supports Bass et al.'s (1991) assertion that caregiving and

bereavement should be considered as a single, chronic process rather than two separate events. The study findings appear to be consistent with Almborg et al.'s (2000) finding that the availability of support, positive memories, and great burden, are factors which link pre- and post-death experiences. In this study, the perceived negative experiences of professional support during caregiving reported by Mrs A and Mrs B appears to have influenced their psychological adjustment during both caregiving and bereavement.

This study concurs with previous recommendations by researchers (e.g. Almborg et al., 2000; Bull, 1998; Jones & Miesen, 1992; Parkes, 1993) about the importance of developing services to meet the professional healthcare needs of, and support the caregiving contributions made by, caregivers of a spouse or family member with dementia.

Critical review of the 'quality' of this study

Attempts have been made to establish criteria to evaluate good practice in qualitative research (e.g. Elliott et al., 1999; Lincoln & Guba, 1985; Stiles, 1993). This part of the review seeks to evaluate the quality of this study according to a number of these criteria.

Stiles (1993) proposed that reliability and validity are important criteria when seeking to establish high-quality qualitative research, in that "reliability refers to the trustworthiness of observations or data, and validity refers to the trustworthiness of interpretations of conclusions" (p.607). Spence (1982) asserts that a good story has the power of truth and, as part of the process of developing a grounded theory, the research paper sought to tell a trustworthy story about participants' caregiving and bereavement adjustment experiences.

Owning one's perspective

Henwood and Pidgeon (1992) assert that the grounded theory approach is made more complete by acknowledging the multiple dimensions of subjectivity that ground knowledge claims in science. Charmaz (1990) challenged an implication of the original grounded theory (Glaser & Strauss, 1967) that theoretical concepts and categories simply 'emerge' from the data, with the researcher as a passive observer. Charmaz proposed a social constructionist revision of grounded theory with the researcher as an active, not neutral, observer in a process where new ideas arise from an interaction between the researcher and the data. According to Charmaz, the researcher brings a particular perspective to the data, subsequently referred to as 'forestructure' (Stiles, 1993), that influences the types of questions that are asked, and therefore, the shape of the whole analysis.

I brought to this study an expectation that participants would report some quite traumatic caregiving and bereavement experiences. This expectation was influenced, firstly, by a close friend's mother who had Alzheimer's disease before her death and, secondly, from experience of working with people with dementia and their caregivers as an assistant psychologist and a trainee clinical psychologist. I have vivid memories of conversations with my friend, during which she described the distress felt by herself and her father about her mother's condition. I also remember seeing my friend's mother at a social gathering and feeling shocked and uneasy in the presence of this once charming and intelligent lady who had become very confused and disorientated, and seemed like a stranger.

In accordance with the grounded theory approach (Strauss & Corbin, 1990) a reflexive journal was kept throughout the study. One entry (dated 7.12.2001)

describes how the process of interview transcription and open coding enabled me to get 'close' to the data but, at the same time, aroused intense emotions, including empathy and sadness, about participants' experiences. Another entry (20.2.2002) recorded my surprise that, contrary to what I had read about spousal bereavement adjustment prior to this study, several caregivers reported an expectation that their grief reactions would continue indefinitely.

This study used in-depth interviews, lasting around ninety minutes, based on a semi-structured interview format. The influence of this researcher's knowledge and experience of dementia caregiving and bereavement in developing interview questions is acknowledged and the initial and revised interview guides are included as appendices (Appendix 7, Appendix 8). The transcribed interviews of the five participants in this study appeared to yield a conceptually rich body of data, from which the proposed model of caregiving and bereavement adjustment emerged. However, it is difficult to ascertain the extent to which characteristics relating to this researcher, such as the wording and delivery of questions to participants, verbal and non-verbal responses to participants' contributions, my age (I was 21 years younger than the youngest participant) and position (i.e. trainee clinical psychologist), may have influenced participants during the interview.

In order to establish rapport, I informed participants that I was interested in hearing about their personal experiences and disclosed the limits of my knowledge about spousal dementia caregiving and bereavement. On several occasions during interviews when participants became emotional, I also felt emotional. However, whilst I attempted to display sensitivity towards participants at all times, I also tried to keep in mind the potential influence on the interview process of displaying too much

empathy or responding too quickly to fill 'silences', thereby not allowing participants time to compose themselves and finish what they had started to say.

Providing credibility checks

A good qualitative study will address a clinical problem through a clearly formulated question, using more than one research method, and the analysis of qualitative data can and should be done using explicit, systematic, and reproducible methods (Greenhalgh & Taylor, 1997).

The validity of qualitative research can be enhanced by developing an audit trail (Lincoln & Guba, 1985). This enables other researchers to check how study conclusions are reached (Henwood & Pidgeon, 1995). This study attempted to outline the steps involved from initial recruitment of participants to generation of a grounded theory, so that as Glaser and Strauss (1967) suggest, "the synthesis provides readily apparent connections between data and lower and higher level conceptual abstractions of categories and properties" (p.37). To facilitate this, supplementary information was included in the appendix section of this large scale research project. However, the word limit precluded the inclusion of a full interview transcription.

As another credibility check, in accordance with the grounded theory approach (Strauss & Corbin, 1990), Mr E was recruited on the basis of his potential for 'negative case analysis'. Mr E's inclusion enabled a comparison to be made between his experiences during 7 months of bereavement and other participants who had been bereaved a minimum of 18 months. This yielded an important finding regarding the stages involved in participants' bereavement adjustment transitions. For, whilst Mrs B, Mrs C and Mrs D identified a process of grieving first for the spouse with Alzheimer's disease and then grieving for the

spouse as they were before Alzheimer's, Mr E reported that, as yet, he had been unable to grieve for the wife he knew before the onset of her dementing illness.

Grounding in examples

The results section of the research paper (Part C) contains examples of quotes from participants' accounts to illustrate the attributes of each transition in the proposed model. However, to assist readers to develop a fuller picture of participants' accounts, a set of additional quotes was compiled (Appendix 11).

Coherence

Coherence refers to the apparent quality of the interpretation, in Stiles' (1993) words "does it hang together?" Internal coherence was achieved through the process of constant comparison, which enables the researcher to check for ambiguities and unexplained contradictions in interpretations. Coherence was also sought by attending regular meetings with two research supervisors to discuss the data analysis and the emerging theory. Both supervisors have strong clinical and research interests in the area of dementia, including caregiving, and one is an expert in the field of grounded theory methodology and carer adjustment to Alzheimer's disease. For this researcher, supervision sessions provided an opportunity to have time away from fieldwork for reflection, planning and consultation with colleagues. This, according to Britten et al. (1995), helps to maintain the flexibility of the iterative approach and avoids the danger of researchers sliding into sloppiness if they cease to be clear about what they are investigating.

Coherence was also achieved by conducting follow-up interviews with participants to seek respondent validation. Participants' responses suggest that the proposed model has ecological validity and achieved a key aim of establishing

“coherence and integration whilst preserving nuances in the data” (Elliott et al., 1999; p.222). In addition, respondent validation was obtained from each of the participants in the study in the form of verification of a verbal narrative summary of their initial interview transcription.

Other considerations and process issues

One of the key difficulties in conducting grounded theory research in the final year of clinical training is the limited time available. I often wondered whether I would have sufficient time to do justice to the grounded theory approach. For example, I had far greater difficulty than I imagined in recruiting participants, and so became concerned that this smaller than expected sample might not achieve saturation of attributes.

Participant interviews in this study were guided by a semi-structured interview format using open questions in an attempt to gain an understanding of the complexity of participants' experiences. However, this may have added to the complexity of the data analysis because open questions tend to generate large amounts of data that are time-consuming to analyse (Miles & Huberman, 1984). Furthermore, Barker et al. (1994) point out a number of disadvantages of asking open questions, including the difficulty of assessing the reliability and validity of the data, and the influence of interviewer bias and informant deception, exaggeration and fabrication.

During the final stages of data analysis and 'grounding' of the emerging theory, the richness of the data sometimes felt overwhelming. On the long journey from initial data analysis to the generation of theory, I tried to keep in mind a quote by Glaser (1999) that “those who can tolerate confusion and regression love the openness of grounded theory and the chance to really generate concepts that make sense of what is going on” (Glaser, 1999; p.838). For me, coping entailed 'hanging in there'

and trying to tolerate the chaos and confusion caused by masses of data. Surprisingly, the pleasure I experienced from developing a model (after about twenty attempts) that appeared to be grounded in, and be an accurate reflection of, participants accounts, did feel worth the pain I had endured during the research process.

The limits of transferability (Lincoln & Guba, 1985) of the study findings beyond this sample of Alzheimer's Society carers' group members is acknowledged. However, it must be borne in mind that qualitative research is not concerned with an 'on average' view of a population (Greenhalgh & Taylor, 1997) but, rather, an in depth understanding of the experience of particular individuals or groups. Moreover, Henwood and Pidgeon (1992) make the point that "rich and dense grounded theory, which is conceptually sensitive at diverse levels of abstraction, will itself suggest its own sphere of relevance and application" (p.108).

Specific methodological limitations of the study

This study did not fully achieve the aim outlined in the research ethics committee proposal (Part A of this large scale research project) to recruit up to a maximum of one dozen participants who had been bereaved between 18-24 months. After contacting several North West region Alzheimer's Society branches, I discovered that relatively few bereaved spouses maintain contact with carers groups for 18-24 months or longer.

One of the difficulties in retrospective research studies is the potential for bias, due to inaccurate recall from memory (Schulz et al., 1997). Whilst there is no obvious reason to question the validity of participants' accounts in this study, the potential for bias in recalling events from, in some cases, 10 or more years ago must nevertheless be recognized. Interestingly, this researcher's reflexive journal contains an entry (dated 12.01.2002) that comments upon participants' apparent difficulties in

establishing a time perspective, i.e. the sequence and timing of participants' caregiving and bereavement experiences. Future research using a prospective approach might help to overcome problems associated with the validity of participants' retrospective accounts (Schultz et al., 1997).

The research paper (Part C) contains a table summarising the characteristics of this non-clinical sample recruited from Alzheimer's Society carer groups. This sample neglects a large population of bereaved spousal caregivers who are not affiliated to such groups, and who may or may not be involved with clinical healthcare services. However, as stated previously, this study concurs with previous study recommendations about the importance of developing more adequate healthcare services to meet the needs of this population. This process may well be assisted by evidence from further research investigating the experiences of bereaved spousal dementia caregivers who *are* involved with clinical services.

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Part E

Word Count

Wordcount

| | | |
|----------------------------------|--------------|---------------|
| Abstract | 295 | |
| Part A - Ethics Proposal | 3,119 | |
| Part B - Literature Review | 4,851 | |
| Part C - Research Paper | 4,998 | |
| Part D - Critical Review | 2,869 | |
| | Total | 16,132 |

References and Appendices

| | | |
|------------------------------------|--------------|---------------|
| Ethics Proposal References | 885 | |
| Literature Review References | 2,208 | |
| Research Paper References | 1,002 | |
| Critical Review References | 686 | |
| Appendix Section | 14,428 | |
| | Total | 19,209 |

APPENDIX SECTION

Appendix 1

Letter of Ethical Approval from School of Psychology Research

Ethics Committee

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Appendix 2
Participant Information Sheets

Information Sheets

A Study About the Caregiving and Bereavement Experiences of Wives and Husbands of People with Dementia

About the study and what it involves

You are being invited to take part in a research study involving people whose husband or wife had a dementia (such as Alzheimer's Disease) before their death. The study is looking to interview people who have been bereaved for up to 2 years or longer.

Before you decide whether or not to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read these 'Information Sheets' and the enclosed 'Research Consent Form' carefully. You can discuss this information with friends, relatives and your GP if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

If you decide to take part in this study, I will ask you to talk about your experiences of living with and caring for your partner with dementia, and also about your experience of being widowed. I will be interested to learn from you about how you coped during these experiences, what things you found difficult, and how you feel now.

Our interview will last approximately one hour and can take place in your own home. You are welcome to invite a member of your family, a friend or another Alzheimer's Society member to be present. Or, if you prefer, I could speak to you on your own.

Names and Positions of Investigators in this study:

- (1) Paul Waring, Psychologist in Clinical Training, North Wales Clinical Psychology Course, Bangor
- (2) Professor Robert T. Woods, Dementia Services Development Centre, University of Wales Bangor
- (3) Dr. John Keady, School of Nursing, University of Wales, Bangor

What happens if I decide to take part?

It is up to you to decide whether or not to take part. If you want to take part in the study please do the following:

1. Read through the 'Information Sheets'.
2. Read through the enclosed 'Research Consent Form'.
3. Contact me if you have any further questions or require further information.
4. Complete and sign the 'Research Consent Form'.
5. Send the completed 'Research Consent Form' to the contact address shown below:

Contact address:

Paul Waring
North Wales Clinical Psychology Course
School of Psychology
University of Wales Bangor
43 College Road, Bangor
Gwynedd LL57 2DG

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On the day of our interview, I will ask you to sign an 'Audio Tape Recording Consent Form' giving your permission to a tape-recording being made of the interview. This tape-recording will remain strictly confidential.

What if I don't want to take part or if I change my mind?

If you decide not to take part in the study, there is no problem. If you decide to take part but then change your mind, you are free to withdraw from the study at any time. This includes during the interview or afterwards. If you do decide to withdraw, you don't have to give a reason.

What will happen after the interview?

After the interview has finished, there will be time available for you to talk about how you felt during the interview, and to answer any questions that you may have. I am aware of the sensitive nature of this research and I am particularly concerned to keep any distress that you may feel to a minimum.

The information that you provide during the interview will be analysed along with information given by other people who take part in the study. I may contact you again to ask for a second interview, and this would be to follow-up any particular points of interest.

I will contact you at a later date to let you know about the findings from this research study. Ideally, this should take place face-to-face but, if you prefer, it can be done either by letter or over the telephone.

Confidentiality

The information from our interview will remain confidential. That means that information about you will not be disclosed to other people. Audio-tapes of interviews will be kept securely and destroyed when the research has been completed. The content of the interview will only be discussed and/or written about after the names have been changed. This will make sure that you cannot be identified.

Complaints

If you have any complaints concerning the conduct of this research, these should be addressed to:-

Professor C.F. Lowe, Head of School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG.

***THANK YOU VERY MUCH FOR TAKING THE TIME TO READ THIS
INFORMATION SHEET AND FOR CONSIDERING TAKING PART IN
THIS RESEARCH STUDY***

Please keep these information sheets for your records

Appendix 3

Research Consent Form

Research Consent Form

Consent to take part in a research study entitled:

The Caregiving and Bereavement Experiences of Wives and Husbands of People with Dementia

- Have you read the information sheet about this study? Yes No
- Have you had the opportunity to ask and discuss any questions you have about this study? Yes No
- Have you received satisfactory answers to your questions? Yes No
- Have you received enough information about the study? Yes No
- Do you understand that you are free to withdraw from the study:
 - ❖ At any time Yes No
 - ❖ Without having to give a reason

I agree to participate in this study.

I have been given a copy of this form together with an information sheet about the study.

Signed: _____ Date: _____

(Name – in block letters) _____

Appendix 4
Audiotape Research Consent Form

Audio Tape Recording Consent Form

Have the reasons for making an audio tape recording of this interview been adequately explained to you? Yes No

Have you had the opportunity to ask and discuss any questions you have about tape recording this interview? Yes No

Have you received satisfactory answers to your questions? Yes No

Have the procedures to ensure confidentiality and security been adequately explained to you? Yes No

Do you understand that you are free to stop the tape recording at any time during the interview? Yes No

Do you understand that, if at the end of the interview, you wish the tape to be erased immediately, you are free to request this. Yes No

I agree to a tape recording being made of this interview.
Signed: _____ Date: _____

(Name – in block letters) _____

I, Paul Waring, Trainee Clinical Psychologist, undertake to maintain proper care of this tape recording. The contents of the tape will be erased as soon as reasonably possible after the interview.

Signed: _____ Date: _____

Appendix 5

Notes for Contributors:

Aging & Mental Health

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Appendix 6

Notes for Contributors:

Dementia: The International Journal of Social Research and Practice

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Appendix 7

Initial Semi-Structured Interview

Semi-Structured Interview Guide

PART A – CAREGIVING

What are your memories of being a caregiver?

How was caregiving for you?

Prompts

- what did your role as a caregiver entail?
- what was the course of caregiving (was it the same or did it change over time?)
- what particular challenges/difficulties did you face?
- what exactly changed? e.g. did you have to stop work

Looking back, how did the caregiving role affect you?

Prompts

- emotions/mental health (e.g. sadness, grief, guilt, anger, frustration, depression)
- thoughts - description of thoughts (-ve/+ve)
- identity – view of self as result of caregiver role
- physical health – impact – did you become ill or remain in relatively good health?
- family/social effects?

What did YOU do to try to adjust/come to terms with/or cope with the caregiving role?

Prompts

- emotionally? – cry? be stoical?
- behaviourally? – activities, plans, goals
- personal strengths that helped you

What support was available to help you to adjust/come to terms with caregiving?

Prompts

- social support → family? friends?
- professional support/help → GP's, counsellors, etc – did you seek help?
- other → self-help groups? church?

What positive memories, if any, do you have of caregiving?

Prompts

- any awareness of positive impact of caregiving on subsequent coping/adjustment?

PART B – BEREAVEMENT FOLLOWING CAREGIVING

I am interested to know what being bereaved meant to you at the time?

---i.e. what did the loss mean to you?

In what ways do you think bereavement affected you?

Prompts

- emotional/mental health
- physical health
- socially/interpersonally

What did it mean to you when your role as a caregiver role came to an end?

Prompts

---were you relieved? sad? both relieved and sad?

In what way(s) might caregiving have helped you to cope with bereavement? In other words, were there any positive effects of caregiving?

Prompts

---+ve impact on subsequent coping after spouse's death?

---being there at the death

---being able to say saying goodbye

What did YOU do to try to adjust/come to terms with (xxxx's) death?

Prompts

-emotionally? – cry? be stoical?

-behaviourally? – activities, etc

-personal strengths that helped you

What support was available to help you to adjust/come to terms with the loss of (xxxx)?

Prompts

-social support → family? friends?

-professional help → GP's, counsellors, etc - did you seek help?

-other → self-help groups? church?

You have been bereaved now for (e.g. two years). How do you think you have adjusted to/come to terms with the loss of (xxxx); what stage are you at now?

Prompts

-OK - e.g. getting on with life?

-having difficulties in adjusting/coping? → what-guilt?/acceptance of loss?

-good and bad days?

How do you (and your family) remember xxxx now?

---person with dementia? →traumatic memories?

---person pre-dementia/ → the good times/marriage/kids?

Has this experience changed how you view your own death?

---do you feel your own life has now lost it's meaning?

Appendix 8

Revised Semi-Structured Interview

Revised Semi-Structured Interview Guide

Part A - Caregiving Experiences

What are your memories of being a caregiver?

How was caregiving for you?

- what did caregiving entail?
- what was the course of caregiving (was it the same or did it change over time?)
- what particular challenges/difficulties did you face?
- what exactly changed? e.g. did you have to stop work

Looking back, how did the caregiving role affect you?

- emotions/mental health (e.g. sadness, grief, guilt, anger, frustration, depression)
- thoughts - description of thoughts (-ve/+ve)
- identity – view of self as result of caregiver role
- physical health – impact – did you become ill or remain in relatively good health?
- family/social effects?

What did you do to try to adjust/come to terms with/or cope with the caregiving role?

- emotionally? – cry? be stoical?
- behaviourally? – activities, plans, goals
- personal strengths that helped you

What support was available to help you to adjust/come to terms with caregiving?

- social support → family? friends?
- professional support/help → GP's, counsellors, etc – did you seek help?
- other → self-help groups? church?

Part B- Caregiving-Bereavement Transition

When do you feel that you lost your spouse?

- At what stage in caregiving do you feel this happened?
- how did this affect you?
- how did you cope at this time?
- Did that in any way prepare you to cope with the subsequent bereavement?

How did you experience the final loss of xxxx?

- were you there when xxx died?
- were you able so say goodbye?
- meaning of saying goodbye vs. meaning of not saying goodbye
- how was it for you to be there when xxxx died?
- do you feel that being there helped you?

Anticipatory grief concept

- had the process of grieving begun during caregiving?
- if so – in what way did this grief affect you?
- were you ready to let go at the end
- was there a sense of relief?

—when did you feel you were ready and able to let go?

What did it mean to you when your role as a caregiver role came to an end?

—were you relieved? sad? both relieved and sad?

In what way(s) might caregiving have helped you to cope with bereavement?

Were there any positive effects of caregiving?

—+ve impact on subsequent coping after spouse's death?

—being there at the death

—being able to say saying goodbye

Part C - Bereavement Experiences

I am interested to know what being bereaved meant to you at the time?

—i.e. what did the loss mean to you?

How did your caregiving experiences affect how you coped after the death of xxx?

—did they make it harder to cope/easier to cope?

How has the bereavement affected you personally?

What personal difficulties did you have to cope with after you were bereaved?

—emotional/mental health problems (e.g. depression?)

—physical health problems (any illness/disease?)

—socially/interpersonally (become withdrawn/isolated?)

How did being bereaved make you feel? What kind of emotions/feelings/thoughts do you remember having?

—emotions (e.g. sadness, grief, guilt, anger, frustration)

—thoughts (-ve/+ve)

Do you feel that coping with bereavement might have been different if your spouse had died from natural causes? Or even from another type of illness.

-in what ways might it have been different?

How do you (and your family) remember xxx now?

—person with dementia? → traumatic memories?

—person pre-dementia/ → the good times/marriage/kids?

Has this experience changed how you view your own death?

—do you feel your own life has now lost it's meaning?

What did YOU do to try to adjust/come to terms with xxx's death?

—emotionally? – cry? be stoical?

—behaviourally? – activities, etc

—personal strengths that helped you

What support was available to help you to adjust/come to terms after xxxx's death?

- social support → family? friends?
- professional → GP's, counsellors; did you seek help?
- other → self-help groups? church?

You have been bereaved now for (e.g. two years). How do you think you have adjusted to/come to terms with the loss of xxxx

- where are you now? At what stage are you now?
- OK - e.g. getting on with life?
- having difficulties in coping? guilt?/acceptance of loss?
- good and bad days?
- what is it like on birthdays/anniversaries, etc?

How do you (and your family) remember xxxx now?

- person with dementia? → traumatic memories?
- person pre-dementia/ → the good times/marriage/kids?

Has this experience changed how you view your own death?

- do you feel your own life has now lost it's meaning?

Appendix 9

Summary of Open Coding of Categories/Attributes/Concepts

Summary Of Open Coding Of Categories/Attributes/Concepts

Course of Spouse's Condition/Spouse Behaviour

Pre-Onset Life Stressors
 Pre-diagnosis
 Post-diagnosis
 Physical
 Behavioural
 Unusual behaviours
 Cognitive
 Emotional
 Change in spouse's personality
 Medication

Course of Caregiving

Confusion re: time span/events
 Pre-Onset Caregiver Health Status
 Home
 Reaction to diagnosis
 In care facilities

Factors involved in the transitional process

Wondering about initial change in spouse behaviour
 Spouse at home
 Transition/coping after spouse goes into nursing care
 The loss of spouse
 Coping with caregiving and bereavement
 Caregiving as preparation for bereavement

Impact/Consequences of Caregiving

Neglect of self
 Emotional impact
 Health impact
 Mental health impact
 Physical
 Positives from caregiving
 Regrets
 Loss
 Difficult vs easy
 Personal failure
 Coping 'on your own'
 On identity

Caregiving Role

Attitude to caregiving
 Initial:
 Helping spouse re: medication
 Caregiver having to give up job

Everyday life
 Spouse physical problems
 Spouse personal care
 Spouse behavioural problems
 Spouse emotional problems
 Cognitive problems
 Coping with deterioration in spouse
 Visiting spouse in care facilities
 Prior to death
 Positives

Caregiver stress

Spouse behaviours
 Social embarrassment/spouse behaviour in social situations
 People not being understanding
 Family stress
 Witnessing change in spouse
 Feeling spouse's pain/distress
 Lack of sleep
 Loss of spouse in everyday terms
 Isolation
 Threats to personal safety
 Concurrent life stressors
 Caregiving strain
 Spouse going into full-time care
 Positive factors during caregiving

Coping style/Caregiver coping strategies

Problem solving
 Distraction
 (Positive) reframing of caregiver role
 Emotional expression
 Utilising time while spouse alive
 Seeking/Utilising social support
 Seeking/Utilising GP help/advice
 Seeking GP help/advice when coping became too difficult
 Seeking/Utilising day care/respite care
 Seeking help re: spouse going into full-time nursing care
 Rationalising: re: decision to put spouse in care
 Day-by-day coping
 Keeping things as normal as possible
 Compassion for spouse and their plight
 Passive coping

Social Support

Negative effects

Positive effects

Professional support

Positive support

Negative support

Psychological adjustment tasks/difficulties

Initial

Coping with change

Coping with lack of control

Ruminations

Coping with the death

CAREGIVING TO BEREAVEMENT

Meaning of the death of the spouse

The Meaning of the end of caregiving

Caregiving as preparation for bereavement

Being present at death of spouse (saying goodbye)

Awareness of grief before death

Bereavement reflections (possibly some ruminations) about caregiving

Inadequate professional services

Bereavement reflections about caregiving ability

Memories of the spouse now

Initial Impact of Bereavement on the individual

Emotional impact

Remembering the spouse

Bereavement adjustment – concurrent stressors

Bereavement adjustment – coping strategies

Active

Passive

Bereavement adjustment – coping style

Attitude

Perception of self as copier

Coping alone

Isolating oneself

Bereavement adjustment – positives

Course of Bereavement adjustment

Initial

Life beginning to return to normal stage

Re-integration into social support network

Stage after 18-24 months

Stage after 10 years

Stage of bereavement adjustment NOW
Tasks still to be done – unfinished business?

Bereavement - social support

Isolating oneself- not utilizing available friend/family support
Family/Friends, etc

Bereavement – professional support

Seeking professional support or not

Bereavement psychological adjustment tasks/difficulties

Tasks

Adjusting to the change in daily life/loss of role
Adjusting to loss of person

Difficulties - Inadequate professional services

Appendix 10

Story Line

STORY LINE

The main story seems to be about how caregivers of a spouse with dementia adjust to, or live with, a series of transitions during their experiences as, firstly, a caregiver and, secondly, a bereaved spouse. During caregiving, participants in this study typically faced a series of gradual losses over time, during a period when caregiving became an increasingly demanding, often 24-hour, job. Caregivers often felt helpless as they witnessed the demise of their loved one, and with it, their own hopes and expectations of the future. Although many caregivers sought and received help from healthcare professionals and social support (e.g. friends and family) to cope with looking after their spouse, they reported that, over the course of several years, they became physically and emotionally drained/exhausted. An additional source of stress was that caregivers had an uncertain future, in that they didn't know how or when their ordeal would end. Eventually, participants sought further help or admission into full-time nursing care when the loss of, or deterioration in their spouse, reached a critical point where, for example, the spouse was 'there but not there', and was unable to speak, completely dependent (i.e. requiring round-the-clock care), extremely confused and disorientated, and was unable to recognise the spouse. However, nursing care decisions almost always led to initial feelings of guilt on the part of caregivers, and a concern that they had abandoned their spouse and their matrimonial duty.

Death for many brought a combined relief and grief; an initial relief that their ordeal was over, followed by a yearning and longing for the spouse. Participants also reported a sense of initial shock and confusion, and an awareness of further loss, particularly the loss of caregiving role, which had become central to their self-perception, or identity. Some felt guilty about still being alive. Feelings of intense sadness and crying were commonly experienced. After this transition, participants appeared to describe a subsequent stage characterised by learning to live with the loss of their spouse. During this time of building a new life and identity, grieving continued but appeared to become less intense over time, and perceptions of coping increased. As part of living with or, perhaps, despite the loss, participants began to re-establish a single identity in personal and social terms as they gradually grieved and 'let go' of their spouse. However, many participants were aware that their grief was ongoing, and would continue to be for the foreseeable future. Some participants felt they had yet to grieve for the spouse before they had dementia, for this represented the way they wanted to remember the spouse. Interestingly, no participant reported an expectation that they would fully recover, although many reported that they had learned to live and cope better with the death as time progressed. Some participants were aware of tasks still to complete, such as letting go of anger towards healthcare professionals and establishing a single, uncoupled identity.

The basic social process that emerges is about living despite the loss of the spouse and the final transition of several participants seems to be about continuing to grieve, yet trying bit by bit, piece by piece, to re-establish or reconstruct their lives.

Appendix 11

Transitions/Attributes – Additional Quotes By Participants

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Transition 1 – Becoming a Caregiver

Awareness of changes in spouses' memory/behaviour – Early caregiving

Mrs C: (re: her decision to keep a diary) “I started it off because I didn't know whether it was him or me being stupid, er....and then I realised it was him, so I just went on doing it” (i.e. keeping a diary re: her changes in her husband)

Seeking/receiving diagnosis of Alzheimer's disease

Mrs D: “I thought he had Alzheimer's..at the back of me mind, you don't admit it...'cos his Mum died of senile dementia, and when his memory started going, it was always at the back of me mind”

Mr E: “I wrote to Dr (GP)....because I noticed three things...firstly, her shopping list...there was only one item on it... it said bread spelled b.r.e.d....I thought ‘that's strange, she's the speller of the house’ ...and when she was signing her pension book she spelled (first name) no problem, (surname) started getting sort of wobbly...and then one night she couldn't find her way back to bed”

Role acceptance vs. role ambivalence

Mrs A: “well, caregiving for me, being in the NHS (as midwife before retirement), it just sort of comes naturally”

Mrs C: “I began to worry at first about how bad he would get and if I could cope”

Mrs D: “we told him he had an Alzheimer's-type disease..which he...he accepted, but he was sad about, he didn't really take in the full implication....I was so busy comforting him feeling sorry for him and I had to break the news to the four children, who all took it differently..”

Transition 2 – Intense Caregiving

Gradual spouse deterioration

Mrs A: “he just deteriorated very slowly; he was 6 foot tall and he weighed about 14 stone...13.5-14 stone..”

Mrs A: “he lost the use of his tongue, and that’s why he couldn’t eat”

Mrs A: “he’d get up, he was up at night a lot... and sometimes I’d have to shower him 4 and 5 times a night with the diarrhoea, erm, so, we’d sort of get up, go to bed and then.....getting agitated, I’d sort of get up and erm, and either take him to the loo, ‘cos he’d not have his Parkinson’s medication at the time, which you see from 10 o’clock, it’s a long time from 10 o’clock to 8 o’clock in the morning, so he couldn’t really walk, he was shuffling, trying to shuffle along because he couldn’t walk....”

Mrs B: “he got me round the throat one night when I was putting him to bed...and he used to smash things....one day when I was doing the garden, he threw an axe at me, which...stopped a couple of inches from my foot”

Mrs C: “he got to the stage where he didn’t speak,...didn’t know who I was”

Mr E: “for the last 4 years, she never spoke...and she was totally immobile...but she was a very gentle soul”

Exhausting role

Mrs A: “I was just absolutely worn out, it was all night and all day and, erm,I used to sluice the washing when I’d changed him, I used to sit him on the toilet and strip his bed, sluice it off and bring it downstairs, put it in the washer, and then I would shower him - hopefully he would have finished by then, and then I would shower him and put him into his clean bed...”

Mrs B: “he got to the point where he couldn’t speak properly....it was difficult when he started to wet the bed at night....that was difficult because I couldn’t get him changed...he was such a strong chap...the personal care was the difficult bit....I mean, you just have no life really”

Mrs B: “you just start in the morning and say ‘well, let’s get through today’ ...and that was the only way I could cope with it...I suppose it’s like having a baby again”

Mrs C: “it like looking after big child, really”

Mr E: “the last 3.5 years were the most physically demanding..... I was changing beds at 2 o’clock in the morning, things like that...and she just stopped eating and she lost 3 stones...12 stones to 9 stones in about as many months...

Ability to utilise sources of social support

Mrs B: “all your friends dropped off, people couldn’t cope with his behaviour, you were just at home with this stranger really...it’s very difficult if you’ve got someone who doesn’t speak”

Mrs D: (caregiving) “is a very lonely process”

Witnessing loss of living spouse

Mrs D: “he’d stopped being aware of me.....it was if he was dead in a way....and that was by far the worst thing”

Mrs D: “I used to sit and cry for the man who was no longer with me when he was with me”

Mr E: “it was so difficult sitting there night after night with someone with no conversation...it was as though she was there but not there, if you know what I mean”

Mr E: (awareness of ‘loss’ of wife) “well, I think you kid yourself for a bit.....you almost deny it’s happened...you talk to her the same....I think in the last couple of years when you didn’t get any real response...”

Seeking professional support home/respice:

Mrs A: (family) “they live locally and they’re very, very good but they’ve got 3 children each as well, and er, and I thought, you know, this has really got to stop... they can’t go, as much as they want to look after him, it really isn’t feasible...er, so then (husband) started to go for day care...well he had to go to day care, he had to go in respice care as well, er during the 8.5 yrs that I was looking after (husband) my Dad had cancer of the bladder and died, my brother had respiratory disease died 2 years 4 months later and my mother died 2 years after....and I had ops on both me knees.... so there’s all these other things going on, it was a nightmare”

Mr E: “I did it...the gentle way, but persistent way....I got on with everybody...got a lot of help but I’m sure I got it because I persisted but I didn’t bang the table or anything like that”

Seeking professional support re: nursing care

Mrs C: “there were times when I could have given him poison.....and eventually after 6 years, Mr (consultant) said ‘ you do know, you’re looking for long-term care now, don’t you?’

Transition 3 - Spouse in nursing care

Decision to put spouse in nursing care

Mrs C: “it’s a very difficult thing to do because you feel as if you’re betraying them, or letting them down, or being selfish...but I thought ‘he’s (consultant) said it...I haven’t had to say it, he’s said it’ ...I thought ‘thank God for that’...I couldn’t believe my luck”

Grieving for spouses' absence

Mrs C: “for quite a while I was at a loss because...I was wondering what to do with myself....but...my friend got me organised (re: social activities)...”

Mrs B: “I went every second day...it really helped me to get used to him not being at home..because for all that he was extremely difficult to live with when the AD got worse...he was still the man I had loved all those years...”

Positive and negative experiences of nursing home care

Mrs C: “I was lucky because I got him in a place where the woman who was in charge..looked after them like a family, so I didn't have to worry”

it was quite nice to visit there..it was funny, it was like your home, you couldn't wait to get there, which seems silly really”

Mrs C: “I think I was lucky because I had those 4 years (when spouse in care) on my own...so I mean he didn't die here and I suddenly found there was nobody in the house anymore...so I had 4 years to get used to that idea”

Mrs A: (re: visiting nursing home)...“I wanted to make sure he was getting his fluids, so that he was getting some food down because it was taking such a long time... I can't expect somebody in a home to go and spend one hour getting one mashed banana down (husband), I don't think that's fair...but I had a very good friends... they used to come with me...we would wake (husband) up, he was asleep, and shave him, wash him, dress him, clean his teeth, get his bed...all clean linen on and make it look really nice....”

Transition 4 – Death: The Final Loss

Initial impact – relief/shock/numbness

Mrs D: “the first 48 hours was just relief... ‘cos I felt this big pressure had been lifted off me...”

Mrs A: “you don’t know what you want..you don’t know why you want it and you don’t know why you’re there...time...just didn’t seem to move”

Mrs C: “it was as though everything was in cold storage...my brain just went walkabout...at the funeral...I don’t even remember who was there”

Mrs D: “it wasn’t like depression....it wasn’t that sort of feeling..it was the nothingness...it was just the loss”

Mr E: “I don’t think there were tears as such...tears came after.... I sat here and I thought ‘you know, I’ve had these feelings before...for a long time’....”

Guilt

Mrs A: “I felt guilty about putting him in a home and the way he died”

Mrs D: “I felt very guilty, I felt I had no right to be alive...I felt guilt and a bit of anger to God or whoever”

Mr E: “I still have one or two guilt feelings...one is I never said goodbye to her properly...(and)..I wished I’d talked to her more...I sometimes times think ‘could I have done more in the stimulation side of things?’...”

Grieving/yearning for spouse

Mrs A: “you just really miss him...I’ve had days when I’ve got up in the morning..and, well, stayed in bed all day, haven’t answered the telephone, the door, don’t want to speak to anybody...and I’ve had days when I’ve got up and I can’t stay in....you have such bad days”

Mrs A: “at first it was very bad...the first 6-7 months after (husband) died...it’s just gone on, but it has improved all the time”

Mrs B: “I couldn’t put a time limit on it, because it’s still going on really”

Mrs C: “anyway, it (i.e. the grief) eases off after time, doesn’t it?”

Mrs D: “I used to go to bed at night and long for him...it would just wash over you, the grief and you’d have to just cry and feel stupid in the middle of something”

Mrs D: (in first year of bereavement)....“I would have loved to...to be able to think of what he used to be like before the Alzheimer’s...but I couldn’t...I was just so sad about losing my (husband) who I’d looked after ”

Mr E: “you’re not thinking ‘I miss her’, you just weep, pure and simple...thoughtless weeping.....but I don’t call weeping depression”

Loss of caregiver role/identity

Mrs D: “I thought that (i.e. caregiving) was my role for the rest of my life...I never expected to be a widow, I didn’t want to be a widow”

Mr E: “I think the big problem..er...which was both an emotional problem and a physical problem..is that when she died...I was by myself...people had been coming 4 times a day...suddenly a terrific structure was taken away..I’d lost my role...I suddenly didn’t know what to do with myself”

Transition 5 – Carry on grieving

Oscillation between coping and grieving

Mrs A: after 2 years... “I still miss him....it is just gonna take so long for me to get... over.... I would say I’m at the half-way mark, or just past it...I’m doing really well in lots of ways....”

Mrs B: "I suppose your life takes over and you get back to doing things...you don't think about things so much....but I still feel it sometimes....what it was like when he was there"

Mrs D: "it's not as often...I can't say it's not as deep, but it's not as often as it used to be"

Mrs C: "I've moved on, definitely.....you can't hang on (to grief) forever can you? Some people hang onto grief for ages"

Grieving for Pre-AD spouse

Mrs B: "well, I try to forget the difficult times, because he was a lovely fellow up until he was taken ill, it's such a long time ago when he was well, that it's difficult to remember sometimes, but I do try and remember the happy times we had"

Mrs C: "well, I try to remember the good bits...the best bits....you try not to remember the bad bits...I'm quite happy to think of him as he was, as he used to be, not as he became "

Mrs D: "I'd say only in the past few months, I've started grieving for (husband) for who he was...I'm remembering how he was before he got the Alzheimer's..so now I'm grieving for my husband...before I was grieving (for) me husband with Alzheimer's"

Mrs D: "it's as if I hadn't allowed meself to think about how he was before he had the Alzheimer's..."

Mrs D: "when you grieve for someone with Alzheimer's, I think you have very complicated grief"

Mr E: "the physical side hasn't gone yet...if I think of her, I can't envisage what it was like coming down to breakfast when she got breakfast ready...I can't even envisage normal things"

Increasing social re-engagement

Mrs C: “after a couple of months...started helping my neighbour next door, taking her shopping, taking an art class...generally doing things for other people as well as myself”

Mrs A: “since the first anniversary of (husband) death...after that I started going to Alzheimer’s (carers meetings) again...I talk to a lot more people now than I used to”

Mrs A: “I’m going out more...I go to sewing classes...I go to furniture restoration classes...and I joined a walking club last year”

Mrs B: “I had a friend who...we used to go to the Halle together and I used to enjoy that...it was taking up where you left off really...I went to keep fit, and then the Alzheimer’s (carers group meetings)”

Mrs C: “my friend kept saying to me ‘ you’re going to do it...do it’..so I did; she pushed me into it...truly she was doing it for me, wasn’t doing it for her”

Mrs D: “I started getting back in very slowly, about 6 weeks after (husband) died...I gradually could do more...I have a new granddaughter so I look after her...I see my sister for lunch, I go swimming twice a week....I have always had a busy social life”

Unfinished business

Mr E: “it was very difficult to reconstruct the real (wife)...that’s why I’m doing these” (i.e. 3 albums of photographs of wife and her paintings and embroidery)