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Conceptualising the Experience of Loss and Meaning-Making in Caregiving in Dementia

by

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A thesis submitted in partial fulfilment of the requirements for the degree of
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Declaration

This thesis was carried out under the supervision of Dr. Julie Elliott, Chartered Clinical Psychologist; Dr. Stephen Joseph, Chartered Health Psychologist and Ms. Andrea Evans, Chartered Clinical Psychologist. Mr. Derek Smith, Clinical Psychologist, South Warwickshire Combined Care NHS Trust and Dr. Amanda Gatherer, Chartered Clinical Psychologist, North Warwickshire NHS Trust provided access to participants.

All material presented here is the candidate's own work. No part is based on collaborative research with any other parties.

Material presented has not been used before nor published to date. However, it is anticipated that chapters one, two and three *may be* submitted for publication. Nominated journals for submission and *provisional* authorship are as follows:

Moore, K. (in preparation). Anticipatory Grief: A Review of the Literature. To be submitted to *Social, Science and Medicine*.

Moore, K., Elliott, J. & Evans, A. (in preparation). Conceptualising Loss in Dementia: A Grounded Theory of Study of Daughters Providing Informal Care for a Mother with Dementia. To be submitted to *Illness, Crisis and Loss*.

Moore, K. & Joseph, S. (in preparation). Existential Dimensions of Meanings in Caregiving in Dementia. To be submitted to *Qualitative Health Research*.

(see **Appendix A** for details of all nominated journals and submission notes for authors).

This thesis has not been, nor will it be, submitted for a degree at another university.

Summary

An initial review of the literature concerning anticipatory grief was executed to foreground a qualitative study focusing on the experience and conceptualisation of loss by adult daughter caregivers in dementia. A chronological overview was presented and key studies and major developments identified. Inconsistencies in empirical findings were summarised; and preceded a consideration of methodological issues including: problematic research design and definitional confusion regarding conceptual underpinnings. Key recommendations for further research were made.

The main study adopted a grounded theory methodology and sought to explore the nature and process of losses experienced by daughters providing care for a mother with dementia. Open, in-depth interviews (N=10) functioned as the primary data source for analysis. Further data included: participant notes and letters; demographic details; researcher's notebooks and reflective and analytical memos. Concurrent data collection and analysis proceeded, in three phases, and the resulting, emergent, theoretical model was presented using Strauss & Corbin's (1990) framework. A full explication of the model followed and its relationship to relevant literature elucidated. Implications for clinical practice and further research were addressed.

In the course of analysis it was noted that caregivers made reference to existential themes in their accounts of caregiving. This precipitated a further study in which Reker & Wong's (1988) dimensional model was used to guide the content analysis of the existing transcribed interview data. Findings indicated that participants expressed existential themes at both an implicit and explicit level. Considerable breadth, depth and diversity was observed in relation to caregiving experienced. Caregiving appears to pose both existential challenges and opportunities for growth. Implications for clinical practice and further research were identified.

In conclusion, further methodological considerations; dissemination issues and personal reflections were addressed in a brief Research Review.

Chapter 1:

Anticipatory Grief: A Review of the Literature

Abstract

A chronological overview of the anticipatory grief literature spanning some six decades is presented here and key studies and major developmental themes identified. Inconsistencies in empirical findings are summarised and precede a consideration of methodological issues. The impact of research population diversity and difference; and problematic research design issues are discussed. The consequences of conceptual confusion and problems of definition are considered for empirical work and clinical practice. Implications for further research are considered and recommendations proposed.

1.1 Introduction

Much has been written about 'anticipatory grief' over the past six decades. Significant disagreement is present in the empirical literature, particularly regarding the potential benefits of anticipatory grief (Fulton & Gottesman, 1980; Rando, 1986a; Smith, 1985). This is reflected in empirical studies spanning work with a range of different clinical and non-clinical populations. Studies have reported on a range of diverse applications of anticipatory grief and more recently, 'anticipatory mourning' (Rando, 2000a) from organ donation (Holtkamp, 2000); human-animal bond (Meyers, 2000); child disability (Ashton & Ashton, 2000); pre-natal diagnosis (Hitchcock Pappas, 2000); to the more densely researched areas of Alzheimer's (e.g. Doka, 2000; Jones & Martinson, 1992); HIV and AIDS (e.g. Brown & Powell-Cope, 1993;

Jacoby Klein, 2000); and terminal illness, e.g. cancer (e.g. Bozeman, Orbach & Sutherland, 1955).

In addition, a number of papers have focussed on more theoretical issues, exploring the *conceptual confusion* which characterises the field (e.g. Fulton, Madden & Minichiello, 1996; Rando, 1986a). Indeed, what anticipatory grief is; how, when and if it takes place has become a rather controversial issue amongst bereavement theorists. Some theorists dispute the very existence of 'anticipatory grief' (Silverman, 1974; Wortman & Silver, 1989). Such theoretical contributions however, have gone some way to elucidating, in part at least, the contradiction present in empirical findings (Evans, 1994; Fulton, Madden & Minichiello, 1996; Rando, 1986a, 2000b; Siegel & Weinstein, 1983, Sweeting & Gilhooly, 1990).

A number of reviews of the literature have been published to date (Garner, 1997; Rando, 1986a, 2000b; Siegel & Weinstein, 1983; Sweeting & Gilhooly, 1990), so why is another required? The majority of reviews to date have tended to focus on empirical studies and have failed to engage in the published debate regarding conceptual confusion and problems of definition. As theory is the bedrock from which much, if not all (as one would hope), empirical work grows, it would appear essential that this conceptual debate be acknowledged. In addition then to providing a brief chronological overview of empirical work to date, identifying inconsistencies in findings and critiquing some of the inherent methodological weaknesses in these studies, an attempt to review the debate regarding conceptual confusion will also be made. This review will conclude with key recommendations for further research.

It should also be noted, that it would be unfeasible to aim to be completely comprehensive in reviewing all available literature pertinent to the topic, and consequently the review presented

here is necessarily selective. Nevertheless, an attempt has been made to address key texts and major themes.

1.1.1 *In Search of a Definition*

In order to circumscribe the scope of this literature review, it would be useful to present a 'working' definition of 'anticipatory grief' to function as a starting point. Lindemann (1944) first described the phenomenon of 'anticipatory grief' in his study of spousal adaptation to wartime separation, noting the essential signs of 'true' grief experienced in preparation for bereavement. However, the term has tended to be used in a rather vague way, with 'forewarning of loss' and 'anticipatory grief' being used interchangeably, thus assuming that anticipatory grief takes place where loss is forewarned. This would be quite probable if we take the definition of anticipatory grief as *'the extent to which grief is experienced in advance of the actual death of a loved one'* (Kutscher, 1969: 200), because all that is implied here is that sorrow is felt at the prospect of the loss. But if we take anticipatory grief to mean the accomplishment of *'the most painful part of mourning in anticipation of the loss'* (Kutscher, 1969: 205), then the bereaved-to-be is expected to overcome the shock and gradually absorb the reality of the loss and begin to prepare for change.

This confusion, or disagreement, over what has been understood by the term 'anticipatory grief' is, in part, at the very heart of this literature review and so will be duly explored later in this review. Given that, it is therefore difficult to present all but the most parsimonious definition of 'anticipatory grief' as a starting point.

Aldrich (1974:4) describes 'anticipatory grief' as *'any grief occurring prior to a loss, as distinguished from the grief which occurs at or after a loss'*. For Aldrich (1974) 'anticipatory'

grief is distinct from 'conventional' grief in that, 'anticipatory' grief is usually experienced both by the family of the person with the terminal illness *and* that person themselves. Secondly, it cannot continue indefinitely because death is construed as a endpoint. Thirdly, Aldrich (1974) argues that theoretically it should accelerate rather than diminish with time, which one might arguably expect in the case of 'conventional' grief. Fourthly, 'anticipatory' grief may be more easily denied than 'conventional' grief, and this in turn may result in a potentially negative impact on the relationship between family member and person who is ill. Fifthly, only anticipatory grief can include a phase of hopefulness.

The distinction that Aldrich (1974) makes between 'anticipatory' and 'conventional' grief, reminds us that 'anticipatory' grief is inevitably construed in relation to something else, i.e. theories of 'normal' grief and bereavement. The relationship between the chronological development of anticipatory grief and 'normal' grief will be examined briefly later in this review.

1.2 Chronological Overview

1.2.1 *The Forties, Fifties and Sixties*

As has been previously noted here and elsewhere, Lindemann (1944) was arguably the first to describe the phenomenon which has since become known as anticipatory grief. He observed that some individuals in attempting to adjust to the *potential* death of a loved one, reportedly experienced '*all the phases of grief*', specifically:

...depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him [sic], and anticipation of the modes of readjustment which might be necessitated by it
(Lindemann, 1944:147).

However, Lindemann's (1944) discussion of anticipatory grief focused exclusively on the experience of women facing the possible death of a male relative on active military service. He failed to extend his discussion to include a consideration of whether soldiers facing the possibility of their *own* death engaged in a similar process, nor did he attempt to extrapolate his findings to include those facing a more certain loss, i.e. individuals potentially mourning the loss of a loved one due to terminal illness.

The effects of wartime separation had previously been reported by Rosenbaum (1944) who noted depressive symptomatology in the families of soldiers. Eliot (1946) acknowledged the potential benefits of engaging in an anticipatory act as a partial defence, by examining the effects of what he referred to as '*forewarning*', on potential survivors. He noted that 'pre-bereavements', such as leaving home, good-byes following military leave, lengthy periods of military duty away from spouse, might serve as rehearsals for what would come should death actually transpire.

By the post-war fifties and sixties, empirical work regarding the anticipation of forthcoming losses, had moved away from this initial focus on military personnel and their families, to include other research populations. Indeed, much of the work carried out during this period was conducted prospectively with parents of terminally ill children. For example, Natterson & Knudson (1960) described a triphasic response in mothers whose children survived more than four months following a terminal prognosis: the first phase was associated with denial, the second phase with efforts to prolong the child's life, and the final phase was one of '*calm acceptance*' of the fatal outcome. Mothers expressed wishes for the child's death in order to end suffering and when the child died, Natterson & Knudson (1960) noted that reactions were

a mixture of calm sorrow and relief. Other empirical studies focusing on the reactions of the parents of children with malignant diseases, included: Binger, Albin, Feurstein, Kushner, Zoger & Middelsen (1969); Bozeman, Orbach & Sutherland (1955); Chodoff, Friedman & Hamburg (1963); Richmond & Waisman (1955).

Lehrman (1956) was arguably the first to offer an in-depth elucidation of the significance of anticipation, timing and expectation as critical factors influencing mourning. Following his conclusions regarding the harmful consequences of an unexpected death, he implied that anticipatory mourning may precipitate a beneficial effect post-death for those who could be forewarned. He stated:

The work of mourning is done quickly, because a certain amount of this work (detaching the libido from the object) has already preceded the event of death (Lehrman, 1956: 565).

It is interesting to note here also, that 'detaching' or decathexis is implied to be a necessary part of successful mourning; this point will be revisited later in this review.

Studies concerned with the effects of anticipation, more broadly, also informed the general debate at this time regarding anticipatory mourning. For example, Janis (1958) studied patients coping with the stress of surgery, and revealed that those who carried out the 'work of worry' prior to surgery had better psychological and physical outcomes, experienced less distress postsurgery and adjusted better than those who had not. This provided both clinical and empirical evidence to suggest a potential relationship between rehearsing a stressful event and subsequent coping, thereby underpinning the adaptive potential of anticipatory mourning.

The late sixties saw major socio-cultural and medical developments that were to have a considerable impact on the field of bereavement work, and therefore consequences for the study of anticipatory grief and mourning. Two events in particular, are worthy of note. Firstly, St.Christopher's Hospice, London was founded in 1967 by Dame Cicely Saunders, signalling the beginning of the modern hospice movement. This precipitated a re-examination of care of the terminally ill and their loved ones. Secondly, Kubler-Ross published her seminal text '*On Death and Dying*', in 1969. Her stage model: denial and isolation, anger, bargaining, depression and acceptance, focused on elucidating the experiences of those coming to terms with their own death. Kubler-Ross's (1969) 'stage' model has received much criticism more recently, but there is little doubt that it functioned as a catalyst for much academic work in the field of death and dying, as well as bringing the topic into the public arena.

1.2.2 *The Seventies and Eighties*

Fulton & Fulton (1971), spoke directly about the phenomenon of anticipatory grief. Interestingly, along with Lindemann (1944) it is the most often cited resource on this area. Fulton & Fulton (1971) posited three social and psychological ramifications for those who have experienced anticipatory grief. Firstly, anticipatory grief may result in a lack of expected response at time of death, thus potentially leading to negative judgement of the self by the self and others. Secondly, anticipatory grief may result in the withdrawal of the family from the dying person, thereby limiting potential for the provision of family support. Thirdly, anticipatory grief may result in the family deeming a traditional funeral unnecessary, thus depriving all of an important social ritual, with psychological, social and religious functions.

Futterman, Hoffman & Sabshin (1972) were the first to discriminate between the terms anticipatory mourning and anticipatory grief. They defined mourning as an overall process, with grief as one of its component processes. Based on clinical data, Futterman *et al.* (1972) presented a five-fold, interdependent, interactive model incorporating the following processes: acknowledgement, grieving, reconciliation, detachment, memorialisation. McCollum & Schwartz (1972) further elucidated the processes comprising anticipatory mourning. In their study focusing on social work and parental mourning, they identified four defensive processes used by parents fending off acknowledgement of a child's terminal diagnosis: a) defensive processes; b) affective states; c) issues presented; d) adaptive behaviour.

Anticipatory Grief, edited by Schoenberg, Carr, Kutscher, Peretz & Goldberg (1974), was the first book devoted specifically to the phenomenon of anticipatory processes. This ambitious publication comprised 41 chapters, and provided an examination of the topic from a variety of interdisciplinary perspectives. Two chapters in particular are worthy of note here. Aldrich (1974), specified the dynamics of anticipatory grief, distinguishing between pre and post death grief. He noted some parallels but also pointed out important differences in ambivalence, denial, hope, endpoints and acceleration. Gerber (1974), in his chapter entitled *Anticipatory Bereavement* pointed out that a social component is frequently missing from many descriptions of anticipatory grief. He introduced the term anticipatory '*bereavement*' which he argued was less restrictive than anticipatory '*grief*' because it took into account both emotional and social preparations for death.

Rando (1983), in a study focusing on grief and adaptation of parents whose children had died from cancer, 'operationalised' anticipatory grief for the first time. Anticipatory grief was found

to be positively associated with preparedness at death; and more anticipatory grief behaviours engaged in prior to death were significantly associated with less abnormal grief following death. These findings were congruent with other empirical research outcomes during this period, which categorically appeared to provide evidence in support of the beneficial effects of anticipatory grief at post-death. 1986, saw the publication of the second book exclusively devoted to the phenomena of anticipatory grief and mourning, edited by Rando (1986b). It covered clinical issues, treatment strategies, differential concerns for diverse parties in the dying experience, developmental issues, and practical considerations. It was noted for proposing a broader definition of anticipatory grief than that previously outlined. Rando (1986a) argued that '*anticipatory*' grief was a '*misnomer*' because it implied that grieving took place only for anticipated losses, as opposed to both past and current losses. It was also a '*misnomer*' because '*grief*' implied, she argued, the necessity for complete detachment (or deatthexis) from the dying person as opposed to, from one's hopes for, and with that, person in the future (Rando, 1986a).

1.2.3 *The Nineties and the 21st Century*

The nineties were characterised by greater breadth and diversity. It brought the advent of the first psychometric measures developed to assess aspects of anticipatory grieving (Levy, 1991; Theut, Jordan, Ross & Deutsch, 1991); task-based models were proposed (Corr, 1992; Doka, 1993), reflecting the shift in the wider bereavement field towards the notion of '*griefwork*' and away from stage / phase models; and clinical work broadened to incorporate a systemic perspective (Rolland, 1994). A range of methodologies were represented in the published literature spanning quantitative (Ponder & Pomeroy, 1996; Walker & Pomeroy, 1996) and qualitative paradigms (Brown & Powell-Cope, 1993; Jones & Martinson, 1992).

Epistemologically, the field so previously dominated by a positivist approach now welcomed papers within a social constructionist framework (Fulton, Madden & Minichiello, 1996).

Rolland's (1994) *Integrative Treatment Model*, is of particular clinical interest. Focusing on 'families, illness and disability', he adopts a systemic approach, in which the family or caregiving system, rather than the ill person, is viewed as the central focus of care. The model highlights the interactive processes between the psychosocial demands of different disorders over time and key components of family functioning. Rolland (1994), further, expands the concept of anticipatory grief, which he views as having previously been limited to the terminal phase of an illness. He addresses issues for families dealing with anticipated loss experienced across the entire course of a chronic or life limiting illness. Indeed, he states that the anticipation of loss in physical illness can be '*as challenging and painful for families as the actual death of a family member*' (Rolland, 1994:165).

The experience of anticipatory loss involves a range of intensified emotional and interactional responses over the course of an illness, including separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion and desperation. There may be intense ambivalence toward the ill member, vacillating wished for closeness and distance, and fantasies of escape from an unbearable situation. ... Family members' emotions often fluctuate between these painful feelings and more positive states such as a heightened sense of being alive, of life's preciousness, intimacy, and appreciation of routine daily events, and hope..... (Rolland, 1994:166)

Rolland (1994) emphasises the meaning that family members ascribe to disability, death, sense of competence and threatened loss, highlighting the potential impact that these factors can have on adaptation.

Gilliland & Fleming (1998) carried out an empirical study of spouses of terminally ill patients prior to and following death. They found both 'anticipatory' and 'conventional' grief to be statistically similar in terms of emotional, physical and social dynamics, as measured by the majority of subscales on the *Grief Experience Inventory* (Sanders, Mauger & Strong, 1977). However, anticipatory grief was associated with higher intensities of anger, loss of emotional control, and atypical grief responses. Two factors influencing levels of anticipatory grief significantly were identified: perceived stress and difficulty coping; and gender, men were more inclined to defend themselves against experiencing or reporting grief.

Some of the most current writing regarding anticipatory grief is presented in Rando's (2000d) recently edited volume, which collects together 19 interdisciplinary works, spanning theoretical development and applied case work.

1.3 Inconsistencies in Empirical Findings

The majority of empirical work focusing on anticipatory grief, it seems, has been concerned with the potential benefits that it might yield (or otherwise) for caregivers and family members, following the actual death of the person with a life limiting illness. The key research question has been: to what extent can anticipatory grief mitigate against the effects of 'normal' grieving and to what extent can it facilitate adjustment? The available evidence is inconclusive.

Many of the earlier studies conducted during the sixties and seventies highlight the positive effects of having an opportunity to experience grief prior to death (Ball, 1977; Chodoff, Friedman & Hamburg, 1963; Friedman, Chodoff, Mason & Hamburg, 1963; Fulton & Fulton,

1971; Futterman, Hoffman & Sabshin, 1972; O'Bryant, 1990; Pine, 1974) and provide evidence to support the idea that anticipatory grief results in better adjustment to bereavement (Parkes & Weiss, 1983; Vachon, Rogers, Lyall, Lancee, Sheldon & Freeman, 1982).

Ball (1977), in a postal questionnaire of 80 widows, found both age of widow and mode of death of spouse were significantly related to the intensity of the grief reaction; and concluded that anticipatory grief results in improved subsequent adjustment in young bereaved persons. Further, Ball (1977) suggested that, in fact, age is more predictive of outcome than mode of death for whether there is a severe grief response.

In her study of post bereavement adjustment in participants whose children had died, Rando (1983), presented results which she believed confirmed the importance of anticipatory grief prior to the death, finding it to be positively associated with preparedness at the death and with fewer atypical responses after death.

Schwab (1975) provided evidence to support the idea that potential benefits can be yielded by experiencing an *optimal amount* of anticipatory grief. Schwab (1975) stated that individuals whose relatives lived for six months following news of terminal prognosis demonstrated greater post-death recovery than the loved ones of people who lived for a longer or shorter period of time.

Clayton, Halikas, Maurice & Robins (1973), in their study of 81 widows and widowers at three time periods (during illness of spouse, one month and one year after death), showed no relationship between length of terminal illness and anticipatory grief symptoms post-death. An

'anticipatory grief' depressive cluster was found to be positively associated with depression one month after death, but no relationship was observable one year later.

Some authors (Lindemann, 1944; Peretz, 1970) have warned that persons whose loved ones had longer illnesses adjusted less well following death. These results suggest that post-death grief may be intensified despite the longer period of anticipatory grief. This may be due to the heightened loyalty, attachment and commitment developed during this pre-death period and the opportunity for loved ones to witness the steady debilitation of the patient or the ups and downs of successive cycles of remission and relapse (Ponder & Pomeroy, 1996).

Gerber, Rusalem, Hanlon, Battin & Arkin (1975) failed to demonstrate any positive effects of anticipatory grief on post-death grief experience. Their study compared 65 widows and widowers whose spouses had died following a 'chronic' illness (defined as lasting more than two months) with 16 whose spouses had died after an 'acute' illness. No significant differences between those whose spouse died after an 'acute' rather than 'chronic' illness were found, and they tentatively concluded that exposure to anticipatory grief had no effect on subsequent adjustment in this group of participants.

Sanders (1982-1983), conducted the first available study to assess post-mortem grief *directly*, using a questionnaire rather than assuming adaptation from other variables (e.g. depression). Sanders (1982-1983) administered the *Grief Experience Inventory* (Sanders, Mauger & Strong, 1977), a self-report measure, to 102 newly bereaved but found no significant group differences. Bowling & Cartwright (1982), similarly noted no association between subsequent adjustment and length of illness, place of death or whether widow had been aware of fatal prognosis or expecting the death. Other studies have also reported that there was no

relationship between the length of the anticipatory grief period and adjustment following death (Maddison & Viola, 1968; Parkes, 1970).

There are a number of possible reasons for this inconsistency in findings. Firstly, at a contextual level, it should be noted that there is arguably an inherent bias in the publication of much literature, with a trend toward favouring studies with positive results. It is possible therefore, that studies failing to find evidence to support a hypothesis that anticipatory grief may have beneficial effects are under-represented in the published literature. Secondly, many studies fail to adequately state how they are interpreting the concept of anticipatory grief, therefore making the comparison of findings across the field hazardous. Thirdly, and inevitably, it is likely that there are methodological inconsistencies present in some reported studies, thereby raising doubts about robustness and value.

1.4 Methodological Issues

1.4.1 Research Populations: Diversity and Difference

There is considerable variability characterising the empirical field of anticipatory grief which makes comparison across studies difficult. As previously noted here, there has been considerable diversity in the nature of research populations studied in relation to anticipatory grief. Populations have ranged from parents of children with life limiting illnesses, bereaved spouses, caregivers of those with chronic conditions, as diverse as: cancer, Alzheimer's and dementia, irreversible coma, HIV and AIDS; and organ donors. This diversity, in part, clearly indicates considerable interest in the phenomena of anticipatory grief and a desire to expand

the breadth and depth of research outcomes. Nevertheless, diversity in research does not necessarily equate with 'good' research.

Whilst diversity *across* populations is to be welcomed, in principle at least, diversity *within* research populations is somewhat more problematic. Certainly, in the majority of empirical studies, little attention appears to be given to '*within subject*' differences, with only the most essential demographic characteristics being presented. It should be noted though, that more recent qualitative studies in this area (e.g. Brown & Powell-Cope, 1993; Duke, 1998; Jones & Martinson, 1992) have sought to redress this imbalance.

1.4.2 *Research Design Issues*

A range of data collection methods and data sources have been utilised, from 'positivist', postal questionnaires (e.g. Ball, 1977) to lengthy in-depth, unstructured interviews conducted within a social constructionist framework of understanding (e.g. Duke, 1998). Necessarily, a range of data analysis approaches have been adopted, from statistical analyses to grounded theory. It is therefore difficult to make broad comparisons *across* the empirical field. Indeed, as Fulton, Madden & Minichiello (1996) note, it is questionable to compare a study defining grief as a set of emotions with a study that views it as a process of meaning construction.

Sweeting & Gilhooly (1990) in their review of the literature, note the presence of confounding variables. They state that there are numerous elements associated with a lengthy terminal illness besides the possible presence of anticipatory grief, but that this frequently fails to be acknowledged in many studies. For example, Siegel & Weinstein (1983) cite factors such as emotional isolation and physical exhaustion; and suggest that such sequelae of a lengthy terminal illness may serve to negate any gains which result from a period of anticipation.

Importantly, Fulton & Gottesman (1980), note that all studies focusing on anticipatory grief in relation to post-death grief, are necessarily retrospective; and state that the '*...retrospective classification of an illness as terminal in fact tells us little about how any prospective survivor viewed the situation prior to the death*' (1980:48). Further, Fulton, Madden & Minichiello (1996), suggest that the inconsistencies of prior research may have resulted from failing to distinguish between grief that is being expressed for past and present losses and whatever responses occur when individuals focus on various aspects of their future. Previous research has assumed that these time foci are of secondary importance to the emotional response exhibited.

Interestingly, Fulton, Madden & Minichiello (1996) have commented on the methodological robustness of Lindemann's (1944) 'classic' paper, noting that the conclusions he derived, failed to undergo critical evaluation until relatively recently. They go on to suggest that, being based on anecdotal material (Ball, 1977; Parkes, 1970), and by failing to provide operational criteria to define normal, pathological or anticipatory grief (Middleton, Moylan, Raphael, Burnett & Martinek, 1991), it would fail to meet current methodological standards (Stroebe, Stroebe & Hansson, 1988).

Research designs in this area then, would appear to be poor, having been based upon '*untested assumptions and serious methodological weaknesses*' (Siegel & Weinstein, 1983). A variety of dependent and independent variables abound, which are not always considered consistently or appropriately. Inadequate experimental design and poor definition and measurement of key concepts, contribute to this lack of consensus. This variability reflects the theoretical inconsistency and confusion as to the nature of anticipatory grief. It would

seem then, for a study to be considered viable, researchers must, at minimum, clearly identify their underlying assumptions and state their own definition of anticipatory grief.

1.4.3 *Conceptual Confusion: Problems of Definition*

There appears to exist then, considerable lack of clarity regarding the concept of anticipatory grief as expressed in the empirical literature. As noted above, this could in part be due to an obvious and simple omission of definition and terms of reference in some studies, though it may also be indicative of a more fundamental problem underpinning the definition of this concept. Sweeting & Gilhooly (1990) suggest that problems of definition arise from the very nature of anticipatory grief, in that it is a subjective experience which has never been consistently operationally defined.

Fulton, Madden & Minichiello (1996:1349), in their paper *The Social Construction of Anticipatory Grief*, state that the original concept of anticipatory grief was developed from empirical research firmly underpinned by the biomedical model. Further, they argue that the concept became incorporated into the '*institution of health care*', and through a process of '*social objectification*' was raised to the status of '*primary knowledge*'. Inevitably, this led to its very existence no longer being questioned. Consequently, they state, this has resulted in empirical work focusing on the *effects* of anticipatory grief, which in turn has sought to facilitate the development of clinical interventions to help maintain the grief response within what Welch (1982) describes as normal and masterable boundaries.

In focusing primarily on whether anticipatory grief is a psychologically effective means for mitigating post-death grief, the attention is diverted away from the key question of 'what is this thing called anticipatory grief?' Certainly, in the literature there has been a growing debate

about the existence (or otherwise) of anticipatory grief (Rando, 1986a,1988; Weiss, 1988; Parkes & Weiss, 1983). Rando (1986a, 1988) vehemently argued *for* the existence of anticipatory grief. Her argument was basically semantic in origin, suggesting that terminological differences should not obscure the fact that anticipatory grief does exist. Indeed, she entitled her 1988 position document: *Anticipatory Grief: The Term is a Misnomer but the Phenomenon Exists*. More recently, Rando (1993, 1995, 2000a, 2000c) has amended her definition of anticipatory grief, proposing that it is one element of a broader set of 'anticipatory mourning' processes. The distinction she makes is as follows:

grief [is defined] as the reactions to the perception of loss, and mourning – which incorporates grief as its beginning process – as going further to include actions undertaken to cope with, adapt suitably to, and accommodate that loss and its ramifications (Rando, 2000a:4).

Fulton, Madden & Minichiello (1996) have critiqued Rando's (1986a, 1988) semantic stance, for conflating two very different processes of identifying and clarifying a phenomenon and developing an 'accurate nomenclature' to describe it. Further, they suggest that the desire to develop clinical interventions to aid those experiencing painful feelings of loss and bereavement (e.g. Lebow, 1976; Koocher, 1986), is reflected in clinicians' responses to empirical work, i.e. there is a tendency to seize upon potential clinical value, bypassing methodological and conceptual concerns.

This has potentially serious consequences for theory development and the growth of scientific knowledge; and more significantly perhaps, clinicians. Theory development it seems, may become viewed as somehow, less important than empirical work, and almost certainly less of a priority for those practising clinicians wishing to engage in clinically relevant research.

1.5 Discussion

By adopting a chronological approach to reviewing the literature, an attempt has been made to acknowledge the impact of social, cultural and historical factors. Research takes place and exists within a broader social context and one can track the influence of socio-cultural developments. There appears to have been a clear shift within the field of anticipatory grief, from a purely positivist epistemological approach in earlier decades, to a more current, social constructionist view of anticipatory grief, and indeed the literature itself, as social construct.

1.5.1 Recommendations for Further Research

Who?

- Relatively little research has been undertaken with individuals who have life limiting illnesses themselves (Bergerson & Handley, 1992; Hayslip, Luhr & Beyerlein, 1991-92). Outcomes derived from further research with this population could yield important implications for more systemic understanding of the anticipatory grief experience.
- In addition to further predominantly 'academic' research, clinical practitioners are well placed and increasingly, well armed (with appropriate research skills), and should be encouraged to conduct a range of work including theory generation; empirical work; development of further interventions and evaluation of their effectiveness.

What?

- A move away from predominantly 'retrospective' studies focusing on anticipatory processes in relation to post-death grief, toward an examination of 'anticipatory' processes 'as they happen', may aid the development of a clearer and more valid operational concept.

- Further studies specifically utilising qualitative research methodologies could enable accounts of individual's experiences to be accessed. Careful analysis of such accounts can result in robust theory generation firmly grounded in the experiences of individuals.

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Chapter 2:

Conceptualising the Experience of Loss in Caregiving: A Grounded Theory Study of Daughters Providing Informal Care for a Mother with Dementia

Abstract

This grounded theory study sought to explore the nature and process of losses experienced by daughters providing care for a mother with dementia. Participants (N=10) identified themselves as the main carer and were recruited via two regional mental health services for older people. Open, in-depth interviews, lasting between 1¼ and 2¼ hours, functioned as the primary data source for analysis. The data corpus was supplemented with further data in the form of participant notes and letters; demographic details; researcher's notebooks and reflective and analytical memos. Data collection and analysis proceeded concurrently, in three phases. Sampling and coding ceased when saturation of the data was reached. A theoretical model was developed and illustrated using Strauss & Corbin's (1990) framework. Subcategories of each component of the theoretical model were identified and key points illustrated by participant data. Implications for clinical practice and further research are addressed.

2.1 Introduction

It has been estimated that approximately one adult in seven in the UK is involved in caregiving with an elderly person (Challis *et al.*, 1995), with 60% of people with dementia being dependent to some extent on community and informal care networks (Harvey, 1998). Approximately one in three family caregivers is an adult child, often the daughter (or daughter-

in-law) (Brodaty, 1994; Finch, 1989; Lewis & Meredith, 1988), whilst spouses are the most frequent carers of a relative with dementia (Wells *et al.*, 1990).

Whilst there exists a considerable literature on caregiving, which has grown significantly in both volume and sophistication in the last decade (George, 1994), the caregiving literature has largely tended to treat informal carers as a homogeneous group (Moore & Shankland, 1998), and what little literature *has* differentiated between groups of carers has tended to focus on the experience of spouses. Further, much of what has been written has tended to be dominated by either a particular methodological or theoretical stance and has consequently been limited. There remains much to learn about caregiving both conceptually and empirically. Nolan, Grant and Keady (1996), in agreement with Gubrium (1995:268) have suggested that it is time to take stock and question the value of overly simplified causal models and return to questions such as '*What is this thing some call caregiving?*'; and '*How does it relate to the way everyday life is practised in relation to it?*' Nolan, Grant and Keady (1996) state that current definitions and models of caregiving are essentially limited to task-based conceptualisations, and further argue that even those models which purport to offer a more '*sophisticated understanding*' (Parker & Lawton, 1994) seem unable to move beyond the physical dimensions of caregiving.

A number of studies (Aneshensel *et al.*, 1995; Bull, 1998; Kapust, 1982; Morris, Morris & Britton, 1988) have *listed* losses experienced by informal caregivers of those with dementia. Identified losses have included psychological, social, financial aspects and provided a superficial understanding of how these losses function at a pragmatic level in the caregiving process, especially in relation to caregiver burden and stress. Indeed, the main body of

literature within caregiving and dementia has tended to focus on the stress and/or burden experienced by carers, as a result of their caregiving role.

It is often unclear in the literature what these losses are, their origin, how they are experienced, the meaning ascribed to them by the carer, and how the carer conceptualises, articulates and expresses such losses, other than in terms of 'stress'. By returning to caregivers themselves, canvassing their views and subjecting resulting data to systematic analysis, this study attempts to address these latter dimensions and thereby provide a useful contribution to the existing caregiving literature.

2.2 Method

Qualitative methods are particularly well suited to facilitating the exploration of people's experiences and the meanings which they ascribe to them (Hoshmand, 1989; Polkinghorne, 1991). A grounded theory methodology was adopted here to analyse participants' understanding of their caregiving experiences and associated losses that may be experienced.

Ethical approval for this study was sought and obtained from the Warwickshire Research Ethics Committee, Warwickshire NHS Health Authority (see **Appendix B** for letter of approval).

2.2.1 Research Aims

It is not appropriate to state any explicit hypotheses for a grounded theory study. Rather, one of the key outcomes of adopting this approach is the generation of hypotheses (Charmaz,

1983, 1990, 1995; Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1993). Broadly, this study sought to explore the nature and process of loss(es) experienced by daughters providing care for a mother with dementia; and propose a model of loss(es), grounded in the analysis of participant data, to facilitate understanding and contribute to existing literature.

2.2.2 Participants

2.2.2.1 Criteria for Inclusion

Potential research participants were required to be adult daughters who identified themselves as the 'main' carer, but not necessarily the 'sole' carer, for a mother with dementia, who was either living in her own home or in residential care but not with their daughter. Further, the care-recipients would have received a formal diagnosis of Senile Dementia of the Alzheimer's Type (SDAT), multi-infarct dementia or some other form of irreversible, progressive dementia, as defined by DSM-IV criteria (APA, 1994); and be in receipt of ongoing service input from the social, health and/or voluntary sector.

2.2.2.2 Demographic Profile

	Mean	Range	SD
Age: Daughters / Caregivers (N = 10)	52.1yrs	39 – 66yrs	8.9
Age: Mothers / Care-recipients (N = 10)	81.9yrs	74 – 92yrs	6.4
Length of Time Caring	3.8yrs	2 – 7yrs	1.75

Table 2.1 Age Profile for Caregivers and Care-recipients with Length of Time Caring

90% of participants were currently married, and this same 90% had two or more children, with 50% of the total population still having children living at home with them. Six participants were engaged in paid part-time employment. Eight participants had siblings. Nine of the participant's mothers were widows, whilst one lived with her spouse. 40% of participant's mothers lived in full-time residential care, with 60% residing in their own homes.

2.2.3 Procedure

2.2.3.1 Entry into the Field

Participants were recruited via South Warwickshire Combined Care NHS Trust: Services for Older People and North Warwickshire NHS Trust: Psychological Services for Older People and Kingsbury Community Mental Health Team (Older Adults). Twelve potential participants, were identified by regional clinicians and subsequently invited to join the study. Ten agreed to participate: seven from South Warwickshire; and three from North Warwickshire.

Initial contact was made via letter (see **Appendix C**), accompanied by a Research Participant Information Sheet (see **Appendix D**). The letter included a return slip for participants to complete with their contact phone number if they were willing to discuss possible participation further. Respondents were contacted by phone to arrange a preliminary meeting (lasting approximately 30 minutes), at a time and place convenient to them to discuss the research project further. Issues of confidentiality, informed consent, access to and storage of data; and the purpose of the research were addressed at this meeting. In addition, questions arising were answered. At the conclusion of this meeting, potential participants were formally asked whether they wished to take part in the research study. Those who did wish to join the research project, were asked to sign a Research Consent Form (see **Appendix E**).

Participant recruitment took place on a rolling basis, in line with the methodological requirements of the grounded theory approach, with the primary data collection period spanning five months (see **Appendix H** for Timetable of Interviews).

2.2.3.2 Data Sources

The data corpus embodied the following data sources:

- **Demographic profiles:** Summary Information Sheets (see **Appendix F**) were completed by all participants.
- **In-depth, open interviews,** 1¼ - 2¼ hours in length, were conducted with all participants, followed by a debriefing period. Interviews addressed four areas, with greatest emphasis being placed on the final topic: relationship with mother; experience of providing care; managing meaning of caring role; losses experienced (see **Appendix G** for Interview Schedule). All interviews were tape-recorded and subsequently transcribed verbatim (see **Appendix I** for example of transcribed data). Debriefing was not taped.
- **Transcript notes,** accompanying screened transcripts were returned by four carers. The format, breadth and length of notes varied from a single page, A5 letter to in excess of eight or nine A4 pages, returned by two carers (see **Appendix K** for examples of returned Participant Notes and Letters).
- **Research Notebooks and 'Memos',** both analytical and reflective, were maintained throughout the research study period; and provided a record of the research process and development of emergent model (see **Appendix N** for examples of Memos).

2.2.3.3 Data Collection and Analysis

Grounded theory specifically involves processes which are designed to maintain the 'groundedness' of the approach. Data collection and analysis were therefore deliberately inter-related, and initial data analysis was used to direct further data collection. This enabled the 'density' and 'saturation' of recurring categories to be increased over time; provided opportunities to follow up unexpected findings; increased insights and clarified the parameters of the emerging theory (Chamberlain, 1999).

The in-depth, open interview process and schedule was piloted with one carer, immediately prior to the main data collection phase in order to test for comprehension of questions / topic areas; eliminate ambiguities, irrelevancies, jargon; 'fine-tune' the interview schedule; and ascertain total time required for interviewing process. The main data collection (sampling) and analysis (coding) proceeded broadly in three phases. Data collection was guided throughout by theoretical sampling, i.e. sampling on the basis of theoretically relevant constructs rather than for population representativeness.

The first phase of data collection and analysis involved an initial round of interviews to obtain data pertaining to the broad research area. Data were then subjected to open coding, i.e. data were 'broken open' and analysed line by line to identify initial codes (see **Appendix L** for example of openly coded transcript). Relational sampling resulted in a second round of interviews to locate more data to confirm and elaborate categories. Axial coding enabled data to be 'put back together', i.e. categories and the interrelationships between categories were identified, developed and refined (see **Appendix M** for example of Axial Coding). Discriminate sampling resulted in a third round of interviews involving deliberate and directed selection of further data to confirm and verify the 'core category' and theory as a whole, to

ensure that the theoretical account was saturated. Selective coding led to the identification of the core category and elucidated how this related to all other categories. Saturation of the data was considered to have been achieved when no further identification of new categories could be made and the theory appeared to account for all the data obtained. To ensure saturation, discrepant case analysis was conducted, i.e. an examination of negative instances or cases that did not fit the theory was made and subsequently, an attempt made to incorporate all variation.

Concurrent and ongoing questioning, memo writing, hypothesis formulation and drawing of diagrams proceeded alongside data collection and analysis. Data storage and analysis were facilitated by use of a qualitative data analysis package: QSR: NUD*IST Vivo.

2.2.4 Methodological Issues: Reliability & Validity Issues

The following strategies were adopted to address the issues of validity and reliability. However, it should be noted that is more appropriate to use the term **verification**, which *'underscores qualitative research as a distinct approach, a legitimate mode of inquiry in its own right'* (Cresswell, 1998:201). Firstly, an audit trail was maintained, as recommended by Miles & Huberman (1994), outlining the research process and evolution of codes, categories and theory including, the clear presentation of evidential links, traceable from emergent theory to original interview transcripts (see **Appendices L – N** for examples of coding and memos). Secondly, continued effective memo-writing was maintained throughout the research period. This included analytic memos (questions, hypotheses, speculations) and reflective memos (personal reactions to participants' narratives). Memos made implicit thoughts explicit; documented and enriched the analytic process; and expanded the data corpus (see **Appendix N** for examples of memos). This process was facilitated by the ongoing

maintenance of research notebooks throughout the research period. Thirdly, '*member validation*' was sought (Turpin *et al.*, 1997:5). Soliciting informants' views of the credibility of findings and interpretations is considered by Lincoln & Guba (1985:314) to be '*the most critical technique for establishing credibility*'. All participants (excluding the pilot interview participant) were asked if they would be prepared to be contacted again for the purposes of discussing findings, all agreed. Findings were discussed with two participants and feedback incorporated. Fourthly, an 'Interdisciplinary Qualitative Research Collective', as recommended by LeCompte & Goetz (1982), provided an external check of the research process. Specifically, the 'Collective' sought to enhance researcher and theoretical sensitivity; overcome selective inattention; enhance receptiveness to the setting and monitor face validity (Lincoln & Guba, 1985). The 'Collective' met at regular periods throughout the concurrent data collection and analysis period; and during write-up. Fifthly, discrepant case analysis was carried out, i.e. an active search for disconfirming evidence in order to achieve rigor; and finally, the literature review was delayed as much as was practicable, to ensure that the emergent theory was as free as possible from presuppositions.

2.3 Results

Many grounded theory studies simply present a descriptive account of the key themes emerging from the analysis and fail to incorporate these themes into a more coherent, substantive model or theory. An attempt has been made here, to go beyond the simple reporting of key themes to additionally address process issues and present a tentative model of loss in caregiving in dementia. The format of presentation is based on Strauss & Corbin's (1990) framework (see **Fig. 2.1** overleaf). The emergent theoretical model will be expounded

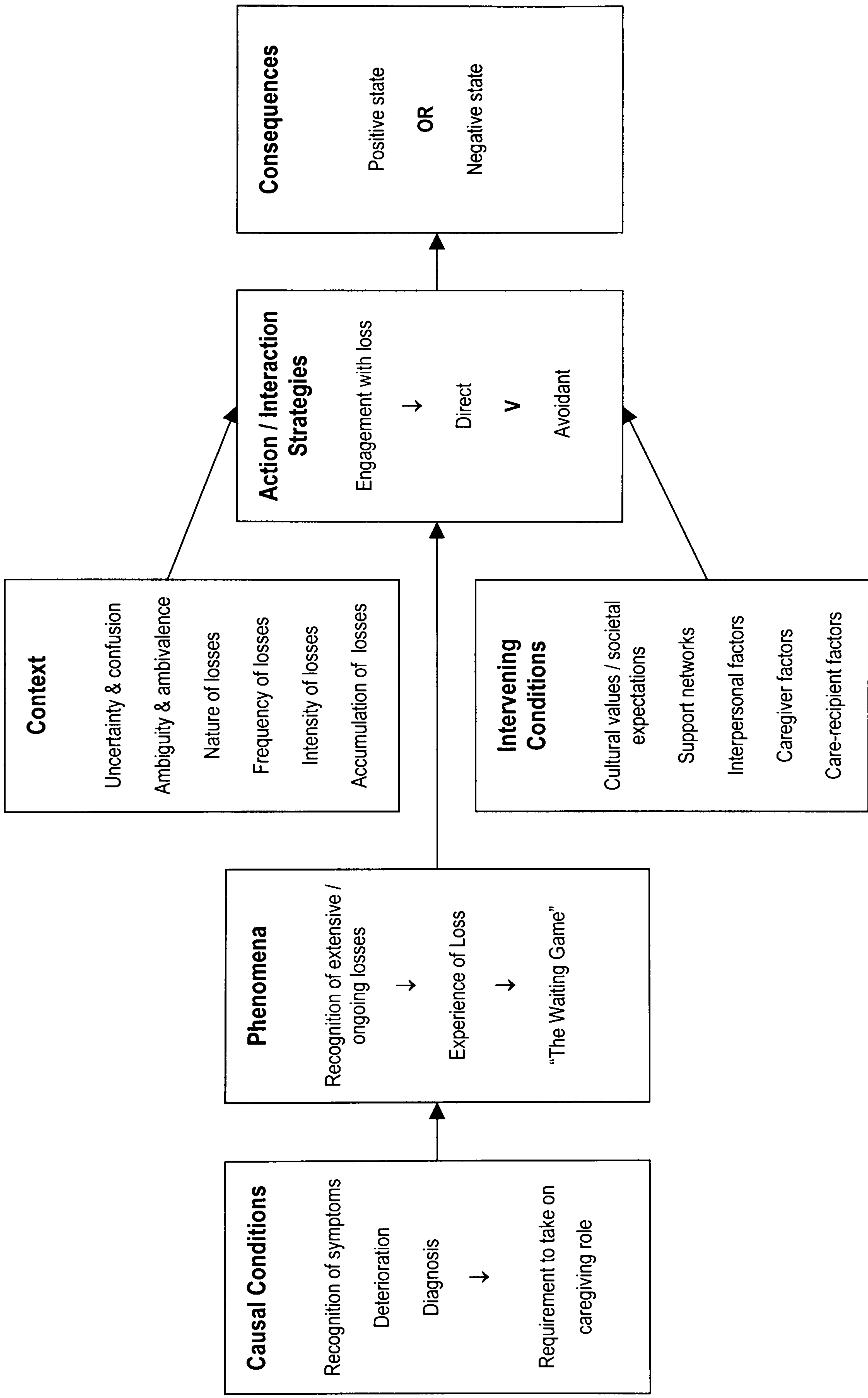


Fig. 2.1 Theoretical Model for Conceptualising the Experience of Loss in Dementia

'box by box', with direct reference made to participant's interview data to aid understanding. It should be noted, that the model presented here is not deterministic; it is not to be considered a literal representation of reality, but rather a heuristic device to enhance understanding.

2.3.1 Causal Conditions

A number of inter-related causal conditions emerged from the data, which ultimately led to certain phenomenological experiences relating to loss in dementia caregiving. The causal conditions were: recognition of symptoms; deterioration; diagnosis; and requirement to take on caregiving role. Recognition of symptoms and interpretation of symptoms, **as** symptoms, is key. The behaviour or thinking of the person with (potential) dementia must be recognised and construed as changed, different or problematic. All carers without exception spoke of the difficulty in establishing when dementia-like symptoms first appeared. Many caregivers described a process of 'slow realisation' that 'something was wrong'.

...I didn't realise what was happening, I just didn't realise anything, I didn't realise anything was up you know that she wasn't paying her bills ... I mean she used to go down town.....she wasn't buying her food properly...she had a thing for meat, she was buying meat but wasn't using it... I suppose I can't really remember I just took over doing things....

However, the majority of caregivers were also able to identify a key event which led to them seeking medical advice for their mother. At this point it appeared that deterioration was such, that problematic behaviours could no longer be ignored. Deterioration of the person with dementia preceded (and inevitably followed) formal diagnosis. Diagnosis was reported as a pivotal point for all caregivers. One caregiver spoke of her response to receiving a formal diagnosis for her mother:

...it was almost like I buried her there that night, I'd buried her...I'd lost her in my head, I'd lost my mum because the shock of being told that she was gonna die...I grieved then...

Diagnosis, then, whether official or unofficial, appeared to precipitate an immediate and devastating 'loss of hope'. A mass of seemingly random bizarre behaviours were subsequently reconstructed as 'symptoms' of a chronic, irreversible, incurable, degenerative illness. In actuality caregivers frequently described diagnosis as confirmatory of often, long held suspicions. However, whilst this confirmation may offer a framework within which a relative's hitherto problematic behaviour can be understood, it also robs both mother and daughter of further hope and signals the start of a future characterised by ongoing losses and uncertainty.

The informal caregiving role may already have been taken on prior to diagnosis, as the necessity for this role adoption is more closely related to the extent and nature of deterioration and difficulties experienced by the person with dementia rather than the diagnosis per se. In addition, diagnosis was frequently cited as precipitating the involvement of formal services: social, health and/or voluntary sector.

2.3.2 *Phenomena*

Recognition, again, is a key element in understanding the 'phenomena'. The extensive and ongoing losses that were experienced by caregivers had to be recognised as such. The recognition of losses experienced, precipitated the experience of loss. Losses were experienced, and reported, in anticipation of a *future* endpoint or next feared loss, by all caregivers. *Past* difficulties and changes were now construed as losses; and abilities that previously had been viewed as temporarily impaired, were now construed as 'lost'.

Additionally, acute grief was very much reported in the *present* for current losses, that were experienced on a daily basis, sometimes moment by moment.

In experiencing these losses caregivers reported something akin to a hypervigilant state, in which all actions and interactions with their mother were scrutinised and assessed for potential change and loss. One caregiver expressed her wishes for an end to the uncertainty and to her mother's suffering, and went on to describe very forcefully '*the waiting game*' that she was engaged in:

...we go up on a Sunday afternoon and we're all sitting there and I'm constantly looking when she's asleep, I'm watching her chest to see if she's dead, and it's like I can't stop myself..It's not that I'm willing her then, to die, because I don't want her to die while I'm there but I'm watching her chest and waiting....it's a vicious circle that goes with wanting her dead and then watching petrified in case she just dies...it's, it's my mind, my mind is screwed up with all of this bloody illness, it's... you just don't know, you never know from one day to the next....

This quote also encapsulates the extreme uncertainty and confusion; and ambiguity and ambivalence expressed by all caregivers.

2.3.3 *Intervening Conditions*

Intervening conditions refer to the broad, general conditions that influenced participants' action / interaction strategies. Intervening conditions included: cultural values / societal expectations; support networks; interpersonal factors; caregiver factors; care-recipient factors.

Cultural values and societal expectations were identified as intervening in at least two ways: firstly, family and societal expectations regarding women, and daughters in particular, as caregivers; and secondly, expectations regarding appropriate grieving and 'normal' losses.

Dementia was identified as being potentially stigmatising both for sufferer and caregiver. Additionally, caregivers suffered from a lack of 'social' framework within which this special type of mourning or grieving could take place.

The presence (or absence) and quality of available support networks was found to be important, especially in mediating the effects of stress. Firstly, informal social support networks comprised family: partner, siblings, children; and friends; and ensured the provision of practical and emotional support and potential for reduced isolation. Secondly, the quality and nature of formal service provision was important. Some caregivers experienced an ambivalent relationship with services. Initial or early contact with formal 'services' frequently brings confirmation of diagnosis or prognosis, precipitating the experience of 'loss of hope'. Continued contact with services for some caregivers was perceived negatively, and triggered feelings of dissatisfaction with their own caregiving.

Interpersonal factors relating to past and present relationships were important. Firstly, in terms of expectations, beliefs and constructs about what constitutes a daughter~mother relationship; and secondly, within a given caregiver~care-recipient dyad, the quality of pre-morbid relationship had a significant impact on how caregiving and losses were experienced for both parties. Similarly, both caregiver and care-recipient factors impinged on how caregiving and losses were experienced. Caregiver factors refers to individual differences; available psychological and physical resources; and previous experiences of providing care (both informally and formally), dementia (or chronic illness), and losses. Care-recipient factors refers to individual differences; the severity of dementia; level of insight; response of care-recipient to living with dementia and their experience of their own significant and ongoing losses; and openness and acceptance (or otherwise) to receiving help and 'care'.

2.3.4 Context

Uncertainty and confusion; and ambiguity and ambivalence, characterise the day-to-day existence of the caregiver, and was implicit in many of the descriptions of caregiving experiences:

...you go through different days...through stages where one day you'd go up and she wouldn't really know you and then the next day she'd be able to hold a conversation with you so it's an emotional roundabout sort of thing with her...

...one day you go in and you feel really, really sorry for her, another day you hate her guts....

The nature of losses expressed varied from caregiver to caregiver and were related to differing degrees to other contextual factors: frequency, intensity and accumulation. Two broad categories of losses were identified: interpersonal losses experienced in relation to the impaired relationship with mother; and intrapsychic losses experienced in response to the demands of caregiving, and as a result of interpersonal losses. Interpersonal relational losses included: loss of 'mother' and consequently, loss of confidante, support, sharing, reciprocity and many other losses that appear to be inextricably linked with the mother's own significant and ongoing losses. One caregiver described this experience:

...to me in my eyes, my real mother, the woman that I could talk to, communicate with and go shopping with, ring up if I needed anything.... the woman that was my friend, she's gone....my mum has gone and I said good-bye to her many times... the real mum has gone, no doubt about it...in my mind, I lost my mum years ago....I have just got to say good-bye to the body part now, but the mind part is gone, it's the mind I said good-bye to....

Other interpersonal losses were experienced in relation to the daughters' families, e.g. loss of time with spouse, children, and in relation to other commitments that daughters had prior to taking on the caregiving role, e.g. losses associated with work, friends, hobbies, social activities. Intrapsychic losses included: loss of hope, confidence, 'space' for self, sense of self, sense of freedom, identity as daughter. Further losses were identified that didn't fall easily into either interpersonal or intrapsychic categories, these included material losses, e.g. one caregiver had had to relinquish an anticipated inheritance.

The accumulation of ongoing losses took its toll on all caregivers, one of whom reported:

...and then that night was when all the tension came out...that build-up was like that had been going on for months and months and months at different stages you would go up and I would look at mum then and I could see bits of her dying so it wasn't just like this Christmas day was like it was a one-day thing it was taking months and months and months...

2.3.5 Action / Interaction Strategies

In the presence of the context and intervening conditions described, four core action / interaction strategies were identified: cognitive; affective; behavioural; and existential and spiritual. Strategies appeared to either enable the caregiver to engage directly with the process of experiencing losses or to engage in a more avoidant way. **Fig. 2.2** overleaf, provides examples of specific strategies identified by caregivers.

Individual participants reported engaging in a diverse range of different types of action / interaction strategies, which were inevitably context specific. Movement between, directly engaging with the experience of loss and seeking to avoid it, appeared to fluctuate, day-to-day, week-to-week, sometimes moment-by-moment.

<u>Strategy</u>	<u>Direct Engagement</u>	<u>Avoidant Engagement</u>
Cognitive	<ul style="list-style-type: none"> • cognitive restructuring & negotiating of 'new' relationship with relative with dementia • active reframing of losses 	<ul style="list-style-type: none"> • attempting to minimise & ignore losses • objectifying relative with dementia
Affective	<ul style="list-style-type: none"> • seeking emotional support via activation of support networks • expressing grief & difficult feelings relating to relative with dementia, e.g. 'death wish' 	<ul style="list-style-type: none"> • rejection of others, e.g. siblings • suppression of grief & difficult feelings • displacement of anger • denial
Behavioural	<ul style="list-style-type: none"> • reclaiming of 'physical' losses in relationship with relative with dementia, e.g. touch, displays of affection 	<ul style="list-style-type: none"> • physical distancing – avoidance of all physical contact apart from essential personal care
Existential & Spiritual	<ul style="list-style-type: none"> • actively searching for meaning in loss(es) experienced • seeking support from spiritual source • seeking understanding of ultimate purpose of experience of loss 	<ul style="list-style-type: none"> • asking "why me?"

Fig. 2.2 Action / Interaction Strategies Matrix

2.3.6 Consequences

Both positive and negative consequences can potentially arise from engaging in the action / interaction strategies adopted here. Two sets of consequences were identified and are illustrated in **Fig. 2.3** overleaf. All caregivers described moving back and forth between these two positive and negative states. Here, as with strategies employed by participants, oscillation took place moment-to-moment, day-to-day, week-to-week or over a longer period. However, some caregivers described experiencing more positive consequences than negative, and others reported the reverse. Arguably, caregivers existing in either a predominantly positive or negative state can precipitate further consequences.

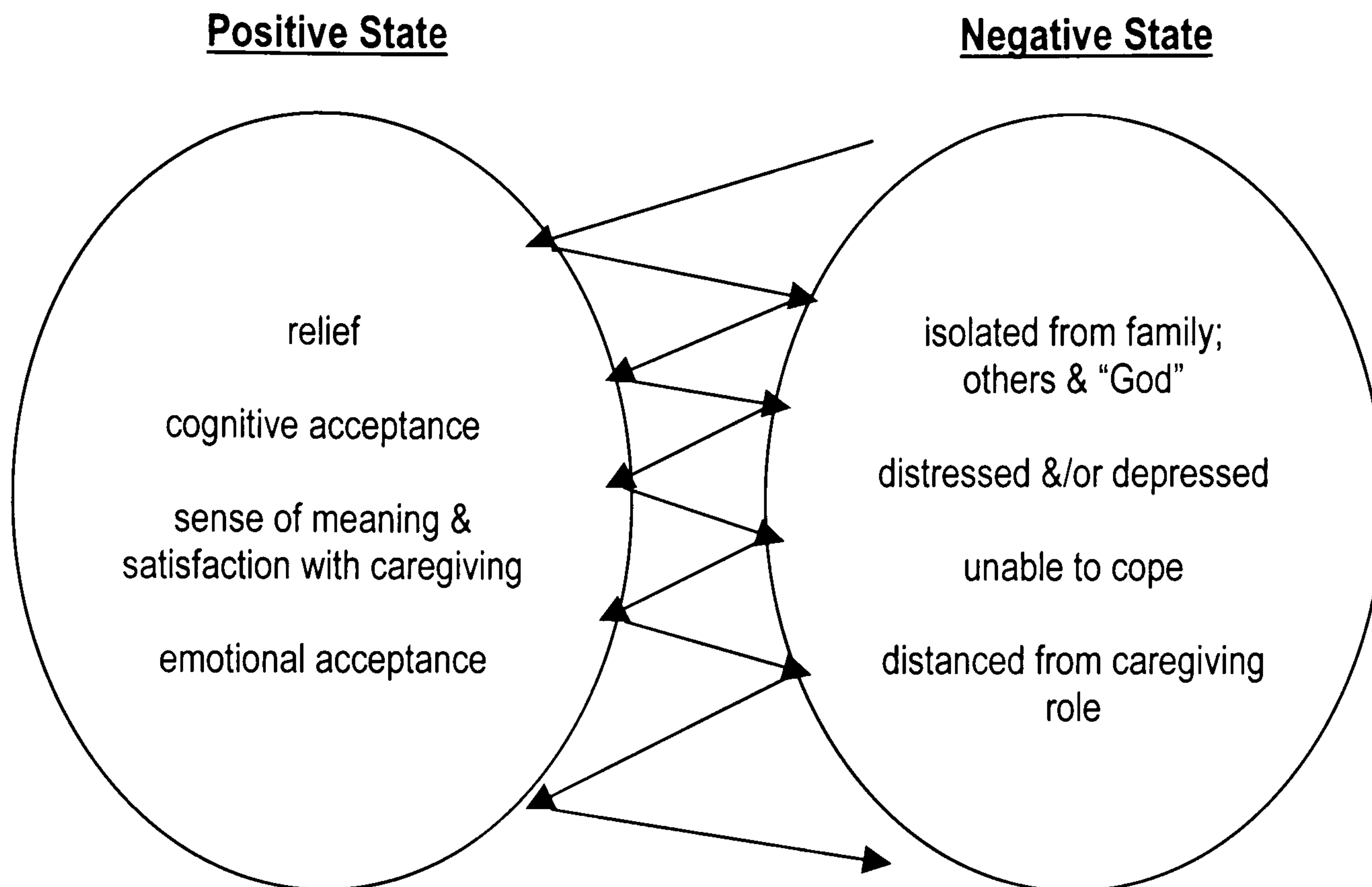


Fig. 2.3 Dynamic Model of Oscillation Between Positive and Negative States

Existing within a predominantly positive state can aid the reconstruction of 'self' and other in relation to the new and shifting roles that dementia demands of both caregiver and care-recipient. This in turn can aid the negotiation and creation of a 'new' relationship with the care-recipient. Existing within a predominantly negative state can potentially and ultimately lead to an existential crisis and/or a breakdown in the relationship with the care-recipient.

2.4 Discussion

Although the caregiving literature is rich with reports of informal caregivers' experiences of providing care in dementia, this study is distinctive in its systematic examination of the experience of *loss in dementia* from the perspective of *adult daughters* caring for a *mother*. A theoretical model conceptualising the experience of loss in dementia was developed through the thorough analysis and synthesis of a large amount of multifarious qualitative data. The

model proposed is intended to facilitate understanding and provide a framework which can be utilised to inform clinical practice.

Various aspects of the model presented here are congruent with the published literature pertaining to anticipatory grief, bereavement and more broadly, to caregiving in dementia. The identified phenomenon 'Experience of Loss' referred to loss experienced within three temporal dimensions, i.e. past, present and future; and was presented as one component of a larger interrelated series of processes. This is congruent with Rando's (1993; 1995; 2000) concept of anticipatory mourning, in which she describes a series of:

generic operations (...) that, within a context of adaptational demands caused by experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present and future (Rando, 2000:4).

One of the key findings of this study, in addition to building a framework to facilitate the understanding of caregivers' experience of loss, was the requirement to recognise, acknowledge and incorporate, the contextual markers of ambivalence, ambiguity, uncertainty and confusion which permeate participants' experiences. The ambivalence experienced by caregivers in their adoption of action / interaction strategies is similar to that observed in the literature on 'normal' grieving and bereavement. For example, Stroebe & Schut's (1999, 2001) Dual Process Model, incorporates the tension between approach and avoidance as its basic dimension. Oscillation provides a central regulating mechanism, between the two, permitting an individual to obtain the benefits of each domain and minimise the costs of maintaining one strategy for too long. The Action / Interaction Strategies Matrix (see **Fig. 2.2**)

here, suggests that caregivers experiencing loss in dementia, maintain a similar movement between strategies of direct and avoidant engagement in relation to losses experienced.

2.4.1 *Implications for Clinical Practice*

Worden (1992) has noted that grieving can become '*complicated*' when the loss experienced is '*ambiguous*' (Boss, Carm & Horbel, 1988), or when a high degree of '*uncertainty*' is experienced on a daily basis (Rolland, 1990; 1994). Ambiguity and uncertainty characterised much of the caregivers experiences, reported here. It has been suggested that these factors can result in the caregiver being at higher risk for complicated grieving (Bull, 1998). Other risk factors have been identified, including potential elder abuse (Hughes, 1997) and suicidal ideation in caregivers and care-recipients (Gilbertson & Bull, 1997). It would therefore seem imperative for service providers and clinicians to be aware of these potential risks and develop methods to assess, and interventions to address, this area.

Dempsey & Baago (1998) have argued that the nature of caregivers' grief puts extra responsibility on those who provide caregiver support to develop an early awareness of the hidden grief process. Few caregiver interventions appear to explicitly address the issue of loss in dementia. However, those interventions which do facilitate reflection on losses experienced during dementia care have been found to lessen caregiver distress, increase sense of psychological well-being and sense of satisfaction with care given (Moore & Shankland, 1998).

In addition, service providers should be mindful of not adding to the losses already experienced by dementia caregivers. Loss of control and increased sense of isolation may result from some service interventions. Indeed, caregivers have been shown to report feeling

that they have little control or choice in the selection of long-term residential care and this has been associated with increased levels of caregiver dissatisfaction, guilt and grief (Cahill, 1997; Gilbertson & Bull, 1997; Johnstone, Leach & Bull, 1997).

The model presented here, could potentially function as a framework to guide clinical work with caregivers, both in terms of guiding assessment and the development of sensitive and appropriate interventions. By conceptualising caregivers' experiences in terms of the model presented, the clinician can locate the caregiver *in* their experience, i.e. the model can facilitate an understanding of what is 'going on'. For example, clarification may be obtained regarding the profile of a given caregiver's losses according to nature, frequency, intensity, accumulation; the types of strategies employed by the caregiver; an indication of whether a given caregiver is existing predominantly in a positive or negative state. etc. This latter identification, in itself, could provide the basis for anticipating further outcomes, e.g. a positive state may offer greater potential to derive existential gains, whilst a negative state could precipitate a breakdown in the relationship with the person with dementia and ultimately lead to earlier institutionalisation for the care-recipient.

Utilising the model as a framework for facilitating assessment of caregiver needs, allows the identification of 'in-roads' or points of entry for clinical intervention. Individual and group interventions which maximise the potential to exist within a 'positive state' could be developed, by exploring and expanding caregivers' repertoire of action / interaction strategies. A key concern for clinicians developing such interventions would be to recognise, acknowledge and validate the continuing uncertainty which characterises the experience of caregiving; in addition to explicitly engaging with caregivers' experience of loss. This model may therefore,

potentially underpin benefits to be derived from addressing caregiver loss and also broader gains within the caregiving dyad.

2.4.2 Implications for Further Research

As is frequently the case in qualitative research, the results of this analysis are unique to the particular researcher, participants, and context of this study. Transferability of this theoretical model takes place as the reader examines these results in the context of specific circumstances of interest. However, further empirical work is required to test the robustness of the model both internally and in terms of generalisability.

This model was developed with a gender specific caregiver population, at a relatively early stage in their caregiving 'careers' (Nolan, Grant & Keady, 1996). Applicability and utility for a broader caregiver population should be explored, e.g. male caregivers; spouses of a relative with dementia; and those providing care for loved ones with other life limiting illnesses. More specifically, it would be useful to expound on the action / interaction strategies presented here, (the presentation of which has been necessarily constrained due to limited space), especially the nature, breadth and depth of existential and spiritual strategies which are seldom addressed in the caregiving literature. It might also be useful to examine to what extent strategies may differ in content and style for those caregivers at different points in their caregiving 'careers'.

In conclusion, the findings presented here suggest that the experience of loss is core to the experience of providing care for a loved one with dementia. Moreover, this can be a complex and at times confusing experience for caregivers. It is hoped that the model presented here can be usefully employed and developed to inform clinical practice.

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Chapter 3:

Existential Dimensions of Meaning in Caregiving in Dementia

Abstract

A qualitative study exploring the nature of existential dimensions of meaning was conducted with daughters caring for a mother with dementia (N=10). Reker & Wong's (1988) dimensional model was used to guide the content analysis of transcribed interview data, derived from open, in-depth interviews. Findings suggest that participants readily express existential themes in their accounts of the caregiving experience at both an implicit and explicit level. A number of diverse 'sources of meaning' were identifiable in participants' accounts, and further evidence indicated that considerable breadth and depth of meaning was derived from the caregiving experience. It would appear that caregiving poses both existential challenges and opportunities. Implications for clinical practice and further research are identified.

3.1 Introduction

The potential for caring to meet existential needs, providing life with meaning and purpose, has long been identified (Davies, 1980) and reaffirmed a number of times subsequently (Pearlin, Mullan, Semple & Skaff, 1990; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991; Nolan & Grant, 1992; Grant & Nolan, 1993; Harris, 1993). Hasselkus (1988) used an ethnographic approach to identify themes of meaning that included: 1) sense of self; 2) sense of managing; 3) sense of future; 4) sense of fear and risk; and 5) sense of change in role and responsibility. Motenko (1989), in a study of wives providing care for a spouse with

Alzheimer's Disease, found that continuity and reciprocity are key concepts in whether meaning is present in the caregiving role. Farran *et al.* (1991) used existentialism as a framework for a quantitative and qualitative longitudinal study of how caregivers of a relative with dementia find meaning in and perceive the caregiving experience. They contended that caring can be seen as meaningful in terms of provisional and ultimate meanings. Provisional meanings are constructed within the day-to-day elements of care whereas ultimate meanings are more intimately tied to the philosophical or spiritual beliefs that an individual holds. Caring, Farran *et al.* (1991) suggest, provides a number of avenues to finding meaning, including creative routes (as means of developing new skills for example); experiential routes (via relationships and feelings); and attitudinal routes (via the exploration of personal beliefs and values). Jivanjee (1993:9), in a study of dementia caregivers, noted similar rewards and was surprised to discover *'the creativity of people in finding rewards in seemingly insignificant events or activities, and the capacity for people to find their own resilience in oppressive situations'*.

Women more often cite existential satisfactions than men (Davies, 1980; Ungerson, 1987; Lewis & Meredith, 1988a; 1988b) although these studies focused primarily or exclusively on women, so it is uncertain whether this conclusion represents a genuine gender difference or is an artefact of the sample studied. Other studies suggest that men also invest significant meaning in caring (Motenko, 1988; Harris, 1993), which is not motivated primarily out of duty, but rather out of pride and love (Motenko, 1988). Caring would appear to invite many caregivers to express 'ultimate' meaning via strongly held religious or personal beliefs (Clifford, 1990; Farran *et al.*, 1991; Nolan & Grant, 1992; Grant & Nolan, 1993; Coleman, Piles & Poggenpoel, 1994) and recent work confirms that this can be observed cross-culturally

(Farran, Lowe Graham & Loukissa, 2000). Of Coleman *et al.*'s (1994) sample, 91% considered that caring had brought them closer to God.

It would seem that the adoption of the role of caregiver for a relative with dementia poses particular existential challenges for the individual. Yalom (1980) has suggested that confrontation with difficult life events, e.g. divorce, divorce of one's parents when a child, bereavement, terminal illness of the self or loved one, may bring people in contact with the ultimate concerns of life, e.g. one's own mortality, existential isolation, etc. This may precipitate a life review or re-evaluation of the meaningfulness of life. Indeed, Frankl (1973) has stated that, in general, the issue of the meaning of one's personal life has no relevance until some personal or professional crisis occurs.

Reker & Chamberlain (2000) state that there is no agreement on a *dominant* framework for understanding existential meaning. However, many have been proposed, some of which have been particularly influential within the field of psychology and psychotherapy (Frankl, 1973; Yalom, 1980; van Deurzen-Smith, 1988). Reker & Wong (1988) propose a model of existential meaning with four dimensions: the content of experiences which hold meaning (*Sources of Meaning*); how meaning is experienced (*Structural Components*: cognitive, motivational and affective); the diversity with which meaning is experienced (*Breadth*); and the quality of the experience of meaning, i.e. degree of self-transcendence involved (*Depth*: conceptualised at four different levels).

Reker & Wong's (1988) model provides a robust means of approaching a difficult conceptual area; and has been usefully applied to empirical work focusing on adults in both middle and later stages of life (O'Connor & Chamberlain, 1996; Reker, 1991). To date, it has yet to be

applied to a caregiving population. This qualitative study provides an exploration of the nature of existential dimensions of meaning as expressed by daughters caring for a mother with dementia; and utilises Reker & Wong's (1988) model to guide the content analysis of transcribed interview data and facilitate the understanding of findings.

3.2 Method

This study was part of a more extensive qualitative project focusing on the experiences of daughters who provide care for a mother with dementia.

3.2.1 Participants

Participants were recruited via South Warwickshire Combined Care NHS Trust: Services for Older People, and North Warwickshire NHS Trust: Psychological Services for Older People and Kingsbury Community Mental Health Team (Older Adults). All participants ($N = 10$) were daughters caring for their own mother with dementia. All identified themselves as their mother's 'main' carer. Length of time spent caring ranged from 2 to 7 years ($M = 3.8$; $SD = 1.8$). All care receivers had been given a confirmed diagnosis of dementia and were in receipt of health and/or voluntary sector services. Caregivers' age ranged from 39 to 66 years ($M = 52.1$ years; $SD = 8.9$). Care receivers ranged in age from 74 to 92 years old ($M = 81.9$; $SD = 6.4$). All carers were white.

3.2.2 Procedure

A letter with accompanying Research Participants Information Sheet (see **Appendices C & D**), outlining the scope of the project and confidentiality issues, was sent to potential

participants. Of 12 caregivers invited to take part in the study 10 agreed. All participants were asked to sign a Research Consent Form (see **Appendix E**).

3.2.2.1 Data Collection

Caregivers participated in a open, in-depth interview lasting between 1½ hours and 2¼ hours, conducted in their own home. The interviews were guided by an interview schedule focusing on four main topics: relationship with mother; experience of providing care; managing meaning of caring role; losses which may have been experienced, following which participants were given the opportunity to debrief. Interviews were tape recorded and subsequently transcribed verbatim in their entirety.

3.2.2.2 Data Analysis

The transcribed interview data were examined for indications of Reker & Wong's (1988) four dimensions of existential meaning. *Sources of Meaning* were initially identified and categorised for the total population; and subsequently examined for evidence of the presence of *Structural Components of Meaning*. *Breadth* was assessed for each participant in two ways: the total number of initially identified *Sources of Meaning* was noted; followed by the number of different categories within which *Sources of Meaning* fell. Individual accounts were analysed for the distribution of *Depth of Meaning* across Reker & Wong's (1988) four levels (from self-oriented sources to those that indicated a sense of ultimate purpose).

3.2.3 *Issues of Validity and Reliability*

Throughout the research process coding and categorisation was discussed with and critiqued by members of an 'Interdisciplinary Qualitative Research Collective' (comprising four members), in an attempt to reduce researcher bias and enhance consistency.

3.3 Findings and Discussion

3.3.1 Sources of Meaning

Sources of meaning refers to the different content areas or personal themes from which meaning is experienced. Research suggests that meaning can be derived from a wide variety of specific sources that vary according to cultural and ethnic background, socio-demographics, and developmental stage (DeVogler & Ebersole, 1980; Kaufman, 1986; Klinger, 1977; O'Connor & Chamberlain, 1996; Yalom, 1980).

A total of 90 specific Sources of Meaning, which could be classified into nine broad categories, were found across caregivers' accounts (see **Appendix O** for further details of content analysis).

- *Reciprocity / Mutuality* with person with dementia: at the heart of the caregiving relationship and includes sense of 'paying back' and/or 'duty'; expressions of thanks from carereceiver; shared time; shared humour.

....well she's still quite appreciative which is good....[AB]

...she put her vest on first and then tried to put her bra on top you know and things like this and we laughed about it.....[AB]

- *Temporal Aspects* of the caregiving experience, specifically in shared, and sharing of, memories with mother; acknowledging that this time will pass; focusing on the future.

...there's so many restrictions at the moment...its reassuring in so far as I've got to believe that there is a light at the end of a tunnel.....[PL]

- *Intimate Supportive Relationships* with partners, siblings, children, friends, companion animals.

[Q. who's there for you?]*...oh Alan, my husband, he is like..he's fantastic, he is...he's 100%, this is hand on heart now....* [KB]

- *Intrapsychic Sources*, specifically pre-existing sense of self-belief, self-esteem.

I thought I'd do a trial night at the swimming baths...it took me a while it took me almost a year to get from the swimming pool to the open water so you know I wasn't rushed or anything I got there in the end you see I got there in the end with my mother I always get there in the end.....[JP]

- *Religious and Spiritual Beliefs*, sense of higher purpose, belief in a God.

I just know I have this faith that I know that there's a God there and somebody bigger which I've never really thought about before....[AH]

- *Philosophy of Daily Living*, specifically finding meaning in 'living one day at a time'; being in the 'here and now', i.e. experiencing the experience of caregiving.

...I always think you should enjoy every minute of it [life] 'cos you never know when you're going to go...I just think you've got to enjoy it....[LW]

- *Creativity*, engaging in creation of 'new' relationship with mother.

...like when I'm giving her a kiss goodbye when I'm leaving it's uh "I'll see you in a week, mum" whereas before it would be "I'll see you in a week Moira" or "give us a ring Moira" but now it's 'mum'... [KB]

- *Social and Community Purpose*, specifically altruistic sharing of experiences of caregiving with others in a similar situation, seeking to make things better for others. All participants,

without exception, gave this as their primary reason for volunteering to take part in the study.

...there must be lots of people out there that need help and maybe I can tell them something....maybe I could help someone....[BF]

- *Personal Development*, at two levels: directly relating to role as caregiver - acquisition of skills, knowledge; indirectly in prioritising time for self and engaging in new opportunities (social, interpersonal, intrapersonal).

...I make more of an effort now to make sure I have time to myself...[AB]

These findings are consistent with Frankl's (1963) four ways of making meaning: creating; experiencing; loving another; taking a courageous stance; and congruent with Reed's (1991) conceptualisation of 'self transcendence' as the expansion of self-boundaries: inwardly, through increased self-awareness and introspection; outwardly, in terms of investing oneself in relationships with others and the surrounding environment; temporally, by integrating memories from the past and hopes for the future to enhance present life.

3.3.2 *Structural Components of Meaning*

Reker & Wong (1988) describe their Structural Components of Meaning as cognitive, motivational and affective. The cognitive component, refers to how people make sense of their life experiences and develop understanding and beliefs. The motivational component, refers to the value system developed by each individual, to the goals which are dictated by this value system, how goals are pursued, how these are attained and how they lead to a sense of purpose. The affective component, refers to the feeling of satisfaction and fulfilment individuals get from their experiences and from achieving their goals.

Some evidence was found to support this feature of Reker & Wong's (1988) theoretical account of meaning. For example, the following quote includes cognitive and motivational components:

I did used to go to church and be quite involved in church but I don't now but it's still there very much so and yeah I have a set of guidelines....a right and wrong sort of in there....so I can't abandon her when she needs me because that would be you know that would be wrong....[AH]

Despite participants reporting a number of sources of meaning, no examples could be found in the data containing all three Structural Components of Meaning. However, participants were afforded only a limited opportunity at interview to provide further details about sources of meaning. A more exclusive emphasis on meaning may have produced data which would have yielded greater evidence to support this feature.

3.3.3 *Breadth of Meaning*

Breadth of Meaning refers to how diversely people experience meaning in their lives. DeVogler-Ebersole & Ebersole (1985) suggest that most individuals derive meaning from a variety of valued sources and only a few rely on a single, central source.

Participants varied in the number of individual sources of meaning identified, reporting on average nine (*Range* = 4-14; *SD* = 2.8), slightly higher than previous findings (DeVogler-Ebersole & Ebersole, 1985; O'Connor & Chamberlain; 1996, Reker, 1994). The occurrence of these sources were spread across the nine broad categories (as identified in 3.3.1), to varying degrees (*M* = 5.5; *SD* = 1.5). For some participants (*N* = 3) sources of meaning fell into only four of the broad categories, whilst one participant exhibited a particularly diverse range of sources of meaning, reporting examples which fell into each of the nine broad categories

identified. The majority of participants reported sources of meaning which fell into five or six of the categories (*Mode* = 4; *Median* = 5.5), again slightly higher than has been reported in other studies (O'Connor & Chamberlain, 1996).

Whilst the discrepancy between findings for this population and those in previous studies might simply be an artefact of the way in which broad categories have been identified here, it is interesting to consider that such a discrepancy might indicate that caregivers are in some way working harder to make meaning of the difficult circumstances that they find themselves in, and consequently find and report a greater number and greater diversity of sources of meaning.

3.3.4 *Depth of Meaning*

Based on Frankl's (1963) premise that the full meaning of life can only be achieved by transcending self-interests and on Rokeach's (1973) hierarchical nature of values, Reker & Wong (1988) define depth as the degree of self-transcendence that is realised. Four levels of depth are proposed into which experiences of meaning could be classified: Level 1: hedonistic pleasure and comfort; Level 2: devotion of time and energy to the realisation of personal potential; Level 3: interpersonal and social, service to others and commitment to a larger societal or political cause; Level 4: holding values that transcend individuals and encompass cosmic meaning and ultimate purpose.

An attempt was made to classify participant's accounts for depth according to Reker & Wong's (1988) criteria. A number of source categories appeared to be closely associated with given levels of depth. For example, greater depth, i.e. a greater level of self-transcendence, was found for the categories of *Religious and Spiritual Beliefs*, *Philosophy of Daily Living* (both

Level 4) and *Society and Community Purpose* (Level 3) than for the other categories, e.g. *Personal Development* (Level 2). Other source categories appeared to span levels of depth. For example, sources of meaning within a specific source category could move from the first level to the third level without mention of material at the second level.

All caregivers expressed sources of meaning at Levels 3 and 4; and appeared to be utilising a belief in an ultimate purpose or meaning to facilitate their understanding of their caregiving experiences. However, caregivers did not *explicitly* express feelings of fulfilment or satisfaction, even when prompted. This is in contrast to Reker's (1991) findings derived from work carried out with non-caregiving populations. Reker (1991) demonstrated that individuals who experience meaning from sources at Levels 3 and 4 are more fulfilled and satisfied with life compared to individuals who experience meaning at Levels 1 and 2. Further work, then, could usefully be executed concerning the association between fulfilment, life satisfaction and depth of meaning in caregiving.

3.4 Conclusion

A number of interesting points have emerged from utilising Reker & Wong's (1988) framework for dimensions of existential meaning in this brief content analytic study. Firstly, some indication of Reker & Wong's (1988) structural components was found in the data but there were some problems with identifying these components in general. In part it is likely to be due to the fact that caregivers were not asked to expand upon Sources of Meaning nor afforded an opportunity to do so. Further data would most likely have yielded further examples to support this dimension of Reker & Wong's (1988) model.

Secondly, greater breadth and depth of meaning have both been associated with a heightened sense of fulfilment and psychological well-being (Reker, 1991; 1994). Further work is required to compare those caregivers who reported greater breadth and depth of meaning with those that did not, in order to see whether this association can be observed in a caregiving population.

In conclusion, findings presented here should be viewed with caution given the small sample size and gender bias. Further work is required to investigate whether similar themes would be identified by a more diverse caregiving population. However, it would appear that participants readily expressed existential themes in their accounts of the caregiving experience at both an implicit and explicit level; and it is interesting to consider to what **extent** the experience of caregiving offers potential for finding increased meaning in one's life. Certainly, Reker & Wong's (1988) dimensions of existential meaning provides a useful framework for facilitating analysis and understanding of caregiver's experiences; and could, therefore, be very usefully adopted to inform caregiver interventions.

Caregivers are engaged in a *process*; a process of attempting to reconstruct meaning through the very act of caregiving, which in itself initially appears to function as a catalyst to precipitate life review. Reker & Wong's (1988) model enables the identification of various dimensions of existential meaning and aids understanding, but it does not illuminate the process of making meaning in its most dynamic sense. Further work is required to address this aspect of existential meaning in caregiving.

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Chapter 4:

Research Review

4.1 Introduction

This review will be primarily concerned with reflections concerning methodology and the **process** of carrying out this research project, specifically:

- Methodological considerations, including epistemological concerns; interview as method of data collection; the process of data analysis including transcription; and use of computer software as analytic tool.
- Research outcomes: the focus will be solely on dissemination issues (considerations for future research and clinical implications having been addressed in Chapters 2 and 3).
- Personal reflections and learning.

4.2 Methodological Considerations

4.2.1 Epistemological Concerns

There has been considerable debate concerning the epistemological underpinnings of grounded theory methodology. Traditionally, leading grounded theorists (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990) have presented their methods as compatible with traditional positivistic assumptions of an external reality that researchers can discover and record. However, a number of researchers (Annells, 1996; Chamberlain, 1999; Charmaz, 1995) argue that grounded theory can bridge traditional positivistic methods and interpretative methods. This is possible because grounded theory methods are used to discover research participants' meanings; they assume an empirical enterprise, and they

provide a set of procedures to follow. These methods can be employed in any approach ranging from highly interpretative to structured positivist analyses.

For Charmaz (1990, 1995), grounded theory can be firmly located within a constructivist paradigm of inquiry. 'Reality' is constructed and accepted to be interpretive; knowledge is created rather than found; and reality is 'provisional' in that it is historically and contextually located. Indeed, Charmaz has argued that the outcome of any research using grounded theory is '*a social construction of the social constructions found and explicated in the data*' (1990: 1165). I have attempted to adopt an interpretative, constructivist approach to my utilisation of grounded theory methods in my main study.

4.2.2 *Interview as Method*

In-depth, open interviewing was adopted as my primary method of data collection (which was complimented by data derived from demographic summary information sheets; participant's notes and letters; and researcher's memos). Collins (1998:1.1) says that there has been a tendency for students to view the interview as a '*kind of smash and grab opportunity*' in which respondents are '*relieve[d]...of whatever useful "data" they may have*'. However, it is more useful to construe the interviewing **process** as an *interactional situation* (Denzin, 1978) and useful to talk of *data generation* rather than data collection (Mason, 1996:35).

4.2.2.1 Negotiating Selves

Much has been written about the inherent power imbalance between the researcher and the researched, predominantly locating power solely within the domain of the researcher. However, the relationship between researcher and researched is fluid and changing, and always jointly constructed, something which I became very much aware of in engaging in the

interview process. Interviews are social interactions in which meaning is negotiated between a number of selves and in which power may be *more* or *less* shared. Collins (1998) states that it is '*rarely obvious*' where the balance of power lies. As interviewers we have a limited control not only over what is being said but also over who we are during an interview.

4.2.2.2 Interviewee as Storyteller

Interviews are not so much sites for the exchange of facts but rather sites for the exchange of stories (Collins, 1998). Carrithers (1992:1) observes that '*we cannot know ourselves except by knowing ourselves in relation to others*'. Many of the interviews that I carried out involved substantial streams of narrative involving the complex interweaving of a number of stories. Interviewees frequently developed a narrative thread quite spontaneously regardless of the questions put to them. Some of these 'meta-narratives' related to the explicit subject under review, some did not. Interviewees, therefore, have a ready means of countering and undermining the unequal relations of power which are said to typify all interviews.

Collins (1998:3.10) states that interviewees, in telling stories about themselves in relation to others, reconstitute themselves. In encouraging the interviewees to tell their stories and in asking them to develop a sub-plot here and a character there, I 'invited' interviewees to take part in the dynamic process of constructing and reconstructing themselves. The **way** in which interviewees told their stories often held more significance than the 'objective facts' presented. Two interviewees started their stories close to tears and despite being offered the option of postponing, cancelling or foreshortening the interview were very certain that they wanted to share their experiences. Indeed, both interviewees appeared to gather confidence and clarity in the very process of sharing their stories. By seizing the opportunity to 'process' previously

unspoken feelings, events and experiences, they appeared to be actively engaged in making meaning; reconstructing their experiences in a more personally meaningful way.

4.2.2.3 The Multiple Roles of the Interviewer

The role of the interviewer is equally dynamic and is negotiated within the researcher/researched relationship. The interviewer need be neither 'objective' nor 'detached', but should rather be 'engaged'. Engagement implies a willingness on the part of the interviewer to understand the interviewee's response to a question or prompt in the wider context of the interview as a whole. However, interviewees will continue to tell stories whether encouraged to or not (Chase, 1995; Collins, 1998). But it remains the job of the interviewer to represent and document these stories. Events recounted and experiences described are made substantial, more real, in being recorded and written down (Josselson, 1995). In this respect the interviewer can act as biographer.

This is not the only role that the interviewer is invited to play. At different times throughout the interview process I was invited to take on the role of witness, confessor, therapist, facilitator and validator. I'm sure that I also took on many other different roles at different times and with different respondents, that I was less aware of. These shifting roles, so often cited as problems to overcome in the more standard research methods textbooks, offered the greatest opportunities, I would argue, to uncover some of the most interesting and intriguing rich thick descriptions of carers' experiences.

4.2.3 *Data Analysis*

A major contribution of grounded theory methods is that they provide rigorous procedures for researchers to check, refine and develop their ideas and intuitions about the data. In addition,

these methods enable the researcher to make conceptual sense of large amounts of data. A grounded theory analysis starts with data and remains close to the data. The hallmark of grounded theory studies consists of the researcher deriving his or her analytic categories directly from the data, not from preconceived concepts or hypotheses. From the beginning, the researcher actively constructs the data together with their participants (Charmaz, 1990). The first question the researcher must ask is 'What is happening here?' (Glaser & Strauss, 1967; Glaser, 1978, 1992).

Grounded theory researchers can gain, both thick description and foster theoretical development by listening closely to their respondents, attempting to learn the unstated or assumed meanings of their statements and shaping their emerging research questions to obtain data that illuminate their theoretical categories. Levels of abstraction are built directly upon the data and are checked and refined by gathering further data (Glaser, 1978; Glaser & Strauss, 1967; Henwood & Pidgeon, 1992; Strauss, 1987). In this way, grounded theory studies yield dense conceptual analyses of empirical problems and worlds. Issues arising from both transcribing and the use of computer software packages for analysing qualitative data, can potentially pose a threat to the ideal of remaining 'close to the data'.

4.2.3.1 Transcribing Issues

Key questions relating to the issue of transcription include 'Should the researcher carry out the task of transcribing interviews or should help be enlisted?' and 'What should be transcribed and/or what should be omitted (if anything)?'

Transcribing the interview data myself, may have led me to become more closely involved with the data, which is presented as a potential benefit in much of the literature (O'Connell &

Kowal, 1995). I *did* transcribe my first pilot interview of an hour and three quarters. However, far from revealing and precipitating useful insights regarding the data, I struggled with the physically arduous task of listening intently and typing very poorly! Therefore, I made the decision to enlist 'professional' help, which allowed me to prioritise my time and resources for focusing on the data in a more productive way.

With regard to what to transcribe and what to omit (if anything), by enlisting help it was possible to get all interview data transcribed relatively painlessly. This maximised the amount of data available for exploration. Had I carried out the transcribing myself; and given that I had experienced this as a less than productive process, I may have been tempted to select out sections of data for transcribing, thereby increasing the potential risk of decontextualising data.

4.2.3.2 Use of Computer Software in Qualitative Data Analysis

Perhaps part of the reason why computer programs have been so popular is that the use of technology confers an air of scientific 'objectivity' onto what remains a fundamentally subjective, interpretative process. This is not to deny the obvious practical benefits to be gained from computer programs, but we need to think critically about why and how we use these programs. Certainly, a number of problems with qualitative computer package use have been identified. Computer packages require the researcher to learn how to use the program, which can involve a considerable investment in time. Grbich (1999:251) reported that NUD*IST users have estimated (anecdotally) that it takes three months to become proficient in the use of this program. In addition, there are numerous potential problems which may be associated with the use of any given program, e.g. graphical user interface, difficulties in file navigation, proliferation of dialogue boxes, etc.

The very 'user-friendly' NUD*IST Vivo was selected to aid data-analysis in this project, as it was appropriate for 'theory building' research. A number of hours were required to ensure proficiency in its use so that meaningful coding of the data could be achieved, but I experienced few problems with the program's 'accessibility'. Perhaps this was due in part to having gained previous experience of using computer software for qualitative data analysis (QSR NUD*IST 3.0). However, program proficiency was not my main goal in utilising NUD*IST Vivo, rather I was concerned with developing a means of handling data effectively to aid data storage and facilitate analysis.

4.3 Research Outcomes

4.3.1 Dissemination Issues

I consider it important to disseminate findings as widely as possible. So in addition to submitting Chapters 1, 2 and 3, to peer review journals, and in order to rapidly disseminate findings to clinicians, I intend to:

- submit brief research reviews to Special Interest Group Newsletters and In-Service journals, e.g. PSIGE Newsletter: Journal of the Psychology Special Interest Group in Elderly People.
- seek out appropriate conferences and submit papers and / or posters.

I am also in the process of producing:

- a short report (not to exceed 1 000 words) for research participants, outlining the main research findings, written in user friendly terms with the minimum use of jargon and technical terminology.

- a short report detailing the main research finding for contacts and collaborators in appropriate NHS Services.
- a summary of the study's findings for the Warwickshire Research Ethics Committee (required upon completion of the study as a stipulation of gaining ethical approval).

4.3.2 *Further Publications*

This grounded theory study has yielded a great deal of information concerning the experiences of those caring for a relative with dementia. Whilst suggestions for further research has been addressed in Chapters 2 and 3, there are a number of papers which can be generated from the existing data corpus. Possible forthcoming papers may focus on: a more extensive presentation of loss and existential themes present in the data; an exploration of identity and concept of 'carer'; and, spiritual and religious aspects of caregiving.

4.4 **Personal Reflections and Learning**

A key personal objective was to engage in grounded theory and learn how to operationalise this methodological approach in pragmatic terms, *in addition* to exploring the topic of caregiving in dementia, particularly aspects of loss. I was certainly given this opportunity, but was not ready for the degree of compromise that I would have to make. One of my key desires was that I should stay as true to the process of grounded theory as was feasibly possible. Concern was expressed by some staff and colleagues that I was intending to 'leave the literature review until last'. However, a well defined characteristic of the grounded theory approach is the requirement to delay the literature review, with the intention of reducing possible bias, contamination and constraining of the interview process; thereby permitting a

theory to 'emerge' from the data. (Charmaz, 1983, 1990, 1995; Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1993).

Certainly, I was alone in my cohort in selecting a grounded theory approach and consequently, whilst I was engaging in data collection and concurrent analysis, the majority of my peers were engaged in clarifying the theoretical underpinnings of their projects and completing the 'write-up' of their literature reviews. I was advised on a number of occasions to get my literature review 'out of the way'. Given the limited time constraints I could see the attraction of doing exactly that. So, the literature review presented here emerged from walking a fine line between succumbing to purely pragmatic concerns regarding time constraints and the desire to 'delay' the literature review as long as possible, in line with a grounded theory methodology.

I felt that I had to contain my own anxiety (and others' at times) about my apparent lack of similar progress to that of my peers. I was intellectually able to acknowledge that my chosen methodology required a different ordering of research tasks, but it was frequently difficult to consistently hold on to this at an emotional level and internalise this belief. My research was a far more lonely and isolating process than I had anticipated – whilst a grounded theory approach offered me an opportunity to get close (sometimes very close) to my research participants, it very much 'distanced' me from my peers and their experiences of the process of their own research (despite extremely sincere and very welcomed support from some peers at a personal level). It was a huge relief to find a fellow trainee on the Birmingham course also engaging in a grounded theory study, with whom I could 'share' my experiences of the research process.

4.5 Conclusion

Doing grounded theory, rather than a tidy process, is as messy as preparing a gourmet meal, where all the parts need to come together at the end.

Keddy, Sims & Stern (1996: 450)

Thankfully, all the parts of my grounded theory study **did** come together at the end but the quote above could equally have been applied to the entire research process. I have learnt much about qualitative research methodology; and I have gained some insight into the experience of loss and meaning making in caregiving in dementia, indeed this work has stimulated my interest such that I would like to carry out further research in this area. However, more importantly the experience of carrying out this research project has also functioned as a kind of existential metaphor for life. I have realised that, with the support of those I love, I can hold my nerve throughout great periods of confusion and anxiety, and have learnt to trust that the process will permit the emergence of something tangible, coherent and useful!

4.6 References

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Appendices

Appendix A	Submission Details for Journals <ul style="list-style-type: none">➤ Social Science and Medicine➤ Illness, Crisis and Loss➤ Qualitative Health Research
Appendix B	Ethics Committee Letter
Appendix C	Initial Letter to Potential Participants
Appendix D	Research Participant Information Sheet
Appendix E	Consent Form
Appendix F	Summary Information Sheet
Appendix G	Interview Schedule
Appendix H	Timetable of Interviews
Appendix I	Example of Transcribed Interview Data
Appendix J	Letter to Participants, to accompany Transcript
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Appendix L	Example of Transcript with Open Coding
Appendix M	Example of Axial Coding
Appendix N	Examples of Memos taken from Research Notebooks
Appendix O	Content Analysis

Social Science & Medicine

Description

Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of research findings, reviews and theory in all areas of common interest to social scientists and health practitioners and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (eg. anthropology, economics, education, ethics, geography, political science, psychology, social policy and sociology), and material relevant to any of the social sciences from any of the professions concerned with physical and mental health, and with health care practice, policy and organisation. It is particularly keen to publish findings or reviews which are of general interest to an international readership.

The journal will publish the following types of contribution:

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- 4) Letters relating to materials previously published in **Social Science & Medicine**, or to topical and internationally relevant issues concerning social science and health.
- 5) Editorials or commentaries commissioned by the Editors.
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Audience

Social Scientists (e.g. Anthropologists, Demographers, Economists, Educationalists, Ethicists, Geographers, Philosophers, Policy Analysts, Political Scientists, Psychologists and Sociologists) interested in health, illness, and health care; and Health or Health Care Professionals and Policy Makers (eg Dentists, Epidemiologists, Health Educators, Lawyers, Managers, Nurses, Pharmacists, Physicians, Public Health Practitioners, Psychiatrists, Surgeons) interested in the contribution of the social sciences.

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Two types of contribution are welcomed: full papers (original research reports or critical reviews of a field, preferably in no more than 8000 words) and short items (short reports of research findings, commentaries on topical issues or correspondence, of no more than 2000 words in length).

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Illness, Crisis & Loss

Editor

Robert Bendiksen *University of Wisconsin, La Crosse, USA*

...is a discipline networking journal based on the premise that significant progress in the fields of life-threatening illness and thanatology will be achieved by bringing together the expertise of many and varied professionals, including those in sociology, social work, nursing and counselling.

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Illness, Crisis & Loss welcomes original manuscripts of merit in the field of grief work and death studies. Submission Guidelines can be found inside the front cover of the journal. Articles including essays, interviews, intervention reports and creative works can be sent to

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The five examples below are references for books, book chapters, journal articles, government documents, and information from the Internet, respectively:

- Nadeau, J. W. 1998. *Families making sense of death*. Thousand Oaks, CA: Sage.
- Small, N. 1997. The public construction AIDS deaths in the United Kingdom. In *The unknown country: Death in Australia, Britain and the USA*, edited by K. Charmaz, G. Howarth, and A. Kellehear, 155-68. New York: St. Martin's.
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The Book Review editor is Dr Anton J Kuzel, Department of Family Practice, Medical College of Virginia, Virginia Commonwealth University, Box 980251, Richmond, VA 23298, USA. Books pertinent to qualitative methodology, health, or both are welcomed for review.

The Computer Editor is Judy Norris (Judy.Norris@UAlberta.ca), 6-10 University Extension Centre, 8303 - 112 Street, Edmonton, Alberta T6G 2T4, Canada. Articles related to computers and qualitative research are welcomed.

PAH

7th July 2000

Westgate House
Market Street
Warwick CV34 4DE

WARWICKSHIRE RESEARCH ETHICS COMMITTEE

Tel: 01926 493491
Fax: 01926 495074

The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

		Documentation Reviewed as itemised in ICH guidelines	
1.	Approved	Protocol	<input checked="" type="checkbox"/>
		Patient Information Form/ Consent Form	<input checked="" type="checkbox"/>
2.	* Approved subject to amendments listed below	Indemnity (signed)	<input checked="" type="checkbox"/>
		CTX	<input type="checkbox"/>
		Protocol Amendments	<input type="checkbox"/>
3.	Rejected for reasons listed below		
4.	Approved by Chairman's Action		

Ethical Committee Minute Number 446/00 Dated 28.06.00

Protocol Title and Reference Number

RE 446 Conceptualising Loss in Caregiving : a grounded theory study of daughters providing informal care for a parent with dementia (Ms Karen Moore)

- ◆ information sheet should be termed less clinically
- ◆ findings would have to be relayed anonymously and this should be made clear to the patient

Signed  Committee Chairman

Dated 10/7/00

This approval is subject to the following standard conditions :

1. the study must begin within one year.
2. the researcher must seek the Committee's approval in advance of any proposed deviations from the original protocol.
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its completion.

Programme Director**Doctorate Course in Clinical Psychology**

Dr Delia Cushway

BA (Hons) MSc PhD AFBPS CPsychol

School of Health and Social Sciences

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C O V E N T R Y
U N I V E R S I T Y

Our ref

Your ref

[Participant's name here]
[Participant's address here]

Karen Moore
Psychologist in Clinical Training
Doctoral Programme in Clinical Psychology
School of Health & Social Sciences
Coventry University
Priory Road
COVENTRY
CV1 5FB

Tel: [*****]

[Date]

Dear [Potential Participant's name here]

[Mental Health Clinician's name here] has kindly given me your name and suggested that you may be willing to consider taking part in my research project.

I am a psychologist currently studying for a doctorate in Clinical Psychology. I have had a long standing interest in the experiences of family members who care for a loved one with dementia and am very keen to continue my work in this area. As part of my studies I am required to carry out a research project and I would very much like to explore the experiences of daughters who provide care for a parent with dementia. I am hoping to carry out interviews in order to gain a deeper understanding of caregiving and aspects of 'loss' that may be experienced. I will then feedback the research findings to health service professionals working with carers and older adults, with the anticipation that the findings will aid professionals in providing effective support services to carers who find themselves in a similar situation to yourself.

I am looking for approximately ten volunteers who would be prepared to take part in a single long (1½ - 2 hours) interview with me. I very much appreciate how precious your time is, but do hope that you may consider taking part in the study. [Please see the enclosed 'Research Participants Information Sheet' for full details of my proposed project.]

Should you decide after reading the 'Research Participants Information Sheet' that you might like to be part of the study, please complete and return the slip overleaf in the stamped addressed envelope provided. It would help me greatly if you could do so within the next 2 to 3 weeks. However, if it takes you a little longer to decide please **do** return the slip at your convenience.

At this point the only thing that you would be committing yourself to, is a short (30 minute) meeting with myself, at a time and venue of your choosing (or telephone call if this is more convenient) to discuss the project further. We will have plenty of opportunity to address questions at our initial meeting, but please feel free to contact me on either the number above or on ***** should you wish to discuss the study prior to this meeting.

Thank you very much for your time.

Yours sincerely,

Karen Moore
Psychologist in Clinical Training
Coventry University & the University of Warwick Doctoral Programme in Clinical Psychology

Supervised by:
Dr. Julie Elliot, Chartered Clinical Psychologist, Coventry University & South Warwickshire Combined Care NHS Trust
Dr. Stephen Joseph, Chartered Health Psychologist, Senior Lecturer, Warwick University
Andrea Evans, Chartered Clinical Psychologist, South Birmingham Mental Health Trust

encl.

Please detach here and send in enclosed envelope

.....

**To: Karen Moore, Psychologist in Clinical Training,
Doctoral Programme in Clinical Psychology,
School of Health & Social Sciences,
Coventry University, Priory Road, Coventry, CV1 5FB**

I **would** be interested in attending a short, initial meeting (or phone call) to discuss the study further.

Signed _____

Name [in block capitals please] _____

Contact telephone number _____

Please indicate preferred time of day for me to telephone you _____

Programme Director
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C O V E N T R Y
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RESEARCH PARTICIPANTS INFORMATION SHEET

What are the project aims?

As briefly outlined in the accompanying letter, I am a Psychologist in Clinical training and I am very interested in exploring the experience of daughters providing care for a parent with dementia.

The project aims are twofold:

- Firstly, by gathering the views of a number of carers, I am hoping to explore and gain a deeper understanding of the caregiving process and the aspects of 'loss' that can be experienced in caring, e.g. social losses, personal losses, emotional losses, etc.

My intention is to feedback findings (via presentations and written reports and papers), both to research participants, and to clinicians working with carers and older adults – with the anticipation that the research findings will enable clinicians to provide a more effective support service to carers who find themselves in a similar situation to yourself.

- Secondly, I am hoping to submit a written form of the research findings for partial fulfillment of my Clinical Psychology doctorate.

What will be involved if I agree to take part in the project?

You will be invited to take part in an interview with me, at a time and location convenient to yourself. The interview will last for about 1½ to 2 hours, will be tape recorded and will focus on exploring the nature of any losses that you may have experienced as a result of providing care for your parent with dementia. Should you decide to take part, you will also be asked to sign a Research Consent Form.

Can I withdraw from the project at any time?

Yes. You are free to withdraw at *any time* or choose not to answer certain questions. This will not affect your right to receive current and/or future services.

What happens to my interview tape after the interview is over?

I will store all tape recorded information under lock and key. However, the cassette tape(s) will remain our joint property.

Who will listen to the interview tape?

Secretarial support staff, who will be employed to transcribe our interview, will listen to the interview tape. Secretarial support will be recruited from 'out of region' [Leeds], to ensure confidentiality and anonymity.

What will the researcher do with the interview data?

The interview data will be transcribed to produce a complete type written script of the interview. You will be offered the opportunity to review this transcript. You are free to veto use of, part of or, the whole script if you are unhappy about the content of your interview being used further.

If you agree to let me proceed with analysing your transcript, I will 'code' the interview script and begin to identify themes related to different aspects of 'loss' experienced by yourself as a carer of a loved one with dementia. These themes will be used to develop existing ideas about how carers experience the changing relationship with the person that they provide care for, especially issues relating to 'loss'.

Will anyone else see my interview transcript?

Possibly. It may be included in the Appendices to my doctoral submission. **However**, only I will be aware that it is **your** transcript. All interview data will be anonymised – you will **not** be identifiable. In addition, I may ask you if I can *directly quote* a number of small, anonymous, passages from your transcript, in the research findings, which I hope to present to clinicians and academics.

What happens if the interview raises some difficult feelings for me?

The nature of this project, with its emphasis on issues of 'loss', may raise some personal issues. We will have an opportunity to 'debrief' after we have concluded the interview. This will not be taped.

What if I wish to complain about the way the project is conducted?

I hope that in the first instance you would feel able to discuss any concerns that you might have with myself (via the address and telephone number given on the accompanying letter). However, if you feel unable to do so you and would prefer to speak to my supervisor, you are invited to contact:

Dr. Julie Elliott, Chartered Clinical Psychologist
Doctorate Course in Clinical Psychology
School of Health & Social Sciences
Coventry University
Priory Street
COVENTRY
CV1 5FB
Tel: 024 7683 8328
Fax: 024 7683 8784

Programme Director
Doctorate Course in Clinical Psychology
 Dr Delia Cushway
 BA (Hons) MSc PhD AFBPS CPsychol
School of Health and Social Sciences
 Coventry University
 Priory Street Coventry CV1 5FB
 Telephone 024 7688 8328
 Fax 024 7688 8784



C O V E N T R Y
 U N I V E R S I T Y

Our ref

RESEARCH CONSENT FORM

	Your ref Please indicate as appropriate Date
Has the researcher explained, to your satisfaction, the purpose of the project?	YES / NO
Have you read the Research Participants Information Sheet?	YES / NO
Have you had an opportunity to ask questions?	YES / NO
Have all questions, concerning anonymising; storage; access and analysis of interview data, been satisfactorily answered?	YES / NO
Are you clear about the intended use of the data?	YES / NO
Do you understand that you are free to withdraw from the research project: <ul style="list-style-type: none"> • at any time; • without having to give a reason for withdrawing • and without affecting your current &/or future health service provision. 	YES / NO
Do you feel that you have received enough information about the research project?	YES / NO
Do you agree to be interviewed?	YES / NO
Has the interviewer explained, to your satisfaction, the reasons for wishing to tape the interview?	YES / NO
Do you agree to the taping of the interview?	YES / NO
Signed _____	Date _____
Name in block letters _____	

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C O V E N T R Y
 U N I V E R S I T Y

Summary Info Sheet

About you:

Your first name? _____ Our ref _____

Your age? _____ Your ref _____

Do you have any siblings? _____

If so, can you give their first names and ages? _____ Date _____

Your marital status? (please delete as appropriate) living with partner / living apart from partner / living alone

How many children do you have? _____

Do any of your children live at home with you? If so, how many? _____

Your employment status? _____

About your mother:

Your mother's first name? _____

Your mother's age? _____

Your mother's marital status? (please delete as appropriate) widow / living with partner / living apart from partner

Where does your mother live? (please delete as appropriate) own home / with you in your own home / with a relative / in a residential home

About your mother's illness:

How long ago did you first notice that your mother was experiencing some difficulties? _____

Have you &/or your mother received a confirmed diagnosis of dementia? yes / no / not sure

If yes, when? _____

From whom? _____

About helping your mother:

How long have you been 'caring' for your mother? _____
 ('Caring', here, refers to any extra duties or activities that you may have taken on for your mother because she is unable to do them for herself or has difficulties in carrying them out due to her illness.)

Are you the main family carer for your mother? _____

Do you share 'caring' duties with your siblings? _____

Is there anything else that you think would be helpful to tell me about? _____

Please write any further comments overleaf.

Thank you very much for your time.

Interview Schedule

Please Note:

In adhering to a Grounded Theory methodology, it is intended that all interviews will be long, in-depth, open interviews (to last approximately 1.5 to 2 hours). It is therefore inappropriate to provide a formal interview schedule. However, I have listed below the key topic areas to be addressed.

It should further be noted that according to Grounded Theory methodology, the content of specific questions in subsequent interviews might differ slightly. The intention is a working towards a refinement of the theory as it 'emerges' from the data, i.e. data gathered from interview will be used to inform subsequent interviews, as data collection and analysis proceeds concurrently.

Key topic areas to be addressed in long interviews:

- relationship with parent with dementia
 - before
 - currently
 - future

*Issues, which may arise in discussion, may include
(prompts will be employed to address these areas if necessary):*

- change
- uncertainty
- loss

- the experience of providing care to a parent
 - role as a carer
 - role as daughter
 - role as mother
 - role as wife/partner
 - role as adult woman
 - role as employee, etc.

*Issues, which may arise in discussion, may include
(prompts will be employed to address these areas if necessary):*

- shift in roles
- renegotiation of role identity
- ambiguity, conflict, enmeshment
- positive aspects

continued overleaf....

- managing 'meaning' of role
 - as carer
 - as daughter
 - as mother
 - as wife/partner
 - as adult woman
 - as employee, etc.

*Issues, which may arise in discussion, may include
(prompts will be employed to address these areas if necessary):*

- transpersonal aspects, e.g. spirituality, peak experiences, etc.
- existential issues

- losses which may have been experienced
 - as carer
 - as daughter
 - as mother
 - as wife/partner
 - as adult woman
 - as employee, etc.

*Issues, which may arise in discussion, may include
(prompts will be employed to address these areas if necessary):*

- nature of losses, e.g. intrapersonal, interpersonal, socioeconomic
- meaning of losses, e.g. framing of experiences: past, current, future
- benefits arising from 'losses'

Timetable of Interviews

No.	Participant	Date of Interview	Data Collection Phase
1	PL	12 th Sept 2000	Pilot Phase
2	AB	18 th Sept 2000	Initial Data Collection Phase
3	JP	2 nd Oct 2000	
4	CS	13 th Oct 2000	
5	KB	14 th Nov 2000	Second Phase: Relational Sampling
6	DR	22 nd Nov 2000	
7	BF	1 st Dec 2000	
8	AH	5 th Jan 2001	Third Phase: Discriminate Sampling
9	GC	9 th Jan 2001	
10	LW	17 th Jan 2001	

Example of Transcribed Interview Data

The transcription of all taped interviews yielded a total of 265 pages of data. It would be impractical to include all transcriptions in their entirety here. A short section of one of the interview transcripts is presented here to illustrate the format of transcribed data.

Taken from participant KB's interview transcript

Date of Interview: 14 / 11 / 00

Length of full transcript: 33 pages

KB:

You do, you do the grieving in your own home. You look at your mum. When you're first told it could be weeks, it could be months, you look at this woman and everything goes through your mind. You know, that she's been there for 30 odd years and everything you look at her and then as years of illness jumps — I mean she went through at the beginning where things were happening very, very quick, you know and you — you do — you know you're losing her. You lose the mother. The mum that you know. Like Maura. Like Maura died, OK? It's like I explained I taught — I called her Maura. So Maura died as in Maura was the lady that I could laugh with, that I could talk with, you know. Some days it would be me and mum versus dad and Artie and things like that we could — because we had that sort of friendly talking relation — example one day me and mum were fed up with Artie and dad. Um this was a Sunday afternoon she goes I meet you in town tomorrow, Monday. I goes yea alright. So I met her on Monday the two of us went in the travel agent and bought two tickets for Cork. I flew out on the Wednesday and flew back in on a Sunday because we were annoyed with them and that was how I worked with her. You see? And then suddenly all that went. And I'd come here and it was like — she was like a stranger in that I couldn't talk to her anymore. And she annoyed me and she — she needed me rather than I needed her. The situation changed then. And I came here and, like I say — I'd lock myself away in the bedroom and I'd cry and cry and cry. And I actually grieved — I did grieve as if she died. To me, in my heart, she died then. She did die. She died all those years ago and then um what happened was it was one Christmas day we — it was all over the Christmas I was really terribly upset and we went up to like Artie's brother and his wife we spend a lot of time with them and we — they were having a party and we'd gone up and they were all going come on have a drink and Artie said leave her, she doesn't want a drink. And in the end, one of his brothers kept saying come on what's wrong with her, miserable cow! Why ain't she drinking. You know normally me and Artin, you know and Art and said look, you know, she's really going through a hard time with her mum. And that's when they all found out what was going on and they were told, you know — we've been told you know could be weeks, could be months, could be years and everything. And it was certainly like I was crying my sister-in-law was crying. One of my brother-in-laws were crying. Everyone was crying and it was like we were at mum's wake. It was really, really weird and then once that had all come out, I had a few beers and it was like, you know, 'cause I'm rea— Art and his family are very, very close. He's one of ten. He's one of ten and they're such a tight-knit family and when you're involved in that, they share your grief. Because like I say mum and dad were always here so they would come in and out and Hi Mick, Hi Maura. So it involved them as well when they were asking. They kept plaguing this blood day. And it was like everything came out and, and the grieving was over. Or it was really — it was so weird, you know. I'm sitting there crying my heart out. They're all crying because they've upset me on Christmas day and — that my mum's ill and everything but once we'd all had a good cry, it, it changed and then that was like — that was the build-up and I needed to let all that — that grief out and I let it all out and then, as I said, to me really Maura went and I was just left with mum's — mum's body. Even her body isn't her body anymore. So to me, mum is this woman and Maura is my mum and mum's just like the body that's up there.

KM:

That sounds like quite a — like a contained sort of thing that happened the way you described it like you know, J and M came along and sort of gave this news that it could be months or years.

KB:

Mm

KM:

And like that sort of started things on this particular Christmas day it's what happened at that point. You've got.....

KB:

It was almost like I buried her there that night. I'd buried her. We'd gone through — I'd lost in my head, I'd lost my mum because the shock of being told that she was gonna die that quick, you know, I thought she was gonna die really, really quick so I grieved then.

KM:

Yeah

KB:

And then that last night was when all the tension came out... That build-up was like that had been going on for months and months and months at different stages you would go up and I would look at mum then and I could see bits of her dying so it wasn't just like this Christmas day was like it was a one-day thing it was taking months and months and months

KM:

Yeah.

KB:

Seeming where [inaudible] I mean here, when you're here [inaudible] like crying and you know like if somebody had died. It was like somebody had died and you didn't know what to do and you couldn't be bothered to get up and you couldn't be bothered to wash and things like that. You go through different days and then the day you get up because you went through stages where one day you'd go up and she wouldn't really know you and then the next day she'd be able to hold a conversation with you so it's an emotional roundabout sort of thing with her. But no, it was almost like — that Christmas day was like I put her down the hole in a box and then we carried on. It's the only way I can describe it.

KM:

Till the next time that you actually saw her?

KB:

Yeah

KM:

You really — you know like the

KB:

No it carried on. It did carry on. It does carry on but now — I say I don't — it's hard to explain to you how I view my mum, you know. Unless you're inside my head.

KM:

Yeah

KB:

To me, my real mother is dead. Alright? That's the only way I can say it to you. My mother died years ago. All I have left is a shell of what was my mum. So to me, I have lost my mum. This is another lady — I can't get through to her.

KM:
Yeah

KB:

To me in my eyes, my real mother — the woman that I could talk to, communicate with and go shopping with, ring up if I needed anything. Or she'd ring me up if she needed anything. The woman that was my friend. She's gone. She has gone because mum has not got that personality anymore. My mother is somebody who sits there, who can hardly get out of a chair — that's not my mum. Right? My mum was an active lady. She was a very clean lady. Everything had to be washed meticulously. So that, that Maura — my mum — has gone and — and I said good-bye to her many times. I said good-bye to her but I still have to say good-bye to this other lady. It's almost like there's two — two ladies. The real mum has gone. Right? No doubt about it. In my mind, I lost my mum years ago. I have just got to say good-bye to the body part now. But the mind part is gone. It's the mind I said good-bye to.

KM:
Yeah

KB:

[inaudible] I said good-bye to the mind, which is my mother. You see. She's not my mother. She's not my mum because your mum is somebody that you can turn to, who supports you, cuddles you, looks after you, protects you. And that's not the description I'm giving of my mum. I'm not. So I know she — Maura died. Maura died and mum's left. You have to understand my relationship with my mum to understand Maura. To me, Maura is the real mum. And mum is just — is just a word. A word, my mum, you know. Maura — because I probably call her mum more now. I never called mum "Mum". I always called her Maura. Because she was my friend. She would meet me when I was working. She would meet me for dinner and we'd go to the pub then and things like that. That was Maura. That was my mum.

Programme Director
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C O V E N T R Y
 U N I V E R S I T Y

Our ref

[Research Participant's name here]
 [Research Participant's address here]

Karen Moore
 Psychologist in Clinical Training
 Doctoral Programme in Clinical Psychology
 School of Health & Social Sciences
 Coventry University
 Priory Road
 COVENTRY
 CV1 5FB

Tel: [*****]

[Date]

Dear [Name of Research Participant here]

Re: Research Project: Interview Transcript

Thank you for taking part in our interview of the:

[DATE & TIME OF INTERVIEW HERE]

Here at last is the transcript of our interview! As you might remember (though as this was some time ago I will take the liberty of reminding you) I said that I would be returning two copies to you. One is for you to retain; the other copy is for you to check, make any additions, amendments or edits and return to me in the stamped addressed envelope enclosed. I do hope that you will have a few moments to do this for me. Your 'check' does not need to be exhaustive, so long as you are happy with me using the transcript. You may just spend a couple of minutes glancing through the many pages or you may choose to examine the transcript line by line, the decision is yours.

Looking at the transcript may trigger some thoughts or feelings that you think might be useful to tell me about. You may have had some thoughts in the days following our interview together that you would like to have included in our interview. If you do have any further thoughts or ideas that you would like me to know about please jot them on a piece of paper and return them to me with your 'checked' interview transcript. Or if you would rather speak to me directly, please call me on one of the phone numbers above (I can call you back, so that any expense for yourself is minimised).

When I receive your 'checked' transcript I will put it alongside the 'checked' transcripts from other interviewees and start to analyse, line by line, what you have said about your experiences by picking out common themes. I will keep you updated with this process and hopefully, toward the end of May (though it maybe June) I will send you a brief report of what has developed from the analysis and details of how this will be fed back to health professionals.

You will also find enclosed a 'Summary Information Sheet'. I would be extremely grateful if you take a few moments to complete it and return with your transcript. I know that much of the information I'm asking you for will have been covered in our interview together, however it's likely that there will be one or two questions that are new.

Please call me if you have **any** questions or concerns and thank you once again [NAME OF CARER HERE] for agreeing to take part in this project.

With very best wishes,

Karen Moore BA (Hons), MA, PGDip Psych, Cert Counsel.
Psychologist in Clinical Training
Coventry University & the University of Warwick Doctoral Programme in Clinical Psychology

Supervised by:

Dr. Julie Elliot, Chartered Clinical Psychologist, Coventry University & South Warwickshire Combined Care NHS Trust

Dr. Stephen Joseph, Chartered Health Psychologist, Senior Lecturer, the University of Warwick

Andrea Evans, Chartered Clinical Psychologist, South Birmingham Mental Health Trust

encl.

Example of Participant Notes and Letters

Some participants included letters and notes with the transcript copy that they returned following screening. A short section of the notes returned by one participant and letter returned by another is presented.

Taken from participant AH's notes:

Over the past 6 years we have had a gradual role reversal. I have become the 'mother' and she the 'child'. For a long time she has referred to me as her best school friend from her younger days. Apparently this friend lived opposite where she grew up. Mum will often ask me how my mother is these days and does not understand when I try to explain she is my mother so I just have to go along with her. She knows my name is 'A' but is adamant I am this friend (Gladys and Isabel were her two best friends – I've never been able to establish which of these I am!) and that I am not her daughter. I have had to come to terms with this as it is a strange feeling – a bit detached, but in some respects I am happy she chose me to be her best friend, not either of my sisters.

I do feel a certain loss of freedom, as I always have to think of Mum's needs before making any arrangements, holiday plans, days out, etc. I occasionally feel resentful as nearly all my married life I have not had complete freedom as my late mother-in-law was widowed 5 years after T. and I married and as T. was an only child we had to include her in most things we did. On good days I feel I want to protect her and am able to hug and put my arms around her and give her a kiss on the cheek – I never used to be that close to my Mum. On bad days when she gets me down I wonder how much longer I have to put up with this caring and feel resentful this has happened to me.

I get no recognition for the running of her home or affairs from her and this can be disheartening at times – especially when I have spent all day washing and cleaning for her and the next day everything needs doing again and she has not even noticed. Mostly though, I just look upon it as a job I am being paid to do and that goes some way to make things feel better. I often have to offload my thoughts and feelings to my husband and daughter – this helps a lot too, although I know I shield them from a lot. I feel I like to be in control of the whole situation and am quite capable of managing which is how Mum used to be. I feel sad I have lost my Mum and think I have already grieved losing her and when she dies it will be a relief in many respects.

Taken from participant AB's letter:

On the day after the interview (Sept. 19th) my mother suffered a slight stroke, which led her to have several nasty falls and sadly she died on October 7th – aged 92 years. Fortunately, the residential home was able to cope and she didn't have to go into hospital; so we were thankful for that.

Although there have been many occasions in the past nine years when my mother was close to death, it was nevertheless a shock when she died. This surprised me. I thought I was prepared for her death. In many ways I think I did most of my grieving last year when she went into care and we had to clear her bungalow. That was quite traumatic – as was coping with sorting out her clothes after she died. I still regret having to put her into a home, but I can still remember how desperately tired I felt this time last year coping with her increasing dementia. We have lots of lovely happy memories of my Mum as she was in her hey-day. We had a lovely funeral service, singing the hymns she'd chosen. I also chose a Psalm and found out that it was one that my mother read aloud in the air raid shelter during the Coventry Blitz.

Having a Christian faith and believing that my mother is now in heaven has been an enormous help.

Example of Transcript with Open Coding

Taken from participant KB's interview transcript

Date of Interview: 14 / 11 / 00

Length of full transcript: 33 pages

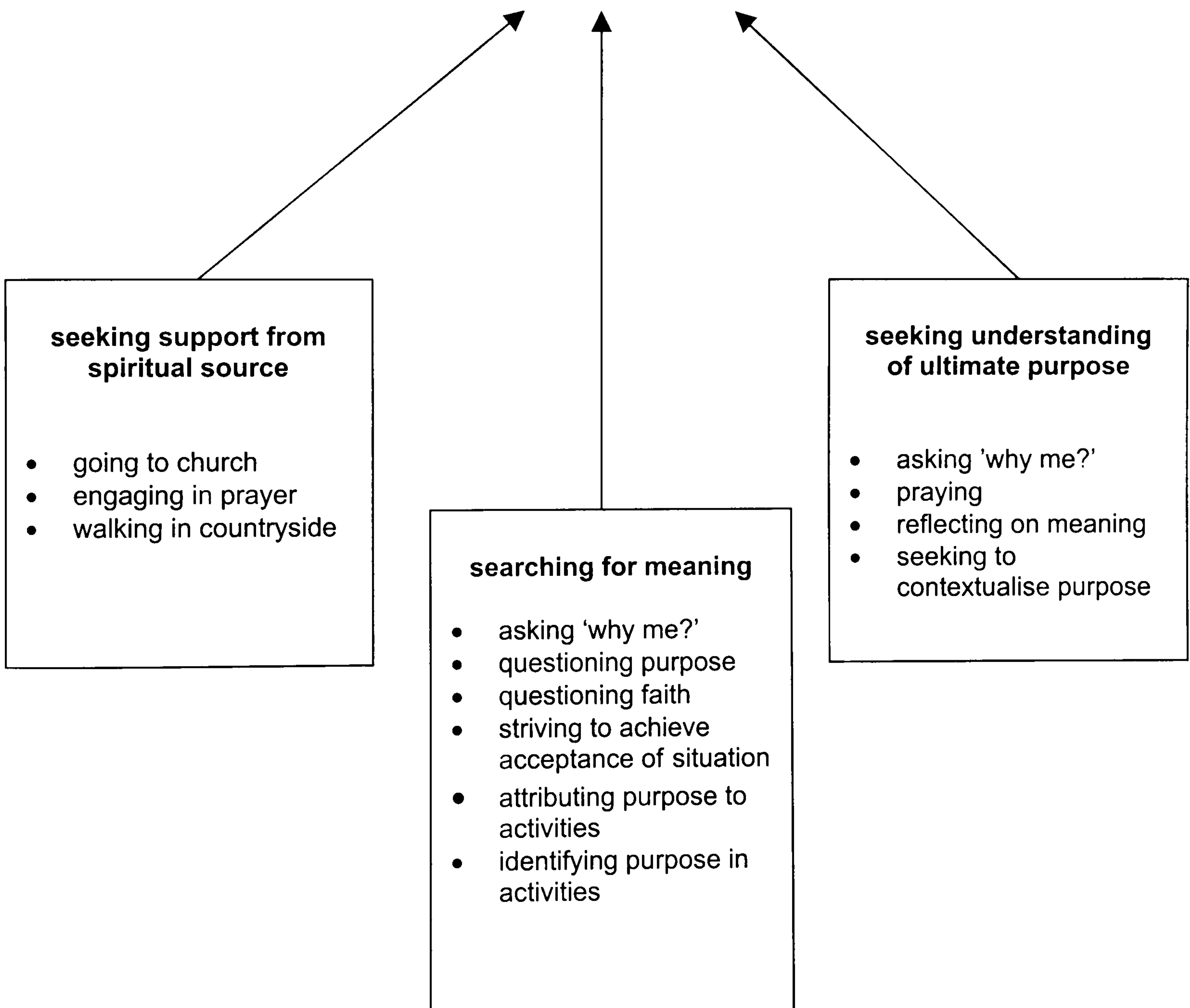
<i>acknowledging change, acknowledging difference, loss of pre-morbid mother</i>	Introduce you to mum as in how she is now or how she was? Because I do.. — I don't see mum as my mum.
<i>seeking validation</i>	You can understand that.
<i>acknowledging change, acknowledging difference, loss of mother as known mother, holding a external idea of 'mum', comparison with pre-morbid relationship</i>	It's who she is now is she is my mum but she's not my mum so before, if you go now, she's somebody who's like a baby. She — she's just not somebody that you would say this is my mum. I remember the relationship I had before she got ill because I'm —
<i>comparison with other relationships, mother as part of 'parent dyad' regret about pre-morbid relationship, acknowledging supportive role of pre-morbid mother</i>	I've always been very, very close to my dad but with my dad comes my mum, even though we didn't have a perfect mother and daughter relationship because I had that with dad, she's always been there for me.
<i>acknowledging supportive role of pre-morbid mother, pre-morbid mother as confidante, protecting dad, pre-morbid mother as dependable, pre-morbid mother as advisor</i>	If I was in any trouble, I knew I could go to her. I would go to her with my troubles rather than upset my dad. It's such a — I wouldn't do anything to hurt him but I knew that she would give me the solid advice. She was, I would say, the one I would turn to if I needed advice on anything rather than asking dad.
<i>pre-morbid closeness to parents acknowledging past routines loss/change of routines cherishing constant relationship</i>	But I mean I spent a lot of time with mum and dad. And when I left home, I left home at what? 19? And when I went to live with Artie. But I've always sort of like if they go out we go out and mum's always had like certain days that she would come to us. And she'd always come on a Thursday and I mean in fact, up to about a year, year and a half ago, every Thursday they'd go to us, do the shopping, they'd come here for lunch and everything so that relationship has been going oh, 20 years. That's every Thursday for 20 years they came here. So it's like — it's something that we've had since I left.
<i>acknowledging change loss of mother as known mother, expressing feelings about mother difficult</i>	But now it's like when she comes in now it's just like she's just so different. It's really, really hard to explain how I feel about her. You know? I'm going to jump into all these sections now.

Example of Axial Coding

Axial coding is the process of relating codes (categories and properties) to each other, via a combination of inductive and deductive thinking. An example is presented below of one of the emergent categories.

Category:

Existential and Spiritual Strategies



Examples of Memos taken from Research Notebooks 1 & 2

The two examples presented here are typical of the many memos recorded in the Research Notebooks.

Reflective Memo

Date: 02 / 02 / 01

Personal reflections in response to re-reading participant AH's interview transcript:

'Mother/daughter' relationship is completely lost when performing intimate care duties. 'Losses' not only temporal dimension over caring career but also potentially within the space of a given day – which can then be reclaimed(??) whilst carrying out other duties / at other times during day. Losses experienced and regained within day, within moment??

Re: mother – *'thinks she is able to run her life and home without help'* - ??similarities with carer's approach to own life and caring role?

?emotional rollercoaster – interventions for carers need not only to embrace practical problem solving but explicitly acknowledge aspects of 'loss' and most importantly 'change' and 'uncertainty' as key themes in carers' careers. Need to provide a context within which carers can understand their own feelings and have these validated by staff and peers in supportive environment.

Themes of loss, change, uncertainty frequently identifiable covertly / underpinning interventions – but bypass need for (explicitly) carers to do emotional work and important task of reconstructing / managing meaning (in existential terms). If interventions fail to acknowledge these themes explicitly they actively run the risk of further compounding and perpetuating feelings of guilt, blame, 'why me?', etc.

Analytical Memo

Date: 23 / 01 / 01

Major themes emerging – themes arising from axial codes.

- loss of particular dimensions / aspects / experiences
- change as temporal artefact / dimension
- restructuring / reconstructing interpersonal / intrapersonal dimensions of the self / of the cared for



this leads to losses, but also positives, e.g. acquisition of new skills / knowledge / discovery

'dynamic process' – characterises carer's experiences of providing care
dynamic model of loss?

Content Analysis

Participant	No. of Sources of Meaning Identified	No. of Categories within which Sources of Meaning fall	Categories within which Sources of Meaning fall	Level of Greatest Depth expressed
PL	10	6	RM; ISR; IPS; PDL; SCP; PD	4
AB	14	9	RM; TA; ISR; IPS; RSB; PDL; C; SCP; PD	4
JP	8	5	RM; RSB; PDL; SCP; PD	4
CS	4	4	RM; ISR; IPS; SCP	3
KB	7	4	RM; ISR; C; SCP	4
DR	12	6	RM; TA; ISR; IPS; PDL; SCP	4
BF	8	5	RM; ISR; RSB; C; SCP	4
AH	9	6	RM; TA; ISR; RSB; C; SCP	4
GC	7	4	RM; TA; ISR; SCP	3
LW	11	6	RM; TA; ISR; IPS; C; SCP	3

Key for Categories of Sources of Meaning:

RM	Reciprocity / Mutuality
TA	Temporal Aspects
ISR	Intimate Supportive Relationships
IPS	Intrapsychic Sources,
RSB	Religious and Spiritual Beliefs,
PDL	Philosophy of Daily Living,
C	Creativity
SCP	Social and Community Purpose
PD	Personal Development

Content Analysis

Participant	No. of Sources of Meaning Identified	No. of Categories within which Sources of Meaning fall	Categories within which Sources of Meaning fall	Level of Greatest Depth expressed
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KB	7	4	RM; ISR; C; SCP	4
DR	12	6	RM; TA; ISR; IPS; PDL; SCP	4
BF	8	5	RM; ISR; RSB; C; SCP	4
AH	9	6	RM; TA; ISR; RSB; C; SCP	4
GC	7	4	RM; TA; ISR; SCP	3
LW	11	6	RM; TA; ISR; IPS; C; SCP	3

Key for Categories of Sources of Meaning:

RM	Reciprocity / Mutuality
TA	Temporal Aspects
ISR	Intimate Supportive Relationships
IPS	Intrapsychic Sources,
RSB	Religious and Spiritual Beliefs,
PDL	Philosophy of Daily Living,
C	Creativity
SCP	Social and Community Purpose
PD	Personal Development