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Relationships, motivations, and meanings in informal caregiving for people with dementia

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SUMMARY

Numerous theoretical models have been developed to explore how caregiving can impact on caregivers' wellbeing. However, less attention has been given to caregivers' motivations for providing care, the meaning they find in caregiving and their relationship with the care-recipient. The aim of this thesis was to explore the role of relationships, motivations, and meanings in dementia caregiving. This thesis utilised a mixed methods approach. Two systematic reviews suggested that relationship quality, motivations, and meanings could individually impact on caregivers' wellbeing. The reviews indicated that the interrelationships between caregiving motivations, the quality of the relationship with the care-recipient, and ability to find meaning in caregiving, and the relative contributions of these factors to caregiver wellbeing, have not previously been examined. Based on the findings of the reviews, a qualitative study with twelve caregivers explored their subjective experience in relation to motivations, meanings and relationships, and found that they were engaging in a process of 'balancing needs', in which they constantly struggled to balance their needs with the care-recipient, creating dilemmas which had to be managed as part of everyday life. A second qualitative study incorporated the perspectives of caregivers, care-recipients and Admiral Nurses into six case studies. These members were engaged in a process of 'negotiating the balance', which describes their ongoing struggle to balance the views of the other members against their own needs. Building on the findings of these studies a cross-sectional questionnaire study assessed associations between relationships, motivations, and meanings, and the impact of these factors on caregiver wellbeing. The questionnaires were completed by 447 caregivers. This study found a positive association between motivations, meanings, and relationship quality. These factors could also influence caregivers' wellbeing. Predictors of finding meaning were also discussed. The findings suggest that a greater understanding of meanings, motivations, and relationships could aid the development of more effective interventions for caregivers.

Chapter 1: Introduction

Introduction

Informal caregiving has been conceptualised as a career which can commence even before the care-recipient has been diagnosed with a condition, such as dementia (Pearlin, 1992). In this thesis the term 'caregiver' is used to describe a person who provides regular help and assistance to another person on an informal basis. Zarit and Edwards (2008) described how a relationship develops into a caregiving relationship when one person becomes increasingly dependent on others for assistance with activities of daily living. A person's entry into the caregiving role may be very subtle, and many caregivers may not perceive themselves to be 'caregivers'; rather they are simply helping out a family member or friend (Burton, 2008). With increasing dependency, caregiving transforms into a dominant part of the relationship, which may eventually encompass all of it (Pearlin, Mullan, Semple, Skaff, 1990). Informal caregiving is widespread, in 2001 it was reported that there were 5.2 million informal caregivers in England and Wales (National Office for Statistics, 2001). Care can be provided over long periods of time, and the amount and type of care needed changes as the care-recipient becomes more dependent on the caregiver for help. By conceptualising caregiving as a career, Pearlin (1992) proposes that this career continues even after the care-recipient has been placed into full-time care or has died. Given that caregiving can be longitudinal in its nature, it is important to understand the experience of caregiving so that more effective support can be provided to these caregivers.

It is recognised that we now live in an increasingly aging society. The number of people aged 85 and older, the age group most likely to need care, is likely to increase to 1.9 million in the next decade (Department of Health, 2008). This older population is most at risk of developing dementia. It is estimated that there are currently 683,597 people in the United Kingdom with dementia and it is predicted that this figure will rise to 1,735,087 by the year 2051 (Knapp & Prince, 2007). To put this in context, in the European Union there are 5.4 million people with dementia (Alzheimer's Europe, 2006) and over 5 million people with dementia in the United States (Alzheimer's Association, 2009). Thus, it has been argued that dementia is a major public health issue for the 21st century (Alzheimer's Europe, 2006).

A growing awareness of the prevalence of dementia has resulted in an increased interest in the impact of dementia on those expected to give informal care. Informal care is normally provided by family and friends. It is recognised that this traditional source of care is changing as a result of the reduced availability of people to provide care. Therefore UK policy now recognises that the challenge is to balance the number of people who need care with those willing to provide care. UK policy is prioritising earlier diagnosis of dementia (e.g. Department of Health, 2009) and this provides the opportunity for earlier intervention with both caregivers and people with dementia. Several policies have been developed to support the needs of informal caregivers (e.g. NICE-SCIE, 2006; Department of Health, 2008; Department of Health, 2009) however it has previously been found that caregivers have reported that their needs were not being met (Carers UK, 2003). In order to provide more effective support to both caregivers and people with dementia, there should to be a better understanding of the needs of caregivers and the factors that can help sustain caregiving. The aim of this thesis is to examine some of these factors, and explore their role in the development and continuation of the caregiving relationship. In order to understand the relevance of these factors it is important to understand the impact of dementia on caregivers.

Dementia and caregiving

It is estimated that in the UK one in twenty adults aged over 65 and one in five adults aged over 80 has a form of dementia (Knapp & Prince, 2007). Dementia results in a progressive decline in multiple areas of function including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this decline, people with dementia may develop behavioural problems, such as wandering and psychological symptoms such as aggression and depression (Snyder & Nussbaum, 1998). As the severity of the illness progresses, this increases the amount of care the person requires. In the UK it is estimated that two thirds of people with dementia reside in the community, the majority of whom will require an extensive amount of informal care (National Audit Office, 2007). In the US 10 million caregivers provide 94 billion hours of care (Alzheimer's Association, 2009), whilst in the UK it was found that over 1 million caregivers were each caring for over 50 hours per week (National Office for Statistics, 2001).

Theoretical models of caregiving

Caregiving has traditionally been perceived as an extremely stressful activity; indeed studies have found that caregivers have worse health and wellbeing than non-caregivers (Pinquart & Sörenson, 2003a; Vitaliano, Zhang, & Scanlan, 2003). Given that caregiving has been perceived as having a negative impact on caregivers, numerous theoretical models have been created to explore how caregiving can impact on caregivers' wellbeing. Some of the more dominant models will be briefly discussed here, and some will be further discussed in later chapters. Although not specifically designed for caregiving, the Double ABCX model (McCubbin & Patterson, 1983) has been utilised in research with caregivers of people with dementia (e.g. Cohler, Groves, Borden & Lazarus, 1989; Rankin, Haut & Keefover, 1992). This model proposes that a build up of stressors from an adverse life event interacts with a family's existing resources and their appraisal of the event to result in either 'bonadaptation' or 'maladaptation'. Thus, this model indicates that there can be a positive or negative outcome to a stressful event. In relation to dementia caregiving, Cohler et al. (1989) proposed that the adverse life event could be the diagnosis of dementia and the stressors could emerge from caregiving. The caregiver may appraise caregiving as stressful or burdensome, for instance having little time for him/herself. This model has been modified by Rankin et al. (1992) who combined it with the Circumplex model. The Circumplex model proposes that a family's functioning is affected by two dimensions: adaptability and cohesion. Adaptability relates to the family's ability to respond to stressors by changing the power structure and roles. Cohesion relates to the emotional connectedness between family members. In addition it is suggested that a third factor, communication, can influence a family's response to stressors. Rankin et al. (1992) proposed that both the family's adaptability and emotional cohesion can influence their ability to cope with caregiving. In Rankin et al.'s (1992) model factors from the Circumplex model marital communication and marital cohesion/adaptability were considered to be family resources. Rankin et al. (1992) argued that this modified model illustrates the importance of exploring both family and relationship factors when assessing the impact of family caregiving.

The most frequently adapted theoretical framework for research on caregiving is the psychological stress and coping paradigm developed by Lazarus (1966). This perceives coping as a set of constantly changing efforts to manage internal and/or external demands. This involves the person appraising the situation to judge whether the resources s/he has to deal with the stress are adequate. Lazarus and Folkman (1984) identified two ways in which a person can cope with stress. The first involves problem-focused coping in which the person takes action to tackle the problem. Alternatively, emotion-focused coping involves the person taking steps to regulate his/her emotional state. In addition, Kramer (1993b) proposed that there can be relationship-focused coping, which may either preserve relationships or damage relationships. The choice of coping behaviour is determined by the person's appraisal of the stressful encounter. McKee et al. (1997) studied the coping strategies used by caregivers of older adults and found that the majority employed emotion-focused strategies to combat stress although the use of problem-focused coping resulted in better perceived coping. Haley, Levine, Brown and Bartolucci (1987) utilised this framework with caregivers of people with dementia and found that appraisals, coping responses and social support were significant predictors of caregiver outcomes.

Two factor models of caregiving integrate the stress and coping paradigms and the Double ABCX model. These models have been developed which hypothesise that there can be both positive and negative outcomes of caregiving. Lawton, Moss, Kleban, Glicksman and Rovine (1991) proposed a two factor model because on the one hand it is an activity which caregivers may find positively affirming, but on the other hand caregiving can be very stressful and burdensome. Thus, they proposed that caregiver burdens and satisfactions can have differential impacts on wellbeing. In Lawton et al.'s (1991) model, caregiving burden and satisfaction are perceived to be forms of appraisal. Caregiving satisfactions are positive aspects of caregiving or positive rewards of caregiving. Caregiving burdens relate to a negative appraisal of caregiving, with the caregiver perceiving it to be stressful. In this model only appraisals of caregiving satisfaction can influence the outcome of positive affect. Conversely, only appraisals of burden can influence the negative outcomes such as depression. In a conceptual model of caregiving adaptation, Kramer (1997) also proposed that only appraisals of role gain were associated with positive affect, with appraisals of role strain linked to negative affect. Kramer (1993a) proposed that both characteristics of the caregiver and caregiving stressors can impact on caregiver outcomes through mediating conditions. These mediators can be the caregiver's personal resources, such as social support, and coping responses. The outcomes of this process can be maladaptation, a negative outcome such as depression. Alternatively, the outcome could be bonadaptation, a positive outcome such as increased caregiving satisfaction.

Whilst two-factor models focus on appraisal, the Stress Process Model (Pearlin et al., 1990) explores the many different factors that can influence the outcome of a stressful experience. The Stress Process Model (SPM) acknowledges that caregiving is a complex process, where there can be great variation in how a person adapts to and copes with the caregiving role. The SPM proposes that caregiving stress is a dynamic interaction of the changes in the organisation of caregivers' lives and the effects of this re-organisation on their self-judgements (Pearlin et al., 1990). The SPM contains four main components: the background and context of stress, stressors, resources/mediators and outcomes. The background and context variables include aspects of the caregiving history, and social and economic factors. In terms of stressors, this model distinguishes between primary stressors and secondary role strains. Primary stressors emerge from actions directly related to providing care for the care-recipient. These stressors can have objective dimensions, which relate to the actual activities of providing care and subjective dimensions which refer to the immediate impact these stressors have on caregivers (Zarit & Edwards, 2008). Secondary role strains emerge from the changes in the caregivers' lives because of caregiving and can include family conflict, disruption of social and leisure activities and disruption of work (Pearlin et al., 1990). Secondary stressors can also involve 'intrapsychic strains', whereby there can be changes to the caregivers' self-concept. This may involve a loss of a sense of self or identity, although it is also recognised that caregiving may contribute positively to the self-concept (Zarit & Edwards, 2008). The impact of these stressors can be influenced by mediating conditions or resources which can include coping, social support and mastery/control. These resources are not fixed and can be developed or depleted over time. Zarit and Edwards (2008) have argued that there is a dynamic relationship between stressors and resources whereby effective resources may decrease the impact of stressors, whilst ineffective resources may increase stressors. There can be considerable individual variability in the outcomes of caregiving, although in general the outcomes tend to be negative impacts on health and wellbeing. The SPM has been criticised for primarily focusing on the negative outcomes of caregiving and for not exploring the role of appraisal. Some researchers have modified the model to address these criticisms, for instance Yates, Tennstedt and Chang (1989) incorporated the concepts of appraisal from Lawton et al's (1991) model into the SPM.

Kahana and Young (1990) devised dyadic models of caregiving which incorporated both the caregiver and care-recipient. The Congruence model focuses on the interactions between the caregiver and care-recipient. This model concerns the dependency of care-recipients and the dependency inducing behaviours of the caregiver. Caregivers who continually do tasks for the care-recipients may make them more dependent and helpless. This process can result in there being a match or mismatch between the care-recipient's dependency needs and the caregivers responses to these needs. A mismatch would result in negative outcomes. It is recognised that this mismatch may only be transient because the caregiver may develop new strategies to tackle the care-recipient's dependency. Kahana and Young (1990) have also argued that traditional models have tended to interpret caregiving as one directional in which the caregiver provides help and the care-recipient receives the assistance. Bi-directional models interpret this relationship as a two-way relationship, where there can be both positive and negative outcomes. In a bi-directional model focusing on the caregiver, the care-recipient is perceived as both a source of stress and a source of uplift. Uplifts may emerge from caregiving through the caregiver feeling competent in their role. Alternatively uplifts may arise from appreciation from the care-recipient or through seeing the benefits of caregiving on the care-recipient's wellbeing.

This thesis will primarily focus on the SPM, ABCX model, and the two-factor models. It is recognised that these models have their limitations. The SPM has neglected the positive outcomes of caregiving. Although the two factor models include positive outcomes, the two factor models proposed by Kramer (1997) and Lawton et al. (1991) suggest that positive aspects of providing care can only result in positive rather than negative outcomes. More recent research has started to focus on the positive aspects of caregiving. A systematic review by Kramer (1997) identified 29 empirical studies that examined caregiving gain. A meta-analytic review by Pinquart and Sörenson (2003b) identified 28 studies which examined perceived uplifts of caregiving. Kramer (1997) noted that some of the limitations of the studies on positive aspects of caregiving were that they were not based on any theoretical frameworks, and that few studies provided any definitions of the terms being used. Thus, there is need for more theoretically based studies on the positive aspects of proving care, which will contribute to the understanding of caregiver adaptation (Kramer, 1997).

Policy on dementia and caregiving

The models discussed highlight the many different types of stressors associated with caregiving, and indicate that the outcomes of caregiving can be influenced by mediators or resources. Despite the apparent stressors associated with caregiving, the UK government is committed to reducing reliance on the State and instead increasing emphasis on family care (Lloyd, 2000). One of the primary reasons for this is that dementia care is expensive. Wimo, Winblad and Jönsson (2007) estimate that the total worldwide societal costs of dementia in 2005 were $315.4 billion. In England the annual costs of health and social care for people with dementia are £33 billion (National Audit Office, 2007). Informal care also has a cost; in the UK the annual cost of informal care is £5.2 million (National Audit Office, 2007), whilst the worldwide cost of informal care is $105 billion (Wimo et al., 2007). These estimates take into account the loss of income suffered by an informal caregiver who has had to give up work or cut back working hours to provide care. These figures can be also interpreted as the amount of money it would cost to replace informal caregivers if they were not fulfilling this role. Therefore, it has been recognised that informal care represents an economic value from a societal point of view (Wimo et al., 2007). This is supported by the finding by Knapp and Prince (2007) that the cost of care home placement in the UK is £7 billion a year and two thirds of those costs are paid for by the State (National Audit Office, 2007). Knapp and Prince (2007) estimate that it costs less to keep a person with dementia in the community, even in the severe stages, than it does to have them in a care home. Thus it is not surprising that current UK policy emphasizes the importance of informal caregiving and the need to prevent unnecessary institutionalization (Department of Health, 2009).

In UK governmental policy, informal caregiving is viewed as both normative within families but also warranting some extra support from the government. The provision of support has been outlined in several policies, which have tended to address the needs of caregivers and care-recipients separately. Policies on caregiving have tended to treat caregivers as a homogenous group. The Department of Health's National Strategy for Carers published in 1999 focused on offering information, support and care to caregivers. It highlighted the importance of informal caregiving but also the need for caregivers to partake in paid work. This emphasis on employment is still evident in recent caregiving policy (Department of Health, 2008). The policy 'Carers at the heart of 21st century families and communities' states that by 2018 all caregivers will receive support "tailored to meet individual's needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen" (Department of Health, 2009, p.9). In order to achieve this, caregivers will be provided with access to information and respite breaks. In addition, a training program for caregivers entitled 'Caring with Confidence' will be developed alongside a helpline and website.

The role of caregivers has also been recognised in policy for people with dementia. Until recently dementia received little attention in UK mental health policies or policies for older people. Whilst Standard Seven of the National Service Framework for Older People (Department of Health, 2001) did specifically recognise the need to provide support for older people with dementia, this would not encompass the needs of people with dementia who are under 65. Conversely, policies focusing purely on mental health have tended to promote recovery, which would not acknowledge the degenerative nature of dementia (Cook, 2008). In addition, these mental health policies would not fully cover the needs of people with dementia, who could have additional health problems. Cook (2008) has argued that dementia was previously given less attention in policy as there was a belief that nothing could be done to improve the wellbeing of people with dementia. With a change in attitudes towards dementia several policies have been developed to specifically help support people with dementia and their caregivers (e.g. Department of Health, 2009; NICE-SCIE, 2006; Welsh Assembly Government, 2009)

In 2009 the Department of Health published the National Dementia Strategy. The aim of the Strategy was to improve services for people with dementia in order to help them and their caregivers to 'live well' with dementia. The Strategy focused on three main areas. The first was to improve both public and professional awareness of dementia, whilst the second concerned the provision of high quality care. The third area focused on earlier diagnosis, which would enable earlier intervention and support. This support could be through peer support and learning services, breaks and respite (Cook, 2008). Similarly policy in Scotland has also focused on earlier detection and better information and support for caregivers (Cook, 2008). The National Dementia Strategy for Wales (Welsh Assembly Government, 2009) is currently under consultation and consists of four stages. The first concerns 'strengthening the individual' which involves improving the quality of life of the caregiver and the person with dementia. The second involves 'strengthening communities' in order to develop supportive communities, which have knowledge of dementia and better skills to support people with dementia. The third and fourth stages promote healthy living and better access to services such as diagnosis services. The USA currently has no specific policy covering the care of people with dementia; however, the Alzheimer's study group was formed to create a National Dementia Strategy. The Strategy calls for a creation of an Alzheimer's solution project, which covers three main areas: prevention, care improvement and reform of funding for research (The Alzheimer's Study Group, 2009).

It has been argued that UK governmental and social care policies have generally adopted a model in which families were the traditional source of care and social care was only needed where there were no such caregivers available (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). However, it is acknowledged that this traditional source of care is being affected by changes in family life, which are reducing the availability of caregivers (Department of Health, 2008). Families are becoming smaller, so there are fewer people to share the responsibility of care (Zarit & Edwards, 2008). Divorce rates are increasing and families are becoming more geographically dispersed; thus, further decreasing the availability of caregivers. With greater numbers of females in the workforce many families rely on two incomes and would find it financially difficult if someone had to give up work to provide care or cut back their hours. There may also be changes in people's willingness to provide care, for instance changing societal attitudes could lessen the importance of the norm of filial obligation (Doty, 1986; Pickard et. al., 2000). Despite these changes, governmental policy has implicitly assumed that people will be willing to provide care and are expected to do this. There is a clear demarcation between the responsibilities of government and individuals. The central role of government is to help support and improve the health and wellbeing of caregivers. The role of the individual is to provide care:

> The role of the individual is to recognize that caring for a family member, friend, or partner is one of the key responsibilities we all potentially face as part of family life. A key advantage to the provision of care by a family member, friend or partner is that such an approach can result in personalized, responsive, expert and high quality care that is in the best interest of the person being supported (Department of Health, 2008, p.39)

The argument in current policy is that the best environment for care-recipients is to live in their own homes and communities and so policy aims to help support this: 'an expectation that family and friends will always be willing to support those they love when they need it must be accompanied by assistance and recognition from the state and wider community' (Department of Health, 2008, p.39). Thus, the underlying assumption of these policies is that people will always be willing to provide care and the role of the State is to support them.

The assumption that there is a supply of people willing to provide care, seems to implicitly assume that people's willingness to care is not affected by the needs of the care-recipient (Pickard et at., 2000). Care-recipients are not a homogenous group and each may have different care requirements (Burton, 2008). Similarly caregivers are not a homogenous group, and may have different capabilities to provide care. Given the apparent value of informal care for both the care-recipient and society it is important to help those willing to provide care to maintain caregiving. In order to do this there needs to be a better understanding of the factors which influence the establishment and maintenance of the caregiving relationship. This thesis will explore the role of three factors: the caregiver's motivations to provide care, the caregiver's relationship with the care-recipient, and the meaning the caregiver finds in caregiving. The rationale for exploring these factors will be covered briefly below, and discussed in more depth in later chapters.

Motivations to provide care

Given the potential decline in people willing and available to provide care, Doty (1986) has raised the question of whether government should encourage people to provide care or focus on supporting those already providing care. There are two main types of support on offer to caregivers: financial and psychological/social support. Yet policy offering incentives to encourage people to provide care does not take into account the different reasons why people provide care. Theories on motivations indicate that there can be different types of motivations. People may be motivated by altruistic or intrinsic reasons, where the desire is to help the care-recipient. Alternatively people may be motivated by egotistical or extrinsic motivations, which are perceived to be more self-serving reasons for providing care (Batson et al., 1991). Caregivers may also provide care out of feelings of obligation or affection (Cicirelli, 1989; Walker, Pratt, Shin, & Jones, 1990). In some cases, caregivers may have to provide care as they were the only person willing or available to provide care (Campbell & Martin-Mathews, 2003). Schulz, Biegel, Morycz and Visintainer (1989) argue that these motivations may differentially affect the caregivers' wellbeing. Doty (1986) has also argued that it is not just whether people are willing to commence caregiving that is important, but the amount of care they are willing to provide and for how long. This implies that motivations for providing care may change over time and be influenced by other factors. Some of the reasons cited for placing a person with dementia into full-time care include the caregiver's worsening health or lack of time for him/herself and others, or the caregiver's inability to provide the level of care that the care-recipient requires (Doty, 1986; Buhr, Kuchibhatla, & Clipp, 2006). This indicates that a person may be strongly motivated to provide care but that over time other factors may override this initial motivation. In order to sustain caregiving there needs to be a better understanding of the different reasons why caregivers provide care in order to develop more effective support to help those who wish to sustain caregiving.

Relationship dynamics

Montgomery and Williams (2001) have argued that it is the relational connection or history that prompts relatives or friends to commence caregiving in the first place. Both theoretical models on caregiving and UK policies can be criticised for neglecting the role of the pre-existing relationship between the caregiver and care-recipient in caregiving. Models such as the SPM have viewed the relationship as a background factor which has little impact on the experience of caregiving. UK policy has also tended to overlook the complexity of care relationships, viewing the act of caregiving as the defining feature of the relationship (Lloyd, 2000). Policies have emphasised the individual needs of caregivers and care-recipients, thus ignoring the relational aspects of providing care (Henderson & Forbat, 2002). Given that in the majority of cases informal care is provided by someone who knew the care-recipient before s/he needed care, this relationship could have a profound impact on the caregiver's adjustment to caregiving. Yet there has been little research on the role of both pre-caregiving and current relationship quality on caregiving. Lewis and Meredith (1988) have argued that the quality of the pre-caregiving and current relationship is a great determinant of the ways in which caregivers approach, respond to and experience the task of caregiving. Caregivers may experience the gradual loss of their relationship with the care-recipient, although in some cases caregivers may report feeling closer to the care-recipient through caregiving. It should also be recognised that some caregivers may have had a poor quality of relationship with the care-recipient before caregiving commenced, and that caregiving may exacerbate these problems. The caregivers will have to adapt to changes in the balance of their relationship with the care-recipient (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). In addition, the relationship may change from that of a dyadic relationship to a triadic relationship, in which a health care or social care professional becomes involved in caregiving. These relationships may also have an important role in how the caregiver constructs meanings of caregiving (Henderson & Forbat, 2002).

Meaning in caregiving

Current policy has tended to focus on the ways in which support can be provided to buffer the negative impacts of providing care. In addition, models of caregiving have also tended to focus on the negative outcomes of providing care. Yet if caregiving was purely a negative experience then it seems unlikely that many caregivers would persist with their role. Studies have found that caregivers can find positive aspects in caregiving; for instance Cohen, Colantonio and Vernich (2002) found that 73% of caregivers in their study could specify one positive aspect of caregiving. In a European study on dementia, Rimmer, Wojciechowska, Stave, Sganga and O'Connell (2005) asked caregivers about the impact of caregiving. They found that

27% described caregiving as rewarding, 33% found it enriching and 30% found it fulfilling. Positive aspects of providing care may be identified through finding meaning in caregiving. This concept has been derived through research on meaning in life, which involves the search to make sense out of one's existence. Coleman (1995) noted that finding meaning may become more important in old age, as earlier sources of meaning, for instance work or raising a family, are no longer relevant. Studies have found that meaning in life can be linked to wellbeing in older adults (e.g. Reker, 1997). It is acknowledged that not all caregivers will be older adults and research on meaning in life in younger people has also found it can be linked to wellbeing (Reker, Peacock, & Wong, 1987; Zika & Chamberlain, 1992). Since it has been suggested that the search for meaning is a universal human motive and that people will search to find meaning from adversity, then it is possible that some caregivers will search for meaning in caregiving,

Admiral Nurse Service

The research presented is this thesis has been conducted with the support of the Admiral Nurse Service. Admiral Nurses are specialist mental health nurses who provide support to caregivers and people with dementia. The Admiral Nurse Service was established as a result of the experiences of family caregivers and was first piloted in Westminster in 1990 (Woods, Wills, Higginson, Hobbins, & Whitby, 2003). The Admiral Nurses were named in memory of Joseph Levy CBE BEM, who had vascular dementia and was known as 'Admiral Joe' due to his keen interest in sailing. The charity 'for dementia' was founded in 1995 to take forward the development of Admiral Nursing. The Service has expanded greatly since its inception and now has in the region of 70 Admiral Nurses. Admiral Nurses work within Primary Care Trusts and are partly funded by the National Health Service. Admiral Nurses seek to improve the quality of life of people with dementia and their caregivers by providing emotional and psychological support and guidance about accessing services. Admiral Nurses provide information and advice to caregivers on the different aspects of caregiving, helping caregivers to develop their skills throughout the caregiving career (Clare, Wills, Jones, Townsend, & Ventris, 2005).

Aims of thesis

The primary aim of this thesis is to develop a better understanding of the role of relationships, motivations, and meanings in dementia caregiving. To date there has been no exploration of how meaning, motivation, and relationship dynamics are related to and influence each other. In addition there has been no examination of how these factors interact to influence dementia caregivers' wellbeing. The secondary aim of this thesis is to contribute to the development of the Admiral Nurse Service by providing an insight into the needs of caregivers who receive the Service and the factors which can influence their wellbeing. This would enable the Service to provide more effective support to caregivers.

Research Questions

1. How do meanings, motivations, and relationship dynamics influence the subjective experience of caregiving?
2. How do triadic relationships develop between caregivers, care-recipients, and health care professionals?
3. Is there an association between meanings, motivations, and relationship quality?
4. Is there a difference between pre-caregiving and current relationship quality?
5. How does relationship quality influence caregivers' wellbeing?
6. Do intrinsic and extrinsic motivations influence caregivers' wellbeing? If so do they have differential impacts?
7. To what extent does finding meaning in caregiving impact on caregivers' wellbeing?
8. Is there an association between meanings, motivations, and relationship quality in terms of their impact on caregivers' wellbeing?
9. Which factors can predict finding meaning in caregiving?

Research Methodology

In order to address these questions this thesis will utilise both quantitative and qualitative methodology. The benefit of using a qualitative methodology is that it allows the exploration of these factors in the context of the caregiver's subjective experience of caregiving, providing a rich description of the processes involved. This thesis will utilise a form of qualitative analysis, Interpretative Phenomenological analysis (IPA). IPA aims to explore the participant's experience and how the participant makes sense of that experience (Smith, 2004). IPA attempts to make sense of the participant's subjective world through a process of interpretative activity (Willig, 2001). Whilst qualitative methods can explore experiences, quantitative methods have the advantage of enabling a direct examination of differences and relationships between the factors, and their influence on caregivers' wellbeing. This thesis will include a cross-sectional questionnaire study, the participants for which were identified from the client database of the Admiral Nurse Service.

Structure of the thesis

This thesis will follow the format of a series of journal articles or book chapters, which have either been published or will be submitted for publication. Some of these have been adapted for this thesis, with some material being added to them when necessary or material removed to avoid unnecessary repetition. This thesis will follow the structure of two literature review chapters, one methodology chapter and three empirical chapters, and a discussion.

Chapter 2 is a systematic literature review examining the impact of caregiving on the quality of the relationship between caregiver and care-recipient. It also explores the impact of the quality of the relationship between the caregiver and care-recipient on the caregiver's and care-recipient's wellbeing. The review identified that more research needed to be conducted to explore both current and pre-caregiving relationship quality. Chapter 2 has been published in *Aging & Mental Health* (Quinn, Clare, & Woods, 2009).

Chapter 3 is a systematic review examining the impact of both meaning and motivation on the wellbeing of caregivers. The review also investigates individual differences in motivations to provide care. The review found that there had been little empirical research on motivations and meanings, and made recommendations for more research on these topics. Chapter 3 has been published in *International Psychogeriatrics* (Quinn, Clare, & Woods, 2010).

Chapter 4 is a methodology chapter which provides a rationale for choosing the qualitative method Interpretative Phenomenological Analysis (IPA) as the most appropriate method to analyse the qualitative data which was collected for this thesis. This chapter explores the theoretical background of IPA and evaluates it against other qualitative approaches. It outlines a framework for analysing data with IPA, and describes how IPA has been utilised in clinical and health research, focusing in particular on how IPA has contributed to the field of dementia caregiving research. Chapter 4 has been published as a chapter in the book *Nursing Research: Designs and Methods* (Quinn & Clare, 2008).

Chapter 5 is a qualitative study which utilises IPA to explore how meaning, motivation, and relationship dynamics interact to influence the subjective experience of caregiving. The findings from interviews with twelve caregivers described an overarching process of 'balancing needs', in which the caregivers constantly struggle to balance their own needs against those of the care-recipient, creating a series of dilemmas. This chapter has been submitted for publication in *Qualitative Health Research* (Quinn, Clare, & Woods, submitted).

Chapter 6 explores how the dyadic relationship between the caregiver and care-recipient can transform into a health care triad, in which a health care professional becomes involved in decision making and caregiving. This study utilised case studies to explore six triadic relationships containing the caregiver, care-recipient and a specific type of health care professional, the Admiral Nurse. The findings of this study indicate that this triadic relationship could be encompassed under an overarching process entitled 'negotiating the balance', which could influence the success of the working relationship between the triad. The members could have differing perspectives on the situation, and there could be coalitions between the members. This chapter has been submitted for publication to *Dementia* (Quinn, Clare, Woods & McGuinness, submitted).

Chapter 7 builds on and develops the findings of the qualitative studies by using quantitative methodology. Questionnaires were completed by 447 caregivers who were in receipt of the Admiral Nurse Service. The study explored whether there was an association between meanings, motivations, and relationship quality, and how these factors individually and jointly influenced caregivers' wellbeing. All of these factors explained significant variance in the measures of caregiver wellbeing. Differences were found between current and pre-caregiving relationship quality examined. In addition predictors of finding meaning were discussed. These findings are currently being prepared for submission for publication.

Chapter 8 is a discussion chapter which draws together the findings, limitations and implications from the empirical chapters. It evaluates these findings in relation to current research and policy on caregiving and dementia and makes recommendations for future research.

Conclusion

Informal caregiving is widespread and is the main source of care for people with dementia. Given the importance of this source of care it is recognised that caregivers need to be provided with help to enable them to maintain caregiving. In order to provide effective support there needs to be a better understanding of the experience of caregiving. Theoretical models of the caregiving experience are limited by their lack of attention to the caregivers' reasons for providing care, the relationship between the caregiver and care-recipient and the meaning caregivers can find in caregiving. To date there has been no exploration of how meaning, motivation, and relationship dynamics are related to and influence each other. In addition there has been no examination of how these factors interact to influence dementia caregivers' wellbeing. Understanding more about the influence of these factors on caregiving could help improve the support offered to caregivers. In order to disseminate the findings of this thesis, the studies have been presented at the British Society of Gerontology conference (2006), the Gerontological Society of America conference (2007) and the Admiral Nurse Forum (2008).

Chapter 2: The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review

Summary

Relatively little attention has been given to the effects of caregiving context on the experience of family members providing care for a person with dementia. This review aimed to examine the impact of caregiving on the quality of the relationship between caregiver and care-recipient and the impact of the quality of the relationship between the caregiver and care-recipient on the caregiver's and care-recipient's wellbeing. This was a systematic review of peer-reviewed empirical studies. Fifteen quantitative studies were identified which examined the quality of the relationship between caregivers and care-recipients who had dementia, meeting the criterion of using a measure of relationship quality beyond a single item. The findings of this review show that caregiving can have an impact on the quality of the relationship between caregiver and care-recipient. In addition, pre-caregiving and current relationship quality appear to have an impact on caregivers' wellbeing. The care-recipient's needs for help with ADL and level of behavioural problems were found to influence the caregiver's perceptions of relationship quality. Future research should examine both current and pre-caregiving relationship quality. A better understanding of the role of relationship quality in determining the outcomes of caregiving will aid the development of more effective interventions for caregivers.

Quinn, C., Clare, L., & Woods, R. T. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health, 13,* 143-154.

Chapter 3: The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review

Summary

The majority of people in the early and middle stages of dementia are cared for at home by non-paid caregivers, the majority of whom will be family members. Two factors which could have an impact on the quality of care provided to the care-recipient are the caregiver's motivations for providing care and the meaning s/he finds in caregiving. The aim of this review is to explore the potential impact of both meaning and motivation on the wellbeing of caregivers of people with dementia. The review also explores individual differences in motivations to provide care. This was a systematic review of peer-reviewed empirical studies exploring motivations and meanings in informal caregivers of people with dementia. Four studies were identified which examined the caregiver's motivations to provide care. Six studies were identified which examined the meaning that caregivers found in dementia caregiving. The review found that caregivers' wellbeing could be influenced by the nature of their motivations to care. In addition, cultural norms and caregivers' kin-relationship to the care-recipient impacted on motivations to provide care. Finding meaning had a positive impact on caregiver wellbeing. The limited evidence currently available indicates that both the caregiver's motivations to provide care and the meaning s/he finds in caregiving can have implications for the caregiver's wellbeing. More research is needed to explore the role of motivations and meaning in dementia caregiving.

Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics*, *22*, 43-55.

Chapter 4: Interpretative Phenomenological Analysis

Summary

Interpretative phenomenological analysis is a form of qualitative analysis which explores participants' subjective experiences. The aim of this chapter was to explore IPA and its contribution to research in clinical and health psychology and related disciplines. Having reviewed the theoretical background of this approach, IPA was then compared with other qualitative methods. This chapter discussed some of the issues to consider when conducting an IPA and provided a practical framework for analysing interview transcripts using IPA. Some of the methods used to ensure the credibility and trustworthiness of an IPA analysis were considered. Finally, the applicability of this approach in clinical and health research was discussed, with a particular focus on its contribution to research in dementia caregiving. By focusing on subjective experience, IPA research can provide a new and different perspective on familiar topics. This chapter has also demonstrated the genuinely broad application of IPA and the feasibility of using IPA with caregivers of people with dementia.

An edited version of this chapter has been published: Quinn, C., & Clare. L. (2008). Interpretative phenomenological analysis. In R. Watson, McKenna, H., Cowman, S. & Keady, J. (Eds.), *Nursing Research: Designs and Methods.* Edinburgh: Elsevier.

Chapter 5: Balancing needs: The role of motivations, meanings, and relationship dynamics in the experience of family caregivers of people with dementia

Summary

Research indicates that the caregiver's motivations to provide care, quality of relationship with the care-recipient, and the meaning the caregiver finds in caregiving can influence the wellbeing of caregivers of people with dementia. However, to date no study has explicitly explored whether these three factors interact to influence the establishment and continuation of the dementia caregiving relationship. This study aims to explore how these factors might interact to affect the subjective experience of caregiving. Twelve family caregivers of people in the early, middle, and later stages of dementia were interviewed. Transcripts of these interviews were subjected to Interpretative Phenomenological Analysis. Eight key themes emerged from the analysis, which were encompassed under an overarching theme of 'balancing needs'. This describes the caregivers' constant struggle to balance their own needs against those of the care-recipient, which created a series of dilemmas. Understanding more about the role of meaning, motivations, and relationships in caregiving should aid the development of more effective interventions for caregivers.

A version of this chapter has been submitted: Quinn, C., Clare. L., & Woods, R. T. (submitted). Balancing needs: The role of motivations, meanings, and relationship dynamics in the experience of family caregivers of people with dementia. *Qualitative Health Research*

Introduction

Dementia is a progressive degenerative condition which results in a decline in numerous areas of function such as communication and memory. It is recognised that dementia care requires an extensive amount of informal care, which represents an economic value from a societal view point (Wimo et al., 2007). Informal dementia caregiving has traditionally been perceived as an extremely stressful process; however, more recent research has started to focus on the positive aspects of providing care (Kramer, 1997). Morris, Morris and Britton (1988a) propose that a range of factors may mediate how caregiving is experienced by a caregiver of a person with dementia. These include the meaning the caregiver attributes to the situation and the quality of the relationship between the caregiver and care-recipient. Another important factor is the caregiver's motivations to provide care, which will have an influence on the caregiver's commitment to continue caregiving. The systematic review in Chapter 2 found that caregiving can have an impact on the quality of the relationship between caregiver and care-recipient. Similarly the systematic review in Chapter 3 showed that the caregivers' motivations to provide care and ability to find meaning can each have an impact on caregiver wellbeing. However, it remains unclear how these three factors might interact to influence the establishment and continuation of the caregiving relationship.

Twigg and Atkin (1994) have proposed that caregiving takes place within a relationship. Thus, in the majority of cases the caregiver and care-recipient will have been well acquainted before caregiving commenced. This relationship between the caregiver and the care-recipient could have an important role in both the development and maintenance of caregiving. Caregivers may be strongly committed to taking on the caregiving role because of their relationship with the care-recipient. For instance, studies have shown that feelings of reciprocity can influence a caregiver's decision to provide care (Lewinter, 2003). Equally, the quality of this relationship could influence the caregiver's dedication to continue caregiving. Whilst quantitative studies can explore the impact of relationship dynamics on outcomes such as caregiver wellbeing (e.g. Morris et al., 1988b), qualitative studies provide a perspective on the subjective experiences of caregivers as they react to the changes in their relationship with the care-recipient. Since a relationship can transform gradually over time, qualitative research allows for a more in depth examination of these changes. For instance, Blieszner and Shifflet (1990) utilised qualitative methodology to illuminate the transition of a relationship into a caregiving relationship. Qualitative studies have also explored the complex changes in the relationship between the caregiver and care-recipient. Perry (2002) interviewed wives caring for husbands with dementia, and identified a process of 'interpretive caring'. Integrated into this process were changes in the relationship between the caregiver and the care-recipient. The caregivers dealt with these changes by creating new identities for their husbands incorporating aspects of their husbands' personality which they attributed to the dementia. In addition, the caregivers revised their own identity to reflect their new roles and responsibilities. Perry (2002) found that the caregiver's perception of relationship changes was influenced by the couple's past relationship and the wife's commitment to her husband.

The relationship between caregiver and care-recipient can also have an important influence on caregivers' motivations to provide care. In a study with caregivers for older parents, Merrill (1996) found that the majority of caregivers were motivated to provide care out of love for the care-recipient or from a desire to reciprocate past help. Qualitative methodology has enabled researchers to explore the different reasons caregivers have for providing care. Globerman (1996) found that sons-in-law felt obligated to help out of feelings of duty, whilst daughters-in-law felt obligated to care because of social norms and expectations. Feelings of obligation to provide care were not linked to affection towards the care-recipient. However, Cahill (1999) examined motivations in an interview study with female caregivers of people with dementia and found that the majority of the caregivers cited being motivated by concern, followed in descending order by love, duty, moral obligation, and guilt. Horowitz and Sindelman (1983) reported that caregivers for older adults cited being motivated by formal obligation, affection and reciprocity, and that these motivations may overlap. These findings indicate that the relationship between the caregiver and care-recipient may influence motivations to provide care. Quantitative research with caregivers for older adults who do not have dementia has found a link between motivations, relationship quality, and caregiver wellbeing (Lyonette & Yardley, 2003). However, the advantage of using a qualitative methodology is that it allows the exploration of these topics in the context of caregivers' subjective experience of caregiving, providing a rich description of the processes involved.

In addition to being linked to relationship quality, motivations to provide care have been associated with the meaning caregivers find in caregiving (Noonan & Tennstedt, 1997). Finding meaning in caregiving has been conceptualised as either a positive outcome of caring (Noonan et al., 1996), or a coping strategy (Pearlin et al., 1990). Both definitions indicate that finding meaning can be beneficial for caregivers' wellbeing. The majority of studies which have examined the ways in which caregivers find meaning have tended to employ a qualitative methodology. For example, Hasselkus (1988) explored finding meaning in interviews with family caregivers of older people. Caregiving meant that the caregivers had to adjust to new roles and responsibilities. Although they could find it difficult, the caregivers did have a sense that they were managing well with caregiving. The caregivers were concerned about whether they would be able to continue caregiving if the care-recipient's condition deteriorated, and had thought about the possibility of nursing home placement. Whilst this study indicates that there is a tentative link between meaning and motivation, it does not explore how these factors interact to influence caregivers' commitment to caregiving. Hirschfeld (1983) found that mutuality between the caregiver and care-recipient was important to the caregiving relationship. This mutuality developed through the caregivers' ability to find gratification in the relationship and derive meaning from the situation. Thus, this implies that meaning may be linked to reciprocal aspects of the relationship.

The available evidence suggests that relationship dynamics, motivations and meaning have an important role in the development and maintenance of caregiving. However, to date there has been no exploration in dementia caregiving of how meaning, motivation, and relationship dynamics are related to and influence each other. Understanding more about the factors which have an impact on caregiving could assist in the development of more effective interventions to enable caregivers to continue caregiving. The aim of this study is to explore how meaning, motivation, and relationship dynamics combine to influence the subjective experience of dementia caregiving. A qualitative methodology will be utilised as it allows an in-depth examination of the caregivers' experiences, the results of which can inform future quantitative studies.

Method

Design

This was an exploratory study using qualitative methodology. Transcripts of semi-structured interviews conducted with the participants were analysed using Interpretative Phenomenological Analysis (IPA).

Ethical Issues

Ethical approval for this study was obtained from the relevant NHS Local Research Ethics Committee. In order to maintain confidentiality, the participants' details were anonymised and pseudonyms were used in the transcripts.

Participants

The participants were 12 primary caregivers of people with dementia. Participants were recruited from the caseloads of Admiral Nurses (specialist mental health nurses for caregivers of people with dementia) based in the North-West of England. Purposive sampling was used in order to obtain an equal number of caregivers caring for people in the early, middle and later stages of dementia, as determined by scores on the Clinical Dementia Rating (CDR; Hughes, Berg, Danziger, Coben & Martin, 1982). The CDR assesses the severity of dementia across six domains and scores range from 0 (no impairment) to 3 (severe impairment). The CDR score was assigned in each case by the Admiral Nurse who had been working with the caregiver and care-recipient. All the caregivers were White British and had a mean age of 65 (*SD*= 13.85), with ages ranging from 41 to 86. The care-recipients had a mean age of 76 (*SD*= 13.54), with ages ranging from 41 to 88. The participants consisted of 4 female adult-child caregivers and 8 spousal caregivers, of which six were female. The length of the spousal caregivers' marriage to the care-recipient ranged from 8-68 years, and two of the spousal caregivers were in their second marriage. None of the caregivers were in employment and were either retired or had given up work in order to provide care. All of the caregivers had been caring for the care-recipient at home, and at the time of the interview two care-recipients had recently moved into full-time residential care.

Data Collection

Potential participants were initially approached by the Admiral Nurses to see if they were interested in participating in this study, and those who expressed an interest were then visited by the researcher (CQ) who explained the study. Those who consented to take part were interviewed individually at their homes by the researcher. The interviews lasted from 38 to 98 minutes depending on the loquaciousness of the participants, with the average length of the interviews being 66 minutes. These interviews were tape recorded for transcription. The interview followed a semi-structured interview schedule. The interviews explored the caregivers' reasons for taking on the caregiving role, and whether they received any support from family or friends with caregiving. The caregivers were asked to consider whether caregiving had affected their relationship with the care-recipient, and if so, in what ways. The caregivers were questioned about how caregiving had impacted on their wellbeing, and whether they could identify any positive aspects of providing care. The caregivers were asked to reflect upon what it meant to them to provide care, and what helped them to continue caregiving. The caregivers were asked to consider whether they felt they would ever stop providing care at home, and those caregivers whose care-recipient was in residential care were asked about the reasons behind this decision. Care was taken to ensure that the interviews finished on a positive note. The participants were advised that if they had any concerns or wished to further discuss any of the topics explored in the interview then they could telephone the interviewer at any time. None of the participants took up this option. The caregivers were also reminded that they could contact their Admiral Nurse for further support if they wished.

Data Analysis

In order to explore the participants' accounts of their experiences, transcripts of the interviews were analysed using IPA. IPA attempts to make sense of the participant's subjective world through a process that combines descriptive and interpretative activity (Willig, 2001). IPA is descriptive in that it attempts to present an account of subjective experience; however, it is also acknowledged that such experience is never directly accessible. Thus, IPA is also interpretative as it acknowledges the researcher's role in creating a thematic account (Smith et al., 1997). Researchers must therefore attempt to identify and reflect on pre-existing values, assumptions and beliefs that may affect the interpretation of data.

In this study the interviews were analysed with IPA using the framework described in Chapter 4. An extract of a theme from the group level analysis can be found in Appendix B.1. Information about how extensively each theme was shared by the participants is provided in a table found in Appendix B.2. In order to ensure the validity of the analysis, the themes identified were re-coded onto the transcripts to check the 'fit' of the themes with the transcripts and guarantee recontextualisation (Malterud, 2001). In order to reduce the risk of personal bias in the analysis, the transcripts were independently analysed by three additional researchers. Differences in interpretations of the data were discussed until consensus was achieved. In order to show that the results are grounded in the data (Whitemore et al., 2001) the themes presented here are illustrated with direct quotes from the participants. In addition, the caregivers' own words were used for the theme titles.

Results

Eight key themes emerged from the analysis. These themes are encompassed under an overarching theme of 'balancing needs', which describes the caregivers' constant struggle to balance their own needs against those of the care-recipient. Trying to balance these needs created dilemmas for the caregivers. The main dilemma for the caregivers concerned trying to preserve their relationship with the care-recipient when it was inevitable that there would gradually be changes in both the balance of the relationship and in their interactions with the care-recipient. The caregivers also faced challenges in their attempts to cope with the changes within the care-recipient. The caregivers tried not to disempower the care-recipient but recognised that they had a new role which involved keeping the care-recipient safe. The caregivers were motivated to provide care, but the battle to balance needs meant that they recognised there may come a time when they would have to put their own needs first.

Theme 1. We knew each other well

The relationship between the caregiver and care-recipient was central to the caregivers' struggle to balance needs. One of the main dilemmas for the caregivers was how to maintain their relationship with the care-recipient. The caregivers described noticing changes in their relationship with the care-recipients. Previously the caregivers felt that they had a good relationship with the care-recipients, but now this relationship was altering:

'I've always been there; well the pair of us have to help one another. We've not been a bad team personally, you know, but now it's coming to an end' (Tony)

There were strong feelings of loss in the caregivers' accounts, reflecting loss of a relationship and loss of a future together. Some caregivers became distressed because at times the care-recipients no longer recognised them or the relationship:

'You do get a bit upset. I mean you've got to call me mam Barbara and things like that. I mean that to me is horrible but you've got to do it because she understands the name Barbara' (Patricia)

The loss of the relationship resulted in some caregivers describing how their feelings towards the care-recipient had changed. However, others felt the same towards the care-recipient and believed that the care-recipient still cared about them. Some caregivers were still able to identify positive aspects of the relationship with the care-recipient:

'I've had afternoons here laughing with him, you know, we've had evenings and we've been laughing at the things he's been saying, stories from when he was a lad and that. Had some lovely times with him' (Deborah)

Theme 2. This person is different

Coupled with the feelings of loss of the relationship was the perceived loss of the person that they had had the relationship with. This created difficulties for the caregivers as they tried to cope with the changes in the care-recipient. The caregivers described the care-recipients as previously being very competent and hardworking. Emotionally, the care-recipients had been very caring and supportive:

'He was always a very patient and tolerant person' (Maureen)

The onset of dementia led to the caregivers perceiving significant differences in the care-recipients:

'It's as though this person's completely different, you know, come in here and the old Jack's away somewhere' (Angela)

Some caregivers felt that the care-recipients' personality had altered, feeling they lacked empathy and tolerance. The caregivers were particularly distressed by the care-recipients becoming cross or aggressive and being verbally abusive. These differences created feelings of uncertainty as the care-recipients were described as being very changeable in their mood. In addition to alterations in the care-recipients' personality, the caregivers commented on the decline in their abilities:

'Well he can't button his shirt. He comes down and says will you do this for me. He comes down with his trousers on back to front and you want to weep' (Joan)

This was particularly distressing for those caregivers who had always perceived the care-recipient to be a very competent person. Difficulties occurred in the caregivers' interpretation of behavioural changes. Some caregivers did accept that the care-recipients' altered behaviour was part of their illness. However, others attributed the behaviour they were observing to the care-recipients being attention-seeking or awkward:

'I can't help but think that there's an element of awkwardness about this. I'm not entirely given to accept the fact that we don't know what we're doing. I'm sure in my own observations I get the strong impression that there's an element of awkwardness about this' (Brenan)

Theme 3. I do miss the companionship

The transformations in the relationship resulted in uncertainty in how to deal with the imbalance in the relationship with the care-recipient. Caregiving impacted on the quality of interactions between the caregiver and care-recipient. The caregivers felt that there had been a decline in the mutual pleasure they experienced in their relationship with the care-recipient. They found they had to balance their needs against those of the care-recipient, and dilemmas occurred because caregiving meant that the caregiver and care-recipient tended to be confined in the house together. Some caregivers would try to get a break by taking the care-recipient out with them on errands or to social activities. Others found this difficult because the care-recipient did not want to leave the house. In addition, feelings of embarrassment about the care-recipient's behaviour, especially when in the company of others, meant that the caregivers tended to want to 'hide away'. Even previously enjoyable joint activities, such as going out for a meal together, were no longer perceived as pleasurable because the caregivers felt they could not relax:

'I mean it's alright going out for a meal but you're still caring because I'm still taking him, still watching; when he goes to the toilet I'm still watching that he comes back and doesn't go out of another door, so you don't relax' (Jill)

The quality of the interactions between the caregiver and care-recipient was also affected by a decline in verbal interactions. Whilst simple communication was generally preserved, the caregivers lamented the loss of the care-recipient being able to join in conversations or discussions:

'Communication is the necessary things in life, whereas we used to sit down at night and have a discussion' (Jill)

This created dilemmas for the caregivers because whilst they tried to keep including the care-recipient in conversations, the caregivers did at times feel that they could not be 'bothered' or had simply 'run out of conversation'. In addition, the caregivers now found that they had to censor what they told the care-recipient. This created a dilemma of trying not to lie to the care-recipient whilst being aware that they had to be careful what to say so as to avoid upset:

'I tell the truth as much as I possibly can. I try not to lie at all and sometimes I find I do because it's just impossible not to' (Carol)

Theme 4. I miss the help

The caregivers described the loss of a mutually supportive relationship, which created dilemmas in how to adjust to these changes. The caregivers' reaction to this varied depending on their pre-illness relationship with the care-recipient. Some caregivers considered themselves to be quite independent, and were used to doing chores by themselves. Other caregivers had previously been dependent on the care-recipient in many ways. However, both sets of caregivers were noticing significant differences in their relationship, as they increasingly had to take charge:

'Now I've just got to make all the decisions and I see to all the money and everything' (Edna)

The caregivers not only had to adjust to these changes by taking over the care-recipients' responsibilities, but also had to take on new responsibilities, for instance making sure the care-recipient took prescribed medication. The caregivers felt as if they were constantly on call:

'He expects me to know everything, if he can't remember something he just turns to me and he wants to know and I find it tiring' (Angela)

They received little help from the care-recipients and felt very overloaded with their new responsibilities:

'All these things I'm having to sort of take on board and I've never done it all before and I think my mind gets, I just get bogged down with it and it adds to the stress, I think, for me as a carer' (Joan)

Theme 5. Just trying to find a balance

The caregivers struggled to find a balance between not wanting to disempower the care-recipients, and at the same time wanting to keep them safe:

'The thing is it's always this balance isn't it. I'm not going to stop him from doing things that he would get some sort of satisfaction from doing, you just have to kind of judge whether it's completely unsafe for him' (Carol)

The caregivers felt it was important to the care-recipient's self-esteem to be allowed to do things, even if the outcome was unsuccessful. In addition, some caregivers felt it was important to keep the care-recipients busy in order to keep their minds active and prevent them from deteriorating any further. However, this did create a dilemma for the caregivers because they acknowledged that this created extra work, and that sometimes it would be easier if they just did things themselves:

'Sometimes it's easy doing it yourself because you just think I'm explaining things all the time and I'm thinking just, you know, just do it yourself because it's easier but then you've got to keep him going with things otherwise he'll just sit here and go worse' (Paula)

Whilst the caregivers wanted to keep the care-recipients active, they also felt that it was their responsibility to keep them safe. They did this by limiting what the care-recipient was allowed to do. The caregivers restricted the chores the care-recipient could do, limited contact with other people, and tried to prevent the care-recipient from going out alone. The caregivers felt that in order to keep the care-recipient safe it was necessary to be vigilant. Trips out were perceived as stressful because the caregivers had to constantly make sure the care-recipient did not wander off:

'We don't go out as often as we used to because I find that stressful because I've got to keep my eye on him all the time. I can't go out and leave him in the house on his own because I just don't know what he would do' (Edna)

Despite finding being trapped in the care-recipient's company stressful, some caregivers felt they had little choice if they wanted to keep the care-recipient safe.

Other caregivers made the decision that if they needed to go out then they would have to leave the care-recipient alone:

'I take the view if something's going to happen it will happen when I'm not here either for five minutes or for a reasonable period of time. I wouldn't go out and leave her for say more than an hour or two at the extreme without getting somebody in to sit with her but I do go out' (Brenan)

These caregivers took precautions to try to ensure the care-recipient's safety, such as locking the care-recipient in the house. As the caregivers struggled to find a balance between their own and the care-recipient's needs, their relationship with the care-recipient became strained. Efforts to help the care-recipient created 'battles' where the caregiver perceived the care-recipient as being obstructive, for instance not wanting to have a bath or not wanting to get changed into nightclothes. Although these battles tended to be over relatively minor issues, the caregivers felt it was important to try to preserve the care-recipient's identity, for example making sure the care-recipient was neat and tidy. The caregivers felt unappreciated and felt that the care-recipient did not understand that they were trying to help.

Theme 6. You just get on with it

The caregivers' relationship with the care-recipient was the primary reason for taking on the caregiving role. Caregiving was perceived to be a natural continuation of their relationship:

'She needed help so who's best to give her help than someone in the family and someone who's willing' (Patricia)

The naturalness of caregiving meant that most of the caregivers had never thought about not caregiving. Some caregivers derived satisfaction from caregiving and felt it made them a better person. However, others felt isolated and trapped in their role; they had to care because there was nobody else who could do it:

'I wouldn't leave him anyway but if I did I mean who would you know who would look after him? It's not fair on the children... it's not fair on them either so you've just got to get on with it haven't you really' (Paula)

Often they received little support from other family members, and some caregivers found they had to take on the role because nobody else was willing to do it. Despite feeling trapped, many persisted with caregiving because they did not want the care-recipient to go into full-time care:

'I wouldn't consider letting him go away even, however bad he gets... I want him at home yeah I don't care' (Joan)

Some care-recipients had previously expressed a fear of residential care. In several cases caregivers felt that they had to continue caregiving because they would feel guilty if they went against the wishes of the care-recipient:

'She used to say that she didn't want to go in a home... and I promised that I wouldn't put her in a home so of course I've kept me promise and that's why I don't really want to put her in a home' (Joyce)

Theme 7. Turning point

Caregiving meant that the needs of the care-recipient were often prioritised above the wellbeing of the caregiver. However, some caregivers recognised that there were times when they felt like giving up caregiving, and put their needs above those of the care-recipient:

'There are things that I do need to kind of do so it's again it's balancing you know balancing my needs against his needs all the time and trying to do the best for both of us really I mean there might come a time when I can't' (Carol)

Some caregivers felt that it would be beneficial if they could have a short break from caregiving. Others who were desperate for respite felt they were reaching a breaking-point:

'When it got to Christmas last year when I wasn't getting any sleep I did think yes I can't do that, you know, well there'll have to be some solution because there's a limit if you're caring 24 hours a day 7 days a week and like I've not had a break last year at all' (Jill)

Some caregivers battled with the desire to have a life away from caregiving and fulfil their own needs. Some wanted to be able to socialise with friends or go travelling. Others had to balance the needs of their own families, and felt guilty because caregiving limited the time they could spend with them:

'So long as I'm doing what's best you know for everyone concerned really I mean it's not just my dad it's my daughter as well and my husband' (Carol)

The caregivers recognised that their feelings towards caregiving might change in the future, and there might be a time when they would have to prioritise their needs over those of the care-recipient. Some caregivers had thought about factors which might result in a decision to put the care-recipient into full-time care, such as when the care-recipient physically deteriorates, or no longer recognises them.

Theme 8. I wasn't coping

When the caregivers' needs outweighed those of the care-recipient, this resulted in the care-recipient going into full-time care. The caregivers who had taken this step had found that they could no longer cope with the caring situation. The caregivers' ill health or lack of support from other family members were the main reasons for deciding to place the care-recipient in full-time residential care. The influence of other family members was another factor:

'The decision to have him into respite wasn't one that I took on me own, it wasn't just my decision it was me husband me son me daughter and yeah a little bit of myself because yeah I was ready for it I needed it' (Deborah)

However, this decision did not ease the caregivers' burden, because they felt guilty about putting the care-recipient into full-time care. Guilt emerged from feeling they had let the care-recipient down. Despite recognising that this was the best thing to do, the caregivers were still struggling with their decision:

'You want to get away from it but when I get away from it I want her here' (Tony)

However, one of the caregivers recognised that with time she would eventually feel better about her decision:

'I know it's all for the good and I know what the end result is gonna be and I know in five six weeks he will have settled but it's getting through it' (Deborah).

Discussion

This study sought to explore how the relationship between the caregiver and care-recipient, the caregiver's motivations to provide care and the meaning the caregiver finds in caregiving, interact to influence the subjective experience of caregiving. These factors were encompassed under an overarching theme of 'balancing needs', in which the caregivers struggled to balance their needs and the needs of the care-recipient. The theme of 'balancing needs' can be understood in relation to equity theory. Equity theory proposes that two people will strive to maintain a balance between help given and help received, as an imbalance will result in distress for both (Hinde, 1997). An equitable relationship would suggest high relationship satisfaction, whilst inequality would create tension in the relationship (Kulik, 2002).

In caregiving the caregiver will gradually provide more and more help to the care recipient as his/her dependency increases. This will create a loss of the reciprocal nature of the relationship as the care-recipient cannot redress this balance. However, it is likely that a loss of equality would be expected by the caregivers as they would recognise that the care-recipient's illness precludes an equal role in the relationship. The findings of the current study expand on equity theory as the caregivers' desire to 'balance needs' encompasses more than just trying to adapt to the changes in the balance of their relationship. 'Balancing needs' relates to the complex changes in the caregivers' relationship with the care-recipient, the caregivers' motivations to provide and maintain caregiving, and the meaning the caregivers find in caregiving. Each of these issues will now be considered in turn.

Central to the theme of 'balancing needs' was the caregivers' desire to preserve and maintain their relationship with the care-recipient. Aspects of this theme have been explored in other qualitative studies, particularly with regard to relationship changes. In a study with caregivers caring for their partners in the early stages of dementia, Quinn et al. (2008) found that caregivers discussed alterations in the balance of the relationship. The caregivers gradually took over their partners' roles, and some found there was a reversal of roles as they were now the dominant one in the relationship. In the current study, the caregivers were also trying to adjust to changes within the care-recipient as well as the balance of the relationship. Relationship changes were explored by O'Donnell (2000), in which spousal caregivers were described as 'a couple of one' as the caregivers had to make all the decisions for the couple in relation to aspects of the couple's life, financial issues and the partner's care. Lewis (1998) found that caregivers of people with dementia differed in their interpretations of the change in their relationship. Some caregivers felt that their relationship with the care-recipient was continuing to develop and that they were reciprocating their partner's love through caring. Others experienced a sudden loss of their relationship, as they were no longer treated as a couple or able to work together to resolve past conflicts. The current study extends this research by identifying that the caregivers encountered dilemmas in their desire to maintain the relationship with the care-recipient.

In the themes identified from the caregivers' accounts, relationship quality and motivations to provide care appear to be linked, since the relationship with the care-recipient was the primary reason for taking on the caregiving role. Other qualitative studies have identified the role of relationship as a motivator for caregiving. In the study by Cahill (1999) the relationship between the caregiver and care-recipient was one of the main motivators. Similarly, in a qualitative study, Guberman, Maheu, and Maillé (1992) found that caregiving was motivated by love and feelings of family ties. The role of the relationship in motivating the provision of care has been identified in Commitment theory (Johnson et al., 1999). In Commitment theory, a person's commitment to another may be influenced by a desire to maintain the relationship, for instance out of love. Alternatively there may be a moral commitment to continue the relationship, for instance out of marital duty. There may also be external pressures which constrain a person so that s/he felt s/he had to continue the relationship, for instance because of a lack of alternatives. These three types of commitment may explain caregivers' motivations to continue caregiving. Caregivers may provide care out of love and reciprocity; they may also provide care due to family pressures or inability to afford formal care (Blieszner & Shifflet, 1989).

The current study identified that caregiving may also be motivated by other factors; for instance, because the caregiver was the only person available or willing to provide care. The unavailability of others to help provide care has been described as 'caring by default' (Campbell & Martin-Mathews, 2003) Studies have found evidence that sons are more likely to become caregivers for an older person if there are no other viable choices (Campbell & Martin-Mathews, 2003; Horowtiz, 1985). Similarly, Bliesszner and Shifflet (1989) found that some adult-children provided care due to a lack of alternatives. The caregivers in the current study also found that some family members were unwilling to help out with care. Finch and Mason (1993) have discussed 'legitimate excuses' which is part of the process of negotiating care commitments. Whether an excuse for not providing care is accepted as legitimate is not related to the gender of the person or their kin-relationship to the care-recipient. Rather the legitimacy of the excuse depends on the meaning ascribed to it and the negotiation of responsibilities. It can be argued that in these cases, the caregivers may feel trapped in their role and this could impact on their wellbeing.

The different types of motivations identified in this study relate to theories of motivation, which indicate that people may be motivated by internal desires or external pressures. Extrinsic motivations may emerge from social pressures, pressure from the care-recipient, or the caregivers' feeling that they have no choice but to provide care (Lyonette & Yardley, 2003). Emotions such as guilt may also act as strong motivators. In the current study avoidance of guilt, for example due to feelings of letting the care-recipient down, was a key motivational factor. The central theme of 'balancing needs' indicates that caregivers' motivations to provide care may change as the caregivers struggle to balance their needs with those of the care-recipient. Research indicates that different types of motivations may occur at different times during the caregiving career. Schulz et al. (1989) propose that in the early stages caregivers may be motivated by altruistic motives as they feel empathy towards care-recipients, whilst in the later stages caregivers may be more egotistically motivated.

Integrated into the themes concerning relationship quality and motivations to provide care was the issue of finding meaning. Caregivers derived meaning from their relationship with the care-recipient. Caregiving meant that they were able to meet the needs of the care-recipient and ensure the continuation of their relationship with the care-recipient. The caregivers' derived meaning from a belief that it was their duty to provide care and that they were reciprocating past help from the care-recipient. Some caregivers were motivated to continue caregiving because they could identify aspects of care which gave them satisfaction. However, not all the caregivers were able to describe positive aspects of providing care. The findings of the current study relate to research by Noonan et al. (1996) who explored meaning in caregivers for older people. These caregivers found meaning through deriving gratification from performing their caregiving role and helping to maintain the care-recipient's quality of life. Satisfaction could be derived from keeping the care-recipient out of a residential home. Some caregivers regarded caregiving as a reciprocal action, whilst others viewed it as a responsibility expected due to societal norms, and as a natural part of life. However, caregiving motivations were not a primary focus of the study, and as such caregiving motivations were interpreted as being part of finding meaning. In the current study, in contrast, meaning is encompassed under caregiving motivations.

The findings of the current study suggest a tentative link between caregivers' motivations to provide care and the meaning they find in caregiving. To our knowledge, no study has explicitly explored the connection between meaning and motivation in dementia caregiving. However, in a study of caregiving motivations Guberman et al. (1992) found that caregivers reported that caregiving gave meaning to their lives. Research by Bar-David (1999) indicated that caregivers could find caregiving rewarding which could enhance their motivations to provide care for others. A link between meaning and motivation is suggested in the Interactive Model for Finding Meaning through Caregiving (Farran & Keane-Hagerty, 1991). The model consists of four major components which can result in a caregiver either finding or not finding meaning. The first stage is the antecedents to caregiving, which explores the circumstances in which the person made a choice to take on the caregiving role. In the second and third components people move through a process of becoming caregivers and experiencing caregiving. The fourth component relates to the potential outcomes of caregiving; a positive outcome would occur where the caregiver found meaning in the role.

Two of the caregivers in this study had placed the care-recipient into full-time care. There were many factors which culminated in this decision being made: the caregiver's ill health, a lack of anyone else willing to provide care, pressure from other family members, and feelings of being unable to cope. These findings are similar to those of Buhr et al. (2006), who explored caregivers' reasons for institutionalising people with dementia. The most commonly cited reasons were that the caregiver was unable to provide the level of care that the care-recipient required, or that the caregiver had health problems that precluded continuing to care at home. Montgomery and Kosloski (1994) found that a high sense of duty or obligation to provide care lessened the likelihood of spousal caregivers placing the care-recipient in a nursing home, whilst for adult-child caregivers high levels of affection towards the care-recipient lessened the likelihood of placement. However, the present study demonstrates that although caregivers can be highly motivated to provide care, other factors could eventually influence the decision to place the care-recipient into full-time care.

In considering the findings it is important to take into account the limitations of the present study. The caregivers were recruited through the Admiral Nurse Service and thus may not be representative of the caregivers who do not have access to this kind of specialist service. Whilst it could be argued that the caregivers in this study should be coping better than other caregivers due to the support they were receiving, in fact the caregivers were struggling to balance the demands of the caregiving role. Conversely, it is possible that the caregivers had been referred to the Admiral Nurse Service because they were having particular difficulty in coping with the role. The study included both male and female caregivers, and there can be gender differences in caregiving (e.g. Fitting, Rabins, Lucas, & Eastham, 1986). In addition this study included both spousal and adult-child caregivers, and caregivers may have different experiences depending on their kin-relationship to the care-recipient (e.g. Barber & Pasley, 1995). However, in this study most of the themes were found in the majority of the caregivers' accounts, and there were no differences in the distribution of themes due to the caregiver's gender or kin-relationship to the care-recipient. The final theme 'I wasn't coping' did only emerge from the accounts of the two caregivers who had placed the care-recipient into full-time care, and so cannot be regarded as characteristic of caregivers who continue to provide care at home. There were some gender differences in the caregivers' accounts with regards to gender-linked role responsibilities. The male caregivers had to adapt to being in charge of household tasks like cooking, whilst some of the female caregivers had to learn to take charge of the finances and pay bills.

The caregivers' interviews were analysed using IPA and it is acknowledged that this form of analysis involves an interpretation of the participants' experience, so it was important to try to ensure that there was no personal bias in the analysis. This was achieved through the use of multiple independent analysts and by attempting to ensure that the themes reflected both the positive and negative experiences described by the caregivers, and recognising that some caregivers did not derive anything positive from the experience of caregiving. In addition, information about how extensively each theme was shared by the participants was provided in a table found in Appendix B.2. The validity of the analysis was ensured by recontextualisation, in which initial interpretations of the data are compared with the original material to check whether the interpretation is true to the material (Malterud, 2001). In the current study at both the individual and group level of analysis the themes were re-coded onto the transcripts to check the 'fit' of the themes with the transcripts. In order to ensure the integrity of the analysis, the findings need to reflect the participant's experiences and be clearly grounded in the data (Whitemore et al., 2001). In the present study the themes were illustrated with direct quotes from the participants. In addition, the caregivers' own words were used for the theme titles, thus helping to ensure that we did not simply impose pre-existing theoretical concepts on the participant's experience.

Nevertheless, this study has illustrated that meaning, motivations and relationship quality may interact to influence the experience of caregiving. Further quantitative and qualitative research in this area will help to determine the nature of the relationship between meanings, motivations and relationship quality, and the ways in which these three factors influence caregiver wellbeing. Longitudinal studies would make it possible to explore how meanings, motivations, and relationship quality change over the caregiving career, and how these factors relate to nursing home placement. Future studies in this area could include a more diverse group of caregivers in order to explore cultural differences, particularly in motivations and meaning. The caregivers in this study were either spouses or adult children, and future studies could also include non-familial caregivers in order to explore their motivations to provide care. This study only included the perspective of the caregivers, yet when exploring issues such as relationship quality it would be valuable to include the perspectives of the care-recipient and other key members of the immediate network.

Conclusion

This study has proposed that the relationship between the caregivers and care-recipient, the caregivers' motivations for providing care, and the meaning they found in caregiving can be encompassed under an overarching process of balancing needs. The caregivers' relationship with the care-recipient influenced the caregiver's motivations to provide care and gave caregiving meaning. Meaning was also intertwined with caregiving motivations, as caregivers could identify rewarding aspects of care. The findings of this study illustrate that the caregivers were trying to balance both their needs and the needs of the care-recipient. The caregivers encountered many dilemmas in their role, which added to caregiving-related stress. These dilemmas emerged from the desire to try to preserve the caregivers' relationship with the care-recipient, whilst recognising that this relationship was changing. Since this study suggests that motivations, meaning and relationships can play a role in the development and maintenance of caregiving, future research could explore how these factors interact to impact on caregiver wellbeing. The current study also found that the risk of the care-recipient entering into full-time residential care increased when the caregivers' needs outweighed those of the care-recipients. In order to help those caregivers who wish to continue caregiving more effective interventions need to be developed which can support caregivers in the ongoing task of balancing needs.

Chapter 6: ‘Negotiating the balance’: The triadic relationship between spousal caregivers, people with dementia, and health care professionals

Summary

Informal caregiving for a person with dementia often takes place within a health care triad, whose members include the caregiver, the care-recipient, and the health care-professional. However, there has been little research specifically exploring these triadic encounters in dementia caregiving. The aim of the current study was to examine the developing relationship of a triad, exploring how the members work together with this triadic context. Six spousal caregiving dyads and the three health care professionals who worked with the couples were interviewed. Transcripts of these interviews were analysed to form six case studies, each containing the perspectives of the three members of the triad. The processes emerging in these case studies were encompassed under an overarching dynamic process of 'negotiating the balance'. This describes the ongoing struggle of the members to balance the views of the other members against their own needs. Coalitions could occur as members worked together to tackle problems. The findings of this study highlight the importance of exploring the perspectives of all members of the triad. This should help health care professionals to improve the quality of the support they provide to caregivers and care-recipients.

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Introduction

In an increasingly aging society, there is a growing need for informal caregivers to help support an older person in the community, particularly when that person has dementia. According to Zarit and Edwards (2008), a caregiving relationship emerges when a person becomes dependent on another's assistance to complete tasks. Often caregivers have a gradual transition into their role, where they increasingly provide help to the care-recipient; however, some caregivers may experience an abrupt entry into their role (Gaugler, Pearlin, & Zarit, 2003). Caregiving involves a change in ongoing patterns of exchange between the caregiver and care-recipient (Zarit & Edwards, 2008). Both the caregiver and care-recipient have to adjust to the transformation of their relationship into a caregiving relationship. This includes a change in the balance of roles, as the caregiver takes more responsibility for the welfare of the care-recipient. This responsibility will involve the caregiver taking an active role in encounters with health-care professionals, such as accompanying the care-recipient to an appointment with the doctor. There has been little research exploring the triadic relationships between caregivers, care-recipients, and health care professionals. However, developing a better understanding of the perspectives of the members of the triad will help health care professionals improve the quality of the support they provide to caregivers and care-recipients.

This study will focus on a specific type of health care professional, the Admiral Nurse. Admiral Nurses are UK based specialist mental health nurses who work primarily with caregivers of people with dementia, providing practical advice, emotional support, and information about dementia. Admiral Nurses can also work with the caregiver/care-recipient dyad to identify appropriate respite services and support groups, and can also provide some support to the person with dementia. The Admiral Nurses may continue to support caregivers after the care-recipient enters residential care or dies. In an evaluation of the efficacy of the service, Woods et al. (2003) compared the caregivers who received the Admiral Nurse Service with caregivers who received support from multi-disciplinary community mental health teams for older people. The study found that there was a significant reduction in insomnia and anxiety in caregivers receiving the Admiral Nurse Service. Since Admiral Nurses provide support to both the caregiver and the person with dementia, the encounters between the Admiral Nurse and the caregiver will often include the care-recipient, creating a three-way relationship or triad. Each member of the triad may have differing perspectives on the effectiveness of the encounter.

Research on triadic relationships has tended to focus on the encounters between physicians and older patients. Haug (1994) proposes that one of the main distinguishing factors of the physician-older patient encounter is that often a third person, normally an informal caregiver, accompanies the older person. In addition, the third person may act as a 'hidden patient' who also requires support from the physician (Haug, 1996). Fortinsky (2001) explored the triadic interactions between people with dementia, their informal caregivers, and the medical care system, which could include the primary care physician. Fortinsky's (2001) model of the 'health care triad' indicates that all three members of the triad bring different factors into an encounter, for instance age or culture. All of these factors could influence the quality of the encounter, which could in turn influence health-related outcomes for the caregiver, care-recipient, and physician. Adams and Gardiner (2005) have furthered this model by recognising that the 'dementia care triad' may include health or social care professionals. Adams and Gardener (2005) also recognised that in caregiving situations there may be more than one informal caregiver and equally several professionals involved with the care-recipient.

These models of health care triads indicate that it is important to explore what each member of the triad brings to the encounter. Research investigating encounters has tended to explore the perspectives of just two members of the triad. These studies have tended to utilise a qualitative methodology as it allows for an in-depth examination of the participants' experiences. For instance, Keady, Ashcroft-Simpson, Halligan and Williams (2007) explored how a caregiver and Admiral Nurse worked together. Studies have also investigated the impact of receiving a diagnosis of dementia on the caregiver and care-recipient (e.g. Aminzadeh, Byszeski, Molnar, & Eisner, 2007; Derksen, Vernooij-Dassen, Gillisen, Rikkert, & Scheltens, 2006; Hellström, Nolan, & Lundh, 2007). Robinson et al. (2005) explored the psychological reactions to a diagnosis of dementia in nine couples. They found that the couples engaged in a process of negotiation as they tried to make sense of what was happening to them. The couples seemed to oscillate between an overwhelming sense of loss and difficulty on the one hand and a sense that they can move on, adapt and adjust to living with dementia on the other. Keady and Nolan (2003) described four main ways that dyads 'worked' in response to diagnosis. For instance couples may 'work together' where there are shared and early recognition of symptoms, alternatively couples may 'work separately' where the person with dementia tries to hide their problems and the caregiver is increasing vigilance. These studies illustrate the importance of exploring both perspectives, as the caregiver and care-recipient may react differently to the diagnosis. In addition the findings demonstrate that, when providing support, both members of the dyad should be taken into consideration. In order to improve the support given, it is important to explore the perceptions of the third person in these encounters.

Some studies have included the perceptions of the health-care professionals. Connell, Boise, Stuckey, Holes and Hudson (2004) investigated the attitudes of caregivers and primary care physicians regarding the disclosure of a diagnosis of dementia. The authors found both contradiction and convergence in the participants' accounts of, and preferences for, disclosure. This indicates that caregivers and physicians had differing viewpoints on the best way to disclose the diagnosis. Developing a better understanding of these differences would enable physicians to more effectively meet the needs of the caregivers. Studies have also investigated the differences in perspectives between patients and health care professionals. Dean et al. (2005) compared the perceptions of patients suffering from lower back pain and their physiotherapists regarding exercise adherence. The analysis revealed that there were tensions and conflicts within the participants' accounts. The physiotherapists felt the patients should make more time to do their exercises but the patients found this difficult. Finally, a few studies have examined the perspectives of all three members of a triad. Orrell et al. (2008) utilised quantitative methodology to compare the differences in assessments of the needs of older people with dementia living in care homes, by comparing their perspectives with those of care staff and family caregivers. There were discrepancies in participant's accounts as people with dementia rated fewer met needs than family caregivers and staff. Staff rated more met needs than family caregivers, and family caregivers rated more unmet needs than staff. This study illustrates the importance exploring the viewpoints of all members of a triad to understand the needs of the person with dementia.

Kahana and Young (1990) have argued that health care professionals can have a critical role in shaping the interactions between the caregiver and care-recipient. Given that recent research has emphasised to need to explore these triadic interactions (e.g. Nolan, Grant, & Keady, 1996); this emphasises the importance of exploring all the perspectives of the members of a triad. However, to date little research has been conducted exploring the triadic relationships between the caregiver, the person with dementia and the health care professional. Understanding more about these relationships could enable health care professionals working with caregivers and care-recipients to provide better support. This study will examine the perspectives of all members of the triad: the caregiver, care-recipient and Admiral Nurse. The study will explore how the development of a triadic relationship as members work together. This will involve examining the members' perspectives on the caregiving situation and on the effectiveness of the working relationship with the Admiral Nurse. The current study will explore similarities and differences in the members' perspectives by utilising qualitative case studies. This allows for an in-depth examination of how the triadic relationship is perceived by each member.

Method

Design

This was an exploratory study using qualitative methodology. Transcripts of semi-structured interviews conducted with the participants were analysed to create case studies presenting the perspectives of the caregiver, care-recipient and the Admiral Nurse

Ethical Issues

Ethical approval for this study was obtained from the relevant NHS Local Research Ethics Committee. In order to maintain confidentiality, the participants' details were anonymised. Pseudonyms were used for the caregivers and care-recipients. For reasons of confidentiality, no identifying details about the Admiral Nurses are provided.

Participants

Participants were recruited from the caseloads of three Admiral Nurses based in the North-West of England. The participants were six dyads, consisting of female spousal caregivers and their male care-recipients. These female spousal caregivers were participants in the study presented in Chapter 5. Three Admiral Nurses who had been working with the dyads also took part in this study. The care-recipients were in the early and middle stages of dementia, as determined by the Clinical Dementia Rating (CDR; Hughes, Berg, Danziger, Coben, & Martin, 1982). The CDR assesses the severity of dementia across six domains and scores range from 0 (no impairment) to 3 (severe impairment). The CDR score was assigned by the Admiral Nurse. All the participants were White-British. The caregivers had a mean age of 65 (*SD*= 13.85), with ages ranging from 41 to 86. The care-recipients had a mean age of 76 (*SD*= 13.54), with ages ranging from 41 to 88. The length of the caregivers' marriage to the care-recipient ranged from 8-50 years, and two of the caregivers were in their second marriage. None of the caregivers were in employment. The caregivers had been caring for the care-recipient at home.

Data Collection

Potential participants were identified by three Admiral Nurses, who approached them in order to ascertain whether they would be willing to participate. Those who expressed an interest were contacted by the researcher (CQ), who subsequently visited the couples to explain the study. If the couples consented to take part, then the interviewer arranged for the caregiver and care-recipient to be interviewed individually at their home. At the start of each interview, the participants were asked again for their consent to be interviewed and for the interview to be tape recorded for later transcription. The interviews with the caregivers lasted between 38 and 98 minutes and followed a semi-structured schedule. These interviews explored the caregivers' reasons for taking on the caregiving role, and whether they received any support from family or friends with caregiving. The caregivers were asked to consider whether caregiving had affected their relationship with the care-recipient, and if so, in what ways. The caregivers were questioned about how caregiving had affected their wellbeing, and whether they could identify any positive aspects of providing care. The caregivers were asked to reflect upon what it meant to them to provide care, and what helped them to continue caregiving. Finally, the caregivers were asked to consider whether they felt they would ever stop providing care at home.

The interviews with the care-recipients lasted between 13 minutes to 63 minutes, and explored their perspectives on the experiences of the caregivers, and their relationship with the caregivers. The care-recipients were questioned about their general wellbeing, including any problems with their memory. In addition, the care-recipients were asked about their social and daily activities.

The Admiral Nurses where interviewed on a separate occasion. These interviews took place in a private room in their offices, and lasted between 25 and 56 minutes. The Admiral Nurses were asked to describe the main areas that they had been working on with the caregiver and care-recipient, and how the dyad had responded to their advice. The Admiral Nurses were asked for their views on the quality of the relationship between the caregiver and care-recipient. The Admiral Nurses were questioned about how the caregivers were coping, and whether the caregivers received any support from family members or friends. The Admiral Nurses were asked for their thoughts on the caregivers' reasons behind commencing caregiving, and the caregivers' commitment to continue caregiving.

Care was taken to ensure that the interviews finished on a positive note. All the participants were advised that if they had any concerns or wished to further discuss any of the topics explored in the interview then they could telephone the interviewer at any time. None of the participants took up this option. The couples were also reminded that they could contact their Admiral Nurse for further support if they wished.

Data Analysis

The transcripts of the interviews with the caregivers had been previously analysed, using IPA, and this thematic analysis has been reported in Chapter 5. The final list of themes for these specific caregivers from the study in Chapter 5, were utilised in the current study. For each list of themes, the transcripts of the interviews with the care-recipient and Admiral Nurse were scrutinised to identify all applicable statements. These were placed alongside the relevant extracts from the caregivers within the list of themes. This resulted in a list of themes for each caregiver which included all relevant extracts from the caregiver, care-recipient and Admiral Nurse. This illustrated the perspectives of each member of the triad in relation to the themes arising in the caregiver's account. Any themes for which there was no other perspective available from either the care-recipient or the Admiral Nurse were excluded. These lists of themes and extracts providing a triadic perspective formed the basis for the case studies presented here. An extract from a case study can be found in Appendix B.3.

Results

The six case studies illustrate the similarities and differences in the perspectives of the caregivers, care-recipients, and the Admiral Nurses. These case studies are encompassed under an overarching process of 'negotiating the balance'. This describes the ongoing struggle of the participants to balance their views of the other members against their needs. Coalitions could also occur between members of the triad as they work together to tackle problems. This process of 'negotiating the balance' is a dynamic process as the balance is constantly changing.

Angela and Jack

Angela was caring for her husband Jack who is in the mild stages of dementia (CDR= 1). Angela was having trouble adjusting to the changes in her husband. She felt that he was a completely different person; only rarely would she recognise aspects of his 'old self'. The Admiral Nurse and Angela had differing views on the causes of these behavioural and personality changes. The Admiral Nurse had tried to work with Angela to try to get her to attribute these changes to the dementia. However, the Admiral Nurse recognised that this was hard for Angela:

'She does try to tell herself that this is to do with the dementia, this is not him...but it is so hard for her' (Admiral Nurse)

Angela did find it difficult to attribute Jack's behaviour to his condition, and admitted that at times she could find her husband's behaviour exasperating. However, she was following the Admiral Nurse's advice about trying to keep calm:

'Sometimes I think he does it to wind me up... now I've learnt to keep me cool and say nothing and he'll forget about it. If he thinks it's winding me up he keeps on at it' (Angela)

Both Angela and the Admiral Nurse agreed that Angela had to take over her husband's role of being in charge of the finances. The Admiral Nurse identified that Angela would need support with this:

'I've tried to help her feel more in charge of the situation' (Admiral Nurse)

Angela faced the difficult task of curbing Jack's spending. She initially found this difficult, but with the support of the Admiral Nurse she stopped giving in to his requests:

'It was upsetting at first but I've just got to get hardened to it, that if he wants something that he can't have everything that he sees' (Angela)

Angela felt that Jack was resistant to accept her help because he did not believe that he had any problems with his memory, a view supported by the Admiral Nurse. However, it would appear that Jack did have some awareness that he had some problems with his memory:

'No more so than uh, at my age you know, and my memory is....uh, short term memory, don't ask me what I had for dinner yesterday' (Jack)

Sometimes the solutions provided by the Admiral Nurse were not accepted by Angela and Jack. The Admiral Nurse identified that both Angela and Jack needed some time away from each other. With Angela's support, the Admiral Nurse had arranged for Jack to go into day care; however, Jack suddenly decided that he no longer wanted to go. Whilst this decision baffled Angela and the Admiral Nurse, Jack's comments in his interview revealed that it may have been because attending had made Jack more aware of his decreasing abilities:

'There's a lot of people who are physically impaired as well or... a lot of people that were around from the day centre, I used to think to myself I hope I don't get like that' (Jack)

Similarly, the Admiral Nurse had arranged for Angela to attend a support group, but Angela had stopped going to it because she found it depressing. The Admiral Nurse acknowledged that Angela was still very stressed and so would continue to work with her in the long-term:

'Each time I visit she's always got things that are worrying her, she's always very stressed' (Admiral Nurse)

In summary, in the process of negotiating the balance there were coalitions between Angela and the Admiral Nurse as they worked together to tackle Jack's behaviour. However, Angela and the Admiral Nurse did have differing perspectives on the causes of this behaviour. There were also differences in views on whether Jack was aware that he had a problem with his memory. There was a good working relationship between the Admiral Nurse and Angela, although Jack could be resistant to their help.

Joan and Ron

Joan was caring for her husband Ron who was in the mild stages of dementia (CDR= 1). The Admiral Nurse had found it difficult to help Joan because she was not very open about her feelings. However, the Admiral Nurse did acknowledge that this possibly was because during their meetings Ron was normally in the room, and Joan had admitted that she was not comfortable discussing her feelings in front of him. The Admiral Nurse identified that Joan was struggling to adjust to the changes in the balance of her relationship with Ron. Joan had previously suffered from health problems and was used to Ron caring for her:

'She needs Ron to be able to look after her because she sees herself as the ill one in the partnership. If Ron is ill who is going to look after her?' (Admiral Nurse)

Joan admitted that she found it difficult to adjust to the decline in Ron's abilities. He was now dependent on her and she was responsible for tasks that Ron would have normally done. Joan still wanted to involve Ron in decision making, although Ron felt that Joan should make decisions on her own:

'Oh yeah, no always, they're all decisions made together um ...it is true she feels that there's a restraint, [an] influence there, well there is to some extent. I might say something tone down eight times or something and uh she might wander off and do something else but uh, my feeling is if she wants it, like a dog...well she'd better get a dog' (Ron)

There could be differences in the views of the members of the triad as both the Admiral Nurse and Ron perceived Joan to be coping well; however, Joan felt that she was struggling:

'I don't feel that I am coping very well and Ron says I am doing fine, but I really don't think that I am' (Joan)

There could also be discrepancies in the perceptions of Ron's abilities. The Admiral Nurse believed that Joan had a tendency to perceive Ron as being more impaired than he actually was. She could also be too over-protective of him:

'She's taken things off him that he's quite capable of doing or could do in a fashion, even if it's not perfect. It's her letting him do it and it not be perfect that's probably the crux of it' (Admiral Nurse)

This view was supported by Ron, who felt that Joan was preventing him from doing some work around the house, which he felt he was capable of doing:

'And uh she's all for getting someone in to do the garden I don't know, that's one of the things I can do, why give it away to somebody else' (Ron)

Joan felt that she was just trying to help Ron. She had found that when Ron did a task he did not complete it and this resulted in more work for her. She sensed that Ron did not appreciate her help:

'He doesn't see it as me helping, he sees it as me just wanting these things done and trying to take things off him' (Joan)

The Admiral Nurse recognised that Joan's over-protectiveness just made her more stressed and was concerned about how Joan would cope in the future when Ron deteriorated further. In summary, there is evidence of an imbalance in the accounts of this triad. Joan is trying to take on the views of the Admiral Nurse and Ron but is struggling to balance this against her own needs. There is evidence of similarities in the perspectives of the Admiral Nurse and Ron, indicating potential coalitions occurring between them. Joan's difficultly in expressing her feelings to the Admiral Nurse and Ron impacted on the effectiveness of the working relationship between the triad.

Maureen and Joe

Maureen was caring for her husband Joe who was in the mild stages of dementia (CDR= 1). Although Maureen was coping reasonably well, she was experiencing difficulties dealing with Joe's unpredictable mood, as he could become angry and aggressive. Both Maureen and the Admiral Nurse identified that one of the causes of this aggressiveness was Joe's tendency to drink alcohol and so they had worked together to find a solution to this problem. The Admiral Nurse had also believed that some of Joe's feelings of anger resulted from his lack of insight into his condition:

'He's shown a lot of suspiciousness. A lot of his behaviour is because he doesn't understand what is happening to him' (Admiral Nurse)

However, Joe appeared to have some awareness of his memory problem, although he tended to normalise it:

'I'm slight I'm beginning to slip up a bit now uh, and I'm starting to lose my memory a little bit but you can't avoid that it's one of them things, it happens to everyone doesn't it' (Joe)

Maureen was having trouble accepting the changes in Joe and this would result in disagreements between the couple. Joe wanted to be able to go out:

'When you could be out doing something...more important, you know, and more enjoyable' (Joe)

However, Maureen did not like socialising with Joe as she was embarrassed about his behaviour:

'I don't take him out socially really cause he's always getting at me, nagging me over something or other and makes you feel dead embarrassed' (Maureen)

The Admiral Nurse felt that Maureen had trouble attributing Joe's behaviour to the dementia. Maureen could be very confrontational with Joe, which only resulted in arguments. The Admiral Nurse worked with Maureen to educate her about dementia, which Maureen had found beneficial. The Admiral Nurse believed that Maureen had improved since she had been attending a support group for caregivers:

'Maureen has come to the [support] group and she has learnt quite a lot and developed a greater understanding of his condition. She has started to change her coping strategies and ways of approaching him. This has led to a better quality of life for him and less conflicts between them' (Admiral Nurse)

Although the Admiral Nurse perceived that there had been an improvement in Maureen's interactions with Joe, Maureen was still having problems and recognised that she still could be impatient with him:

'Well I don't always react like I should. I'm impatient person as well...I get angry with him. I wake up every morning and think oh god today I won't be impatient I won't, nothing will phase me today but by the end of the day I know I've not kept that' (Maureen)

In summary, there were coalitions between Maureen and the Admiral Nurse as they worked together to address problems. There were differences in the perspectives of the members of the triad. Maureen and Joe were struggling to find a balance in their needs, which was causing disagreements.

Edna and Bill

Edna is caring for her husband Bill who was in the moderate stages of dementia (CDR= 2). Although Edna had perceived herself to be coping well she had sought help because Bill was becoming aggressive. There were differencing perspectives between the Admiral Nurse and Edna over the way she communicated with Bill. The Admiral Nurse identified that Edna tended to be quite confrontational with Bill, which only agitated him:

'I think that that some of her responses, which tended to correct him or tell him off, certainly weren't helping. I was trying to help her identify that this was not working and to consider what the alternatives would be' (Admiral Nurse)

Edna felt that she is just trying to help Bill, although she found he could react badly to this:

'I think he thinks I'm just telling him things for the sake of telling him but I said I wouldn't tell you to do something or not do something if I didn't think you needed to do it. But this is what, you know, again this is where the aggression sometimes creeps in' (Edna)

Edna and Bill did tasks, such as the housework, together and Bill accepted that Edna would usually intervene and help him:

'I can usually cope with most of it, like I say Edna will leave me doing it for a certain length of time, then she'll say what's your problem and I'll say this and she does it. So I don't mind she can do it all' (Bill)

The Admiral Nurse tried to work with Edna and help her to deal with situations when there was growing tension between her and Bill. However, Edna thought that the solution suggested by the Admiral Nurse would not work for her:

'[Admiral Nurse] has said when he gets... you should get up and go and go for a walk but alright I can go upstairs but I couldn't go out because I wouldn't know what he was doing, even just a walk around the block, I couldn't take that chance' (Edna)

Edna felt that she could not leave Bill alone and constantly needed to watch him. The Admiral Nurse believed that it would be beneficial for Edna to spend some time away from Bill. However, Edna did not want to be separated from Bill as she was nervous about being in the house alone or going out alone. Bill also did not want her going out alone:

'Keep telling her if she's going out for more than two things she doesn't go on her own' (Bill)

The Admiral Nurse speculated that the couple could be resistant to changing longstanding patterns of interaction. Thus, this may be why Edna was unwilling to amend the way in which she communicated with Bill:

'I don't think she does as well as I would have liked for Bill's sake and perhaps for her own sake, in terms of not getting so irritable at times or her responses to him. I think she still tends to confront Bill, still tends to correct him and she still tends [to] complain or at least comment on him' (Admiral Nurse)

In summary, there was evidence of imbalance in the relationship between the members of the triad. There were coalitions between Edna and Bill as they both shared a similar perspective and were resistant to accept the advice of the Admiral Nurse. Despite knowing that Edna's unwillingness to adapt was causing problems between her and Bill, the Admiral Nurse accepted that Edna could not be forced to change.

Paula and Steven

Paula is caring for her husband Steven who is in the mild stages of dementia (CDR= 1). The Admiral Nurse found that Paula was keen to get support with practical issues rather than seeking emotional support. This lack of an emotional response was linked to Paula not being very empathic towards Steven:

'I judged a more limited empathy on her part towards Steven's experiences and a lack of expression to me at times about how this has made her feel other than just some practicalities' (Admiral Nurse)

The Admiral Nurse felt that this lack of empathy was having a negative impact on Paula's interactions with Steven. Paula found it difficult to adjust to the changes in Steven, because he was now very quiet and was less likely to instigate a conversation:

'When I married him, like years ago, he was very funny and he used to mess about and now he hardly talks, so we sit here at night and I ask him questions but he's not really there but that's not his fault'(Paula)

Paula had tried to make an effort to talk with Steven but at times she found this tiring. The Admiral Nurse had tried to work with Paula to help her be more patient with Steven:

'I was mainly concerned about helping her to respond more appropriately to Steven's changed behaviour and his poor communication. She had unrealistic expectations at times of how he might understand and how he might communicate his own thoughts and feelings. I felt that some of her responses simply weren't helping' (Admiral Nurse)

However, Paula admitted that she still got frustrated with Steven, particularly when she felt that she had only asked him to do what she considered a simple task.

Both Paula and Steven found it difficult to adapt to the changes in their lifestyle. Steven was adjusting to spending time at home, as previously he had worked, and enjoyed getting out of the house:

'Yeah don't like sitting in I get bored' (Steven)

Paula found it difficult to adapt to spending all her time with Steven. She found that he wanted to be with her all the time and she had to take him everywhere with her:

'He's there all the time, even when I'm doing a job he is trying to help me and he's behind me, sometimes I turn round and I trip over him' (Paula)

The Admiral Nurse and Paula had differing perspectives on Steven's behaviour; Paula found it frustrating, whilst the Admiral Nurse felt that Steven might be frightened of being left alone. The Admiral Nurse would continue to work with the couple in the long-term, although Paula was still resistant to discussing the emotional side of caregiving. In summary, Paula struggled to find a balance between trying to meet her and Steven's needs. The working relationship between Paula and the Admiral Nurse was impaired by a perceived lack of emotion and empathy shown by Paula.

Jill and Jim

Jill was caring for her husband Jim who was in the mild stages of dementia (CDR= 1). Although Jill believed that she was struggling, the Admiral Nurse felt that Jill was doing better than she thought:

'She was definitely struggling, but actually doing better in my judgement then she might have judged herself to be doing. I think it was that lack of comparison that was probably influencing this slightly more negative view of how she was coping on a her part' (Admiral Nurse)

The Admiral Nurse felt it was important to increase Jill's access to information about dementia and to put her in contact with local support groups so that she could benefit from meeting other caregivers. Jill was keen to get practical, rather than emotional support from the Admiral Nurse. Jill wanted advice on how to deal with the changes in Jim's behaviour and she actively tried to find solutions to his problems. She was concerned that Jim was bored and endeavoured to find activities to keep him stimulated. However, she was struggling to find something to occupy him:

'So really he's doing nothing but I can't occupy him because I can't think what to give him to occupy him, and you can't sit and talk because you can't hold a conversation and I can't think what to do with him' (Jill)

The Admiral Nurse had some concerns about the way Jill interacted with Jim:

'There's occasionally been a slight dismissive manner in her...you've been going out and leaving the doors open haven't you Jim, oh well you don't remember anyway do you' (Admiral Nurse)

However, Jim was aware of his limited abilities and that he was dependent on Jill:

'I know that I'm supposed to be going go and do something and sometimes I achieve that, not every time and so it's a bit of a pain and I think, think, oh poor Jill got to sort it all out'(Jim)

Both Jill and the Admiral Nurse agreed that it was important for Jill to have breaks from caregiving:

'I said I can't carry on, you know, every single day without a break' (Jill)

Although Jim was disappointed not to be able to go away with Jill, he also recognised that it was important for Jill to have a break:

'The fact that Jill still tries [to go away] is really good, really, cause I couldn't do [it's] horrible [to] be stuck in the house most of the time' (Jim)

Jill felt that if she had breaks, it would enable her to maintain caregiving. In summary, there was evidence of differences in perspectives between Jill and the Admiral Nurse on how Jill communicated with Jim. Jill felt she was struggling to meet her and Jim's needs, although Jim seems satisfied with the support he was receiving from Jill. All the members of the triad shared the view that it would be beneficial for Jill to have a break.

Summary of findings

The overarching concept of 'negotiating the balance' encompasses how the members of the triad work together. Each member attempts to acknowledge the perspectives of the other members, but has to balance these against their own needs. The caregivers try to take on board the views of the Admiral Nurses, but can find it difficult to change patterns of communication and alter the attributions they make about the care-recipients' behaviour. The caregivers will try to respect the views of the care-recipients but also have to acknowledge their own needs and what they believe is the best way to care for the care-recipients. The care-recipients may agree with the opinions of the caregivers and the Admiral Nurses, for instance acknowledging that the caregivers need a break from caregiving. Equally, the care-recipients will balance these views against their own perceptions of their abilities and may not want to follow the suggestions made, such as attending support groups. The Admiral Nurses try to balance the needs of the caregivers and care-recipients, as part of their job. However, they may find that they have to prioritise the needs of the caregivers or the care-recipients, for instance recognising that the caregivers need to tackle the care-recipients' behaviour. The Admiral Nurses also have to accept that they cannot force the dyad to follow their advice. There is evidence of coalitions occurring between the Admiral Nurses and caregivers to tackle difficult behaviour. There may be alliances between the caregivers and care-recipients as they decide not to follow the advice of the Admiral Nurses. Finally, there is evidence that the Admiral Nurses and care-recipients can share the same perspective, for instance believing the caregivers are too over-protective, and so may collaborate to deal with this.

Discussion

The findings of the current study indicate that the members of the triad are involved in an ongoing process of 'negotiating the balance'. The findings of this study support Adelman, Greene and Charon's (1987) discussion of the 'physician-elderly patient-companion' triad. They propose that the presence of the third person can significantly change the dynamic of the doctor-patient relationship. The third person may facilitate or inhibit a trusting doctor-patient relationship, and the doctor's and patient's perceptions of this third person may differ. For the patient, the third person may act as an advocate of the patient's viewpoint or as an antagonist. The patient may also perceive the third person as acting as a passive participant in the encounter. Similarly, for the doctor, the third person could be viewed as acting as an advocate or as an antagonist. Adelman et al. (1987) also propose that coalitions could take place, in that the third person could work with the patient against the doctor or work with the doctor against the patient. These coalitions could occur in any encounters with other health care professionals and social care providers. In the current study there is evidence of coalitions occurring between the caregivers and the Admiral Nurses, and between the caregivers and care-recipients. The current study extends previous research as it also indicates the potential for coalitions to arise between the Admiral Nurses and care-recipients when they share similar perspectives.

The idea of coalitions in triads relates to Adams and Gardiner's (2005) theory on communication in 'dementia care triads'. The authors identified two types of communication that can occur in a triad: 'enabling' dementia communication and 'disabling' dementia communication. The first occurs when the care-recipients are encouraged to express their feelings and participate in decision-making. The second occurs when the care-recipients are discouraged from expressing their thoughts and are not included in decisions. There is evidence of both types of communication in the current study, although the findings indicate that 'negotiation' occurs in these interactions. Both the caregivers and Admiral Nurses try to acknowledge the views of the care-recipient and make decisions based on these. However, in some instances there is evidence that the caregivers have disregarded the views of the care-recipients. This may be because the caregivers feel that what they are doing is in the best interest of the care-recipients or because they feel the care-recipients lack insight into their condition. The Admiral Nurses do try to balance the perspectives of the caregivers and care-recipients; however, there were situations where the Admiral Nurses may have overruled the views of the care-recipients. These decisions seem to arise from a desire to enhance the welfare of both the caregivers and care-recipients. The care-recipients could get frustrated because they were not involved in the decision-making; however, it was also possible that sometimes they just accepted these decisions. Gillard (2001) describes how practitioners working with caregivers and care-recipients often face dilemmas when deciding whose needs are more important. For instance a caregiver may want a break from caregiving but the care-recipient cannot understand why s/he has to go into respite.

In exploring these triadic encounters, it was clear that there were differences in the perceptions of the Admiral Nurses and the caregivers. The Admiral Nurses identified that the caregivers were experiencing difficulties in attributing the care-recipients' personality and behavioural changes to the dementia. The Admiral Nurses had worked on these issues with the caregivers, but it was evident from the caregivers' accounts that they were still struggling with this. Other studies have found that when caregivers do not fully understand the impact of dementia on the care-recipient, this tends to result in misunderstandings and misattributions (Mittelman, Roth, Haley & Zarit, 2004; Paton, Johnston, Katona, & Livingstone, 2004). The Admiral Nurses also identified that some of the caregivers needed to change the way in which they communicated with the care-recipients. However, some of the caregivers found it difficult to do this, possibly because it involved changing long-standing patterns of interactions. Other caregivers may have overly adapted the way in which they communicated with the care-recipient. Adapting patterns of communication is important as research indicates that a poor quality of communication between the caregiver and care-recipient has a negative impact on caregiver wellbeing and increases reports of behavioural problems (Roberto, Richter, Bottenberg, & Campbell, 1998). The caregivers' resistance to changing patterns of interactions may be related to their difficulties in dealing with the perceived loss of the person with dementia. Dementia can reduce the ability of the care-recipient to provide emotional and practical support to the caregiver (Almberg, Grafström, & Winblad, 2000). Some caregivers may retain the pre-dementia image of the care-recipient (Baike, 2002), making it harder for the caregivers to accept changes in the care-recipient. Other caregivers may perceive that the care-recipient's personality has altered; however, these changes may fluctuate and aspects of the care-recipient's 'old self' may be evident at times (Almberg et al., 2000).

The differences in the views of the members of the triad influenced the way in which they worked together. In some cases, the caregivers and the Admiral Nurses felt that the care-recipients lacked insight into their memory problems and this may have influenced how they treated them. A lack of an emotional response from some of the caregivers concerned the Admiral Nurses and seemed to influence their perceptions of the caregivers. However, it was possible that the caregivers felt unable to express their true feelings if the care-recipients were present. This does indicate that the caregivers' needed to be provided with opportunities to discuss their feelings away from the care-recipient. Negotiating the balance of these interactions influenced the effectiveness of the support provided by the Admiral Nurses. There were times when both the caregivers and persons with dementia resisted their help. Hasselkus (1988) interviewed family caregivers of older people and identified a 'three-way pattern' of tension between the caregivers, the care-recipients, and the health care professionals. The caregivers experienced a conflict between trying to follow the instructions of the health care professionals and trying to meet the needs of the care-recipient. Often the caregivers would modify the suggestions made by the health care professionals as they felt that they had a 'special knowledge' of the care-recipients and so knew how to meet their needs better than the health care-professionals. However, this study only included the perspectives of the caregivers and the current study highlights the value of exploring all the perspectives of the triad. Equally, the current study emphasises the importance of providing support to both the caregiver and care-recipient. Recent interventions have recognised the need to provide support for and improve communication between both members of the dyad (e.g. Whitlatch, Judge, Zarit, & Femia, 2006).

In considering the findings, it is important to take into account the limitations of the present study. Firstly, this was a small sample; however, this did enable an in-depth examination of the interactions between the members of the triad. The Admiral Nurses were involved in the recruitment of the dyads and thus it could be argued that they only approached dyads who were satisfied with the service. However, it was evident in the accounts of the caregivers and care-recipients that they could be resistant to accepting the help of the Admiral Nurses or following their advice. Similarly, despite having the support from the Admiral Nurse Service, the majority of the caregivers were nevertheless struggling with the demands of the caregiving role. Whilst the Admiral Nurses met regularly with both members of the dyad, in some cases the Admiral Nurses also had individual meetings with the caregiver. However, this did not appear to influence the Admiral Nurses' perception of the dyad.

The method of analysis used in this study also has it limitations. The caregivers' interviews were analysed using IPA and it is acknowledged that this form of analysis does involve some interpretation, and so it was imperative to try to ensure that there was no bias in the analysis. One researcher (CQ) had interviewed all members of the triad and so it was important not to allow any personal preconceptions to influence the analysis. In order to reduce such bias this analysis was independently examined by another researcher experienced in qualitative analysis. Differences in interpretations of the data were discussed until consensus was achieved. In presenting the findings of the analysis, it was essential to ensure that all three perspectives were equally represented in the analysis, with no particular bias towards one perspective. In the present study, the case studies were illustrated with direct quotes from all three members of the triad participants. This ensured that the findings were clearly grounded in the data, ensuring the integrity of the analysis (Whitemore et al., 2001).

The current study has illuminated the triadic relationship between the caregiver, person with dementia and Admiral Nurse. Since this study only involved spousal dyads, future studies in this area could include a more diverse group of dyads, such as adult-child caregivers. Whilst the present study interviewed the participants separately, further qualitative research into this area could involve recording the actual encounters between the three members of the triad. This would enable a more detailed examination of the interactions between the members. Longitudinal studies should be conducted to explore how the relationship between the members of the triad changes over time as the negotiations within the triad continue to try to reach a balance. Longitudinal research could also investigate how the balance of these interactions changes, particularly when the care-recipient enters into the severe stages of dementia. Further quantitative and qualitative research in this area should explore the triadic interactions between caregivers, people with dementia and other relevant health care professionals or formal carers.

Conclusion

This study has proposed that the triadic relationship between the caregiver, care-recipient and Admiral Nurse can be encompassed under an overarching process entitled 'negotiating the balance'. This balance could influence the success of the working relationship between the triad. The members could have differing perspectives on the situation, and there could be coalitions between the members. Since the balance of the triadic relationship is dynamic, future research should explore how this balance changes over time. The findings of this study emphasise the importance of exploring the perspectives of all the members of the triad to understand their working relationship.

Chapter 7: Relationships, motivations and meanings in dementia caregiving: A cross-sectional study

Summary

Numerous theoretical models have been developed to explore how caregiving can impact on caregivers' wellbeing. However, less attention has been given to caregivers' motivations for providing care, the meaning they find in caregiving and their relationship with the care-recipient. The current study explored whether intrinsic and extrinsic motivations, meanings and pre-caregiving and current relationship quality were related to each other and whether they interacted to influence caregiver wellbeing. In addition, predictors of finding meaning were examined. This was a cross-sectional questionnaire, in which the respondents were 447 caregivers of people with dementia who were in receipt of a specialist nursing service. The results showed that intrinsic motivations, meaning, and pre-caregiving and current relationship quality were significantly related to each other, whilst extrinsic motivations were only related to intrinsic motivations and meaning. All these factors were significantly related to aspects of caregiver wellbeing. Variance in finding meaning was significantly predicted by high religiosity, competence, intrinsic motivations and low role captivity. Based on these findings it is recommended that interventions aimed at reducing caregiving stress should take into account the impact of the quality of the relationship and the caregivers' motivations for providing care. Interventions could also help caregivers identify positive aspects in providing care. More longitudinal research is needed to explore how meanings, motivations, and relationship quality change over the caregiving career.

Introduction

It has been argued that dementia is a major public health issue for the 21st century (Alzheimer's Europe, 2006). There are 5.4 million people with dementia in the European Union and over 5 million people with dementia in the United States (Alzheimer's Association, 2009; Alzheimer's Europe, 2006). Given that we now live in an increasingly aging society, it is expected that the number of people with dementia will increase. In the United Kingdom alone, it is predicted that the number of people with dementia will double in the next 30 years (Department of Health, 2009). Thus, dementia presents a huge challenge for society, particularly for those who provide care. The majority of people in the early stages of dementia are cared for at home by informal caregivers, normally family members (Knapp & Prince, 2007). Although there has been extensive research on aspects of caregiving for a person with dementia, relatively little attention has been given to the dynamics of the relationships involved or to the factors which influence the establishment and maintenance of caregiving. In the majority of cases, care is provided by someone who knew the care-recipient beforehand. This relationship will therefore play an important role in the caregiver's decision to commence caregiving, and the changing nature of the relationship with the care-recipient could affect the caregiver's wellbeing. There are other reasons why caregivers start caregiving, and these factors could have an influence on the continuation of the caregiving relationship. In addition, caregivers' ability to find meaning in caregiving, to derive something positive out of it, could reinforce their desire to provide care. The aim of this study is to investigate how these three factors: motivations for caregiving, the relationship between the caregiver and care-recipient, and the meanings attributed to caregiving, impact on caregiving. This study will build on the findings from the qualitative study presented in Chapter 5, which suggested that there may be a link between these factors. The current study will examine whether and in what way these factors are related to each other. This study will also explore the individual and combined impact of these factors on caregivers' wellbeing.

There have been numerous theoretical models developed to explain the process of caregiving (e.g. Kramer, 1997; Lawton et al., 1991; Pearlin et al., 1990). One major commonality between these models is that the outcomes of this process concern the impact of caregiving upon caregivers' wellbeing. Traditionally, there has been a tendency to focus on the more negative outcomes of providing care (Kramer, 1997; Nolan et al., 1996). Research has reinforced the view that caregiving can have a negative impact on caregivers' health and wellbeing. In a systematic review, Vitaliano et al. (2003) found that caregivers reported more health problems than non-caregivers. Sistler and Blanchard-Fields (1993) reported that non-caregivers had significantly higher levels of positive affect than caregivers. In a study comparing caregivers of people with dementia with healthy older adults, Arigimon, Limon, Vila and Cabezas (2004) found that the female caregivers had worse health than the female controls. Although there were few differences between the male caregivers and male controls, the male caregivers did score better on physical functioning, possibly due to the physical demands of caregiving. Studies have also found discrepancies in the wellbeing of different types of caregivers. George and Gwyther (1986) compared a group of caregivers caring for memory impaired adults with a group of older controls. In comparison to the controls, the caregivers had higher stress levels, lower affect, lower life satisfaction and fewer social activities. In a study with caregivers of people with dementia and caregivers of older adults, Crespo, López and Zarit (2005) found that the only difference between the groups was that the caregivers of older adults reported a less intense reaction to memory and behavioural problems. The authors argued that rather than research focusing on the nature of the care-recipient's illness and how it differentially influences wellbeing, it should focus on caregivers' appraisals and resources for managing stressors.

The emphasis on the role of appraisal indicates that a person's perception of a stressful event can have a key role in how they respond to it. Nolan et al. (1996) proposed that if a situation is perceived to be a challenge, rather than a threat, then it will be perceived as less stressful. Therefore if caregivers can identify positive aspects in providing care then caregiving could be perceived as a source of gratification. These positive appraisals could have an important role in influencing the impact of stress (Rapp & Chao, 2000). Two factor models of caregiving acknowledge that caregiving could have positive and negative outcomes. Kramer (1997) proposed a conceptual model of caregiving in which appraisals of role gain resulted in positive outcomes and appraisals of role strain resulted in negative outcomes. Lawton et al. (1991) conceived a theoretical model in which caregiving satisfaction would result in positive affect and caregiving burden would result in negative affect. Whilst both these models contain positive and negative aspects of caregiving, neither allows for positive aspects of care to have an influence on negative outcomes, and for negative aspects of care to have an impact on positive outcomes. However, Lawton et al. (1991) did find that for adult-child caregivers, caregiver burden influenced positive affect. Similarly studies have found that positive aspects of caregiving have been linked to lower burden and depression (Cohen et al., 2002; Pinquart & Sörensen 2003b). These findings are not consistent as Rapp and Chao (2000) found that whilst appraisals of strain and gain both independently predicted negative affect, they did not predict positive affect. Kinney and Stephens (1989) explored the impact of daily caregiving stressors and satisfactions on the wellbeing of caregivers for people with Alzheimer's disease and found that total perceived hassles predicted depression, although total perceived uplifts did not. However, the uplift subscales Activities of Daily Living Uplifts and Behaviour Uplifts were significantly associated with depression.

One way in which caregivers can positively appraise the caregiving situation is to find meaning in caregiving. Finding meaning involves making sense, order and coherence out of one's existence (Reker, Peacock, & Wong, 1987). There have been different conceptualisations of meaning. Some studies interpret finding meaning as a form of coping (Pearlin et al., 1990). Other studies have explored meaning through an existential perspective, whereby finding meaning is a process of searching for and attaining meaning (e.g. Farran & Keane-Hagerty, 1991; Reker, 1997; Reker et al., 1987). Meaning has been viewed as being multi-dimensional, with several components. Reker and Wong (1988) propose that meaning is comprised of three components. Meaning has a cognitive component, as it is a way of making sense of one's experiences, and it has an emotional component as it is linked to feelings of satisfaction and fulfilment. Meaning also has a motivational component as individuals are motivated to pursue goals which lead to meaning in life. These components are said to influence psychological states, and it has been argued that meanings may influence the stress and coping process throughout the lifespan (Lazarus & Delongis, 1983). Studies have found that finding meaning is linked to higher wellbeing (Reker, 1997; Zika & Chamberlain, 1992). Reker, Peacock and Wong (1987) explored meaning in life across the lifespan, finding that it was linked to both physical and psychological wellbeing. Despite its relevance in understanding adaptation to stressful events, there has been little research exploring finding meaning in dementia caregiving. Findings from the systematic review on a small number of studies presented in Chapter 3 indicated that finding meaning can have a positive impact on dementia caregivers' wellbeing. The qualitative study presented in Chapter 5 further explored the role of finding meaning in the caregiving relationship. The findings from that study suggested that finding meaning was linked to caregivers' motivations to provide care and their perceptions of the quality of the relationship with the care-recipient.

Caregiving can affect the quality of the relationship for both the caregiver and care recipient; however, this relationship has tended to be neglected in models of stress and coping. Some models, such as the SPM (Pearlin et al., 1990) have viewed the relationship between the caregiver and care-recipient as just a background factor, yet this relationship will gradually alter throughout the caregiving process. The qualitative study with caregivers presented in Chapter 5 found that caregivers encountered many dilemmas in their role, which emerged from their desire to try to preserve their relationship with the care-recipient, whilst recognising that this relationship was changing. This transforming relationship is likely to impact on the wellbeing of the caregiver and care-recipient. In a study with caregivers for older adults, Synder (2000) found that the quality of the relationship directly impacted on both the caregivers' and care-recipients' reports of burden and satisfaction. The systematic review presented in Chapter 2 found that caregiving impacted on the quality of the relationship between caregiver and care-recipient. The review differentiated between the pre-caregiving and current relationship quality, both of which impacted on caregiver wellbeing. A poor pre-caregiving relationship was linked to lower wellbeing and less satisfaction with caregiving (Kramer, 1993a; Morris et al., 1988b). Some studies have found that the pre-caregiving relationship is rated higher than present relationship quality (deVugt et al., 2003; Morris et al., 1988b), whilst others have found that caregivers report feeling closer to the care recipient in the present than in the past (Horowitz & Sindleman, 1983). The findings of this systematic review indicated that more research is needed to explore the impact of the pre-caregiving and current relationship quality on caregiver wellbeing.

Whilst it has been argued that the relationship between the caregiver and care-recipient can influence the caregiving experience, this relationship will also have an important role in the commencement of caregiving. It is often the relational connection or history that prompts relatives or friends to begin caregiving (Montgomery & Williams, 2001). There has been little research into dementia caregivers' motivations to provide care and the way in which these motivations influence their wellbeing. Motivations to care can influence the quality of care provided, as effective caregiving requires the caregiver to be motivated to accept the responsibility and effort required in providing care. If a caregiver is not adequately motivated then he/she may provide ineffective or low levels of support (Feeney & Collins, 2003). The systematic review of a small number of studies on dementia caregiving presented in Chapter 3 indicated that motivations to provide care can impact on wellbeing. Yet these studies did not group motivations under a theoretical framework. There can be different types of motivations; for instance caregivers may be motivated to care by intrinsic motivations, which relate to internal desires to provide care. Alternatively caregivers may be motivated to care by extrinsic motivations, which relate to external pressures to provide care. Utilising these frameworks can further illuminate how different motivations can influence wellbeing. Research by Lyonette and Yardley (2003) on caregivers of older adults found that poor relationship quality and high extrinsic motivations can interact to increase caregivers' reports of stress. Conversely better relationship quality and greater intrinsic motivations can result in caregivers reporting higher levels of satisfaction (Lyonette & Yardley, 2003).

The available evidence suggests that relationship dynamics, motivations and meaning can impact on dementia caregiving. However, with regard to dementia caregiving, there has been no quantitative exploration of the way in which motivations for caregiving, the meanings attributed to caregiving and the evolving nature of the relationship between the caregiver and care-recipient are potentially related to and influence each other. This study will explore the relationship between these factors and their influence on caregiver wellbeing. This study will draw on theoretical models of caregiving, which recognise that background factors, such as characteristics of the caregiver, can have an influence on caregiver wellbeing. For instance, studies have found that the gender of the caregiver and kin-relationship to the care-recipient can impact on wellbeing (e.g. Fitting et al., 1986; Cantor, 1983). Finally, given that finding meaning can be perceived as a positive outcome of caregiving, this study will look at the factors which predict finding meaning in caregiving. Developing a greater understanding of the factors that make caregiving rewarding will aid the development of better interventions for caregivers.

Research Aims

1. To examine whether there is a significant difference in scores for pre-caregiving and current relationship quality.
2. To explore whether intrinsic and extrinsic motivations, meaning, and pre-caregiving and current relationship quality are related to each other and if so in what way
3. To examine whether intrinsic and extrinsic motivations, meaning, and pre-caregiving and current relationship quality are related to caregiver wellbeing.
4. To explore how much of the variance in measures of wellbeing can be explained by meaning, intrinsic motivations, extrinsic motivations, and pre-caregiving and current relationship quality.
5. To discover which variables predict finding meaning in caregiving.

Method

Design

This was a large-scale cross-sectional postal questionnaire survey exploring the relationship between meanings, motivations, relationship quality and wellbeing.

Ethical Issues

Ethical approval for this study was obtained from the relevant NHS Multi-Centre Research Ethics Committee. In order to ensure participant confidentiality, the Admiral Nurses acted as local collaborators on this project and they alone had access to the participants' details. Participants could write their contact details at the end of the questionnaire, if they wished to receive information about the results, and this information was detached from the questionnaire immediately upon receipt and stored separately to the questionnaire.

Participants

The participants in this study were informal caregivers of people with dementia. These caregivers were identified from the caseloads of the Admiral Nurse Service, a UK based specialist mental health nursing service for caregivers of people with dementia. Caregivers were identified from 12 Admiral Nurse teams based in London, Bolton, Manchester, Preston, Kent, Medway, Warwickshire and Worcester. Caregivers were included in this study if, at the time of the study, they were currently in receipt of the Admiral Nurse Service or had been discharged from the Service within the past six months.

Measures

All the measures included in this study were presented in a questionnaire booklet. Where possible, short versions of the measures were used to reduce the length of the questionnaire.

Demographic characteristics

The caregivers were asked to complete basic demographic information about themselves and the care-recipient. The caregivers were also asked about their caregiving situation, for instance the number of hours per week they spend caregiving. There was one question in which caregivers rated their health on a 5-point scale from 1 (Poor) to 5 (Excellent), with a higher score indicating a better health. Caregivers also rated how religious they were on a 4-point scale 1 (Not at all) to 4 (Very religious).

Primary Measures

Meaning

Meaning was measured using the 12-item Meaning in Caregiving Scale (Noonan & Tennstedt, 1997). Caregivers rated positive aspects of care and the ways that caregivers can find meaning through the caregiving experience on a 5-point scale from 1 (Strongly disagree) to 5 (Strongly agree). A higher score indicated greater meaning in caregiving. Yen, Huang, Ma, Lee, and Lee (2009) have reported a Cronbach alpha coefficient for the 16-item version of this scale as .89. In the current study the Cronbach alpha coefficient was .88.

Motivations to provide care

The caregivers' motivations to provide care were measured by the Motivations in Elder Care Scale (Lyonette & Yardley, 2003), which is comprised of two subscales: Extrinsic Motivations to Care (EXMECS) and Intrinsic Motivations to Care (INMECS). The INMECS subscale consisted of seven questions on intrinsic motivations to provide care. These questions were rated on a 5-point scale ranging from 1 (Strongly disagree) to 5 (Strongly agree), with a higher score indicating greater intrinsic motivations to provide care. Lyonette and Yardley (2003) report a Cronbach alpha coefficient for the INMECS of .77; in the current study it was .81.

The EXMECS subscale consisted of six questions in which caregivers rated extrinsic reasons for providing care on a 5-point scale ranging from 1 (Strongly disagree) to 5 (Strongly agree). A higher score indicated greater extrinsic motivations to provide care. Analysis of the reliability of the scale found that one question (person was gradually becoming more dependent on me) correlated poorly with the other items. Pallant (2005) recommends that items which have correlations below .3 should be removed from the scale. Thus, this item was removed increasing the Cronbach alpha coefficient from .76 to .78. Lyonette and Yardley (2003) report a Cronbach alpha coefficient of .85.

Relationship Quality

Current and pre-caregiving relationship quality was measured using the Positive Affect Index (Bengtson & Scrader, 1982). The measure consists of five items which assess the closeness of the relationship, communication, similarity in views, getting along and shared activities. The phrasing of these questions was amended to assess both pre-caregiving and current relationship quality. The responses were rated on a 6-point scale ranging from 1 to 6, with higher scores indicating greater relationship quality. Lawrence, Tennstedt and Assman (1998) report a Cronbach alpha coefficient for this scale of .85. In the current study the Cronbach alpha coefficient for the pre-caregiving relationship quality was .88, and for the current relationship quality .76.

Outcome measures

Burden

Burden was measured using the short version of the Zarit Burden Interview (Bédard et al, 2001). The scale measures caregivers' appraisal of the impact caregiving has had on their lives. The measure consists of twelve questions rated on a 5-point scale ranging from 0 (Never) to 4 (Nearly always), with higher scores indicating greater burden. Bédard et al. (2001) report a Cronbach alpha coefficient for this scale of .88. The Cronbach alpha coefficient for this scale in the current study was .87.

Anxiety

Anxiety was measured using the Anxiety subscale of the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983). Caregivers responded to seven questions measuring their anxiety in the past week. Responses were rated on a 4-point scale ranging from 0 to 3. The scores on this measure do not relate to a clinical condition of anxiety, and scores between 0 to 8 are in the normal range. Scores ranging from 8 to 10 are suggestive of an anxiety disorder, whilst scores over 11 indicate probable 'caseness' of a anxiety disorder. A recent review indicated that the scale had good internal consistency (Bjelland, Dahl, Haug & Neckelmann, 2002). In the current study the Cronbach alpha coefficient was .84.

Depression

Depression was measured using the Depression subscale of the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983). Caregivers responded to seven questions measuring their feelings of depression in the past week. Responses were rated on a 4-point scale ranging from 0 to 3. The scores on this measure do not relate to a clinical condition of depression, and scores between 0 to 8 are in the normal range. Scores ranging from 8 to 10 are suggestive of an depressive disorder, whilst scores over 11 indicate probable 'caseness' of a depressive disorder. A recent review indicates that overall the scale has good internal consistency (Bjelland et al., 2002). The Cronbach alpha coefficient for this scale in the current study was .79.

Role captivity

Role captivity was measured using a 3-item scale (Pearlin et al, 1990). The caregivers rated the extent to which they felt trapped in their role on a 5-point scale ranging from 1 (Strongly disagree) to 5 (Strongly agree) with higher scores indicating more role captivity. The Cronbach alpha coefficient both for Pearlin et al. (1990) and for the current study was .84.

Environmental mastery

Environmental mastery was measured using a nine-item version of the Environmental Mastery Scale (Ryff, 1989). Items were rated on a 5-point scale ranging from 1 (Strongly disagree) to 5 (Strongly agree). A high score indicates that a person has a sense of mastery and competence in managing the environment, is able to create or choose contexts suitable to personal values and needs, controls external activities, and effectively uses surrounding opportunities. A low score indicates that a person has difficulty managing everyday affairs and is unaware of surrounding opportunities. The person will also lack a sense of control and feel unable to improve or change the surrounding context (Ryff, 1989). Windle and Woods (2004) report that this scale has good internal consistency, with a Cronbach alpha coefficient of .70. In the current study the Cronbach alpha coefficient was .79.

Competence

Competence was measured using the 3-item Caregiving Competence scale reported by Robertson, Zarit, Duncan, Rovine and Femia (2007). The caregivers evaluated the adequacy of their job as a caregiver on a 5-point scale ranging from 1 (Strongly disagree) to 5 (Strongly agree) with higher scores indicating greater competence. According to Robertson et al. (2007) this scale has good internal consistency, with a Cronbach alpha coefficient of .81. In the current study the Cronbach alpha coefficient was .86.

Pilot study

The Questionnaire was piloted with 13 caregivers, seven of whom were male and six were female. Eleven of the participants were spousal caregivers and two were adult-child caregivers. The caregivers were asked to fill in the questionnaire and to comment on its accessibility, content and ease of completion. The feedback from the caregivers resulted in several changes to the content and layout of the questionnaire.

Procedure

Acting as local collaborators, the Admiral Nurses accessed the Admiral Nurse client database and utilised the inclusion criteria to identify participants. Participants' names and addresses were collected and used to address pre-paid envelopes which had been supplied by the researcher. These envelopes contained the questionnaire, an information sheet about the project and a letter which reassured the participants that the information collected would remain confidential, and all their responses would remain anonymous. They were also informed that whether or not they decided to complete the questionnaire would not affect the services they received. At the end of the questionnaire the participants were given the opportunity to leave their contact details if they wished to be informed about the findings of the research. The participants were provided with a freepost envelope in which to return the completed questionnaire to the researcher. Upon receipt the researcher numbered the questionnaires and entered the data into an SPSS (Statistical package for the Social Sciences) database version 16.0. for Windows Vista.

Planned Statistical Analysis

Screening of the data

Prior to analysis the data were screened for the accuracy of data entry and for missing values. It was evident that there was missing data in the measures. It was decided that the missing item scores would be replaced with the participant's mean score for all the other items in the measure (Tabachnick & Fidell, 2007). This replacement was restricted to a maximum of two questions per measure. Sensitivity analyses were performed to confirm the validity of this method. Given that the measures of role captivity and competence only contained three questions, it was decided not to replace any missing data in these measures.

The data were examined for normality of distribution and the presence of outliners. Examination of histograms, plots of normality and box plots indicated that some of the measures were skewed: EXMECS, INMECS, pre-caregiving relationship quality, and competence were negatively skewed and role captivity was positively skewed. In addition, competence, EXMECS and INMECS contained outliers. In order to correct the skewed data and reduce the impact of these outliers, the measures were transformed. The most appropriate method of transformation was chosen for each measure. The scoring of competence was reflected and then a square root transformation was applied. Pre-caregiving relationship quality, EXMECS, and INMECS were reflected and then logarithmically transformed. These transformations reversed the directions of the variables. In order to return the variables back to their original direction they were re-reflected (Munro, 2005). Since role captivity was positively skewed it was transformed using a square-root transformation. For the hierarchical regressions the data was checked for linearity, multicollinearity and homoscedasticity. No changes were made to the data.

Preliminary analyses

Descriptive analyses were conducted to identify the average scores on all the measures. A Wilcoxon's signed-rank test was performed to discover whether there was a significant difference between scores of pre-caregiving and current relationship quality. A non-parametric test was chosen as transformed data cannot be used in tests of difference, unless the other variable is also transformed, and therefore the original data were used (Field, 2005).

Main analysis

Correlational analyses were conducted to indicate whether and in what way there was a relationship between INMECS, EXMECS, meaning, and current relationship quality and pre-caregiving relationship quality. Correlational analyses were also performed to explore the relationship between these factors, selected demographic factors and the measures of wellbeing.

Multiple hierarchical regression analyses were conducted to examine the predictive impact of INMECS, EXMECS, meaning, and pre-caregiving and current relationship quality on each of the outcome measures: role captivity, sense of competence, anxiety, depression, environmental mastery, and burden. Selected demographic variables were also included in these regressions in order to discover which of these variables were the best predictors of the measures of wellbeing.

Since evidence from research indicates that meaning may be considered a positive outcome of caregiving, a hierarchical multiple regression analysis was conducted to explore the predictive impact of selected demographic factors, pre-caregiving and current relationship quality, INMECS and EXMECS, on meaning. As research indicates that both sense of competence and role captivity can be linked to positive outcomes (e.g. (Farran et al., 1997; Gallagher et al., 1994), these variables were also included in the model.

Results

A total of 1228 questionnaires were sent out to caregivers, and 460 completed questionnaires were returned, a response rate of 37.5%. Of these questionnaires 13 were not included in the analysis as they came from caregivers where the care-recipient had died. Therefore, data from 447 questionnaires were included in the analysis

Sample characteristics

The characteristics of the care-recipients are described in Table 7.1. The mean age of the caregivers was 67.81 (range 25-95), 66.9% were female, 68% were spouses and 27% were adult-child caregivers. The majority of the caregivers were White British and were married. The mean age of the care-recipients was 78.58 (range 25-95) and 54% were female. Characteristics of the caregiving situation are described in Table 7.2. The majority of the caregivers resided with the care-recipient. The length of caregiving varied with 22% reporting that they have been providing care for between 2-3 years and 18.9% providing care for 5-10 years. Sixty four percent of the caregivers reported that they provided care for over 50 hours per week.

Table 7.1 Characteristics of the caregivers and care-recipients

Variable	N	%
Care-recipient		
Age (*M, SD*)	78.58 (8.71)	
Gender (female)	241	54
Caregiver		
Age (*M, SD*)	67.81 (12.52)	
Gender (female)	299	66.9
Marital Status (married)	374	84
Relationship to care-recipient		
Spouse/partner	304	68.3
Adult child	121	27.2
Other	20	4.5
Ethnicity		
White British	405	91.2
White European	11	2.5
White other	6	1.4
Asian Bangladeshi	2	.5
Asian Indian	5	1.1
Asian other	2	.5
Black African	2	.5
Black Caribbean	7	1.6
Other	4	.9
Religiosity		
Not at all religious	70	15.8
Not very religious	159	36
Somewhat religious	169	38.2
Very religious	44	10
Health		
Poor	53	12.0
Fair	148	33.4
Good	141	31.8
Very Good	79	17.8
Excellent	22	5

Information on the caregivers' scores on the measures is provided in Table 7.3. On average the caregivers' scores on the measures of anxiety and depression were in the normal range. The caregivers' scored moderately on the measures of competence, role captivity, and burden, and scored highly on environmental mastery. The caregivers reported higher INMECS (M = 30.61, SD = 3.48) than EXMECS (M = 20.31, SD = 3.64). The caregivers reported a high level of meaning (M = 43.61, SD = 7.57). Ratings of pre-caregiving relationship quality (M = 23.09, SD = 5.42) were higher than current relationship quality (M = 17.86, SD = 5.13). Analysis using a Wilcoxon Signed Ranks test show that this difference was significant, T = 95.30, p = .000, r = -.52.

Table 7.2 Characteristics of caregiving situation

Variable	N	%
Length of caregiving		
Less than 1 year	16	3.6
1-2 years	59	13.4
2-3 years	97	22.0
3-4 years	65	14.8
4-5 years	78	17.7
5-10 years	83	18.9
10-15 years	25	5.7
15+ years	17	3.9
Hours of care per week		
Less than 50	148	35.3
Over 50 hours	272	64.8
Live with care-recipient		
Yes	330	74.2
No	104	25.7

Table 7.3 Mean scores on all the measures

Variable	*N*	*M*	*SD*	Range (Actual)	Range (Possible)
Pre-caregiving RQ	443	23.09	5.42	5-30	5-30
Current RQ	437	17.86	5.13	5-30	5-30
Meaning	431	43.61	7.57	20-60	12- 60
INMECS	433	30.61	3.48	16-35	5- 35
EXMECS	435	20.31	3.64	5-25	5-25
Competence	432	11.88	2.09	3-15	3-15
Role captivity	431	7.74	3.09	3-15	3-15
Anxiety	429	8.82	4.30	0-21	0-21
Depression	432	7.45	3.93	0-20	0-21
Burden	431	22.52	8.58	0-44	0-48
Environmental mastery	425	30.49	5.18	17-45	5-45

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations. High scores indicate higher scores on all the measures.

Correlational analyses

Relationships between INMECS, EXMECS, meaning, pre-caregiving and current relationship quality, and selected characteristics of the caregivers

The intercorrelations between these variables can be found in Table 7.4. There was a small negative correlation between gender and pre-caregiving relationship quality

($r = -.18$, $n = 433$, $p = <.001$), and gender and current relationship quality ($r = -.24$, $n = 437$, $p = <.001$). Being a male caregiver was associated with higher pre-caregiving and current relationship quality. The caregivers' relationship to care-recipient was negatively associated with pre-caregiving relationship quality ($r = -.28$, $n = 423$, $p = <.001$), INMECS ($r = -.12$, $n = 412$, $p = .017$), and EXMECS ($r = -.17$, $n = 414$, $p = <.001$) and meaning ($r = -.17$, $n = 409$, $p = .001$). Thus, being a spousal/partner caregiver was associated with higher pre-caregiving relationship quality, INMECS, EXMECS and meaning.

Relationships between INMECS, EXMECS, meaning, and pre-caregiving and current relationship quality

Table 7.4 contains the intercorrelations between these variables. INMECS, meaning, pre-caregiving and current relationship quality were significantly related to each other. EXMECS was only related to INMECS and meaning. There was a medium positive association between pre-caregiving and current relationship quality ($r = .49$, $n = 436$, $p = <.001$). Higher pre-caregiving relationship quality was associated with higher current relationship quality. There were small positive associations between pre-caregiving relationship quality and meaning ($r = .29$, $n = 429$, $p = <.001$), and between current relationship quality and meaning ($r = .25$, $n = 424$, $p = <.001$). There was a medium positive association between pre-caregiving relationship quality and INMECS ($r = .37$, $n = 432$, $p = <.001$) and a small positive association between current relationship quality and INMECS ($r = .23$, $n = 428$, $p = <.001$). Thus, higher pre-caregiving and current relationship quality were related to higher meaning and higher INMECS. There was a medium positive correlation between INMECS and meaning ($r = .45$, $n = 425$, $p = <.001$), higher INMECS were associated with higher meaning. EXMECS was only significantly related to INMECS and meaning. There was a medium positive correlation between EXMECS and INMECS ($r = .44$, $n = 427$, $p = <.001$) and a small positive correlation between EXMECS and meaning ($r = .24$, $n = 424$, $p = <.001$). Higher EXMECS were associated with higher meaning and INMECS.

Table 7.4 Intercorrelations between study variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Gender- cg (0=male)	-																
2. Age- cg	-.26**	-															
3. Relationship (0=spouse/partner)	.18**	-.70**	-														
4. Hours of care (0= >50)	-.16**	.22**	-.41**	-													
5. Religiosity	.10*	.08	-.07	.01	-												
6. Health- cg	.00	-.18**	.10*	-.07	.14**	-											
7. Pre-caregiving RQ	-.18**	.14**	-.28**	.23**	.08	.07	-										
8. Current RQ	-.24**	.08	-.08	.04	.08	.13**	.49**	-									
9. INMECS	-.07	.10*	-.12*	.17**	.13**	-.08	.37**	.23**	-								
10. EXMECS	-.03	.10*	-.17**	.02	.11*	-.08	.09	-.03	.44**	-							
11. Meaning	-.09	.08	-.17**	.11*	.23**	.10*	.29**	.25**	.45**	.24**	-						
12. Role captivity	.27**	-.16**	.15**	.01	-.11*	-.17**	-.34**	-.46**	-.23**	.08	-.36**	-					
13. Competence	-.08	.02	-.09	.13*	.10*	.06	.16**	.20**	.39**	.21**	.46**	-.21**	-				
14. Burden	.29**	-.19**	.14**	.07	-.10*	-.30**	-.25**	-.42**	-.11*	.13**	-.28**	.72**	-.30**	-			
15. Depression	.12*	.07	-.07	.25**	-.16**	-.43**	-.11*	-.26**	.04	.09	-.18**	.41**	-.10*	.58**	-		
16. Anxiety	.31**	-.03	.03	.05	-.05	-.34**	-.07	-.25**	.06	.15**	-.11*	.47**	-.14**	.61**	.63**	-	
17. Environmental Mastery	-.24**	.09	-.11*	-.08	.18**	.40**	.23**	.28**	.08	-.05	.27**	-.47**	.30**	-.65**	-.67**	-.61**	-

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Relationships between INMECS, EXMECS, meaning, pre-caregiving and current relationship quality and measures of wellbeing

Table 7.4 contains the intercorrelations between these variables. Meaning had small negative correlations with burden ($r = -.28$, $n = 426$, $p = <.001$), depression scores ($r = -.18$, $n = 422$, $p = <.001$), and anxiety scores ($r = -.11$, $n = 420$, $p = .021$), and a medium negative correlation with role captivity ($r = -.36$, $n = 424$, $p = <.001$). Meaning had a small positive correlation with environmental mastery ($r = .27$, $n = 420$, $p = <.001$) and a medium positive correlation with competence ($r = .46$, $n = 425$, $p = <.001$). Thus, higher meaning was associated with lower burden, depression scores, anxiety scores, and role captivity, and with higher environmental mastery and competence.

Pre-caregiving relationship quality had small negative correlations with burden ($r = -.25$, $n = 429$, $p = <.001$), depression scores ($r = -.11$, $n = 430$, $p = .026$), and a medium negative correlation with role captivity ($r = -.34$, $n = 429$, $p = <.001$). Pre-caregiving relationship quality had small positive correlations with competence ($r = .16$, $n = 430$, $p = .001$) and environmental mastery ($r = .23$, $n = 424$, $p = <.001$). Current relationship quality had small negative correlations with depression scores ($r = -.26$, $n = 427$, $p = <.001$), anxiety scores ($r = -.25$, $n = 424$, $p = <.001$), and medium negative correlations with burden ($r = -.42$, $n = 425$, $p = <.001$) and role captivity ($r = -.46$, $n = 426$, $p = <.001$). Current relationship quality had small positive correlations with competence ($r = .20$, $n = 425$, $p = <.001$) and environmental mastery ($r = .28$, $n = 419$, $p = <.001$). Thus, a better pre-caregiving relationship was associated with lower burden, depression scores, role captivity, and higher environmental mastery and competence. A high current relationship was associated with lower burden, depression scores, anxiety scores, role captivity, and higher environmental mastery and competence.

EXMECS had small positive correlations with anxiety scores ($r = .15$, $n = 421$, $p = .002$), burden ($r = .13$, $n = 423$, $p = .007$) and competence ($r = .21$, $n = 424$, $p = <.001$). INMECS had small negative correlations with correlations with burden ($r = -.11$, $n = 424$, $p = .021$), role captivity ($r = -.23$, $n = 424$, $p = <.001$), and had medium positive correlations with competence ($r = .39$, $n = 425$, $p = <.001$). Thus, higher INMECS was associated with lower burden, role captivity, and higher competence.

Higher EXMECS was associated with higher burden, anxiety scores, and competence.

Hierarchical Regressions

Hierarchical regression analysis was employed to determine how much of the variance in wellbeing scores could be explained by meaning, INMECS, EXMECS, and pre-caregiving and current relationship quality, beyond that afforded by demographic factors. Due to the number of independent variables, only selected demographic characteristics were chosen. Studies have found that the gender of the caregiver, kin-relationship to the care-recipient, health and amount of care provided can impact on caregiver wellbeing. Hierarchical regressions were performed on each of the wellbeing measures. For each of these analyses, demographic characteristics were entered in the first step, followed by pre-caregiving and current relationship quality, meaning, INMECS and EXMECS, in the next step.

Burden

Table 7.5 provides the percentage variance in burden accounted for by the independent variables. In the first step of the model, demographic characteristics explained 19% of the variance in burden. All the variables made a significant contribution: gender (beta = .28, p = <.001), relationship (beta = .17, p = <.001), ratings of health (beta = -.26, p = <.001) and hours of care (beta = .14, p = <.001). Thus, being a female caregiver, being an adult-child caregiver, having poor health and providing long hours of care predicted higher levels of burden. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS uniquely explained an additional 17% variance in burden, significantly increasing the variance explained to 35%. Current relationship quality, meaning and EXMECS significantly explained variance in burden (beta = -.27, p = <.001; beta = -.20, p = <.001; beta = .22, p = <.001, respectively). Thus, a poorer current relationship, lower meaning and higher EXMECS were significant predictors of greater burden.

Table 7.5 Hierarchical multiple regression predicting burden

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.19	.19**
Gender	5.06	.85	.28**		
Relationship	3.30	.96	.17*		
Health rating	-2.15	.38	-.26**		
Hours of care	2.56	.91	.14*		
Step 2				.35	.17**
Gender	3.73	.78	.21**		
Relationship	3.22	.90	.17**		
Health rating	-1.55	.35	-.19**		
Hours of care	3.24	.83	.18**		
Current RQ	-.46	.08	-.27**		
Pre-caregiving RQ	.14	1.19	.01		
Meaning	-.22	.05	-.20**		
INMECS	-1.67	1.30	-.07		
EXMECS	5.58	1.21	.22**		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Depression

Table 7.6 provides the percentage variance in the scores of depression accounted for by the independent variables. In the first step of the model, demographic characteristics explained 24% of the variance in depression scores. Gender, health ratings and hours of care made significant contributions (beta = .15, *p* = .001; beta = -.40, *p* = <.001; beta = .22, *p* = <.001, respectively). This indicates that being a female caregiver, having poor health and providing long hours of care predicted higher depression scores. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS only uniquely explained an additional 6% of variance in depression scores. This indicates that these variables only made a small contribution to the variance in depression. Adding these variables significantly increased the variance explained to 30%. Current relationship quality and meaning significantly explained variance in depression (beta = -.17, *p* = .001; beta = -.16, *p* = .001, respectively). Thus, a poorer current relationship and lower meaning were significant predictors of greater depression scores.

Table 7.6 Hierarchical multiple regression predicting depression scores

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.24	.24**
Gender	1.22	.37	.15*		
Relationship	.28	.42	.03		
Health rating	-1.48	.17	-.40**		
Hours of care	1.80	.40	.22**		
Step 2				.30	.06**
Gender	.84	.37	.10*		
Relationship	.10	.43	.01		
Health rating	-1.28	.17	-.34**		
Hours of care	1.90	.40	.23**		
Current RQ	-.13	.04	-.17*		
Pre-caregiving RQ	-.21	.57	-.02		
Meaning	-.08	.03	-.16*		
INMECS	.88	.62	.08		
EXMECS	.75	.58	.06		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations

*p <.05 **p<.001

Anxiety

Table 7.7 provides the percentage variance accounted for in anxiety scores by the independent variables. In the first step of the model, demographic characteristics explained 21% of the variance in anxiety scores. Only gender and health ratings made significant contributions to the variance (beta = .32, p = <.001; beta = -.33, p = <.001). This indicates that being a female caregiver and having poor health accounted for higher anxiety scores. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS only uniquely explained an additional 5% in variance. This indicates that these variables only made a small contribution to the variance in anxiety scores. Adding these variables significantly increased the variance explained to 26%. Only current relationship quality and EXMECS significantly explained variance in anxiety (beta = -.17, p = .001; beta = .14; p = .006, respectively). Thus, a poorer current relationship and higher EXMECS were significant predictors of greater anxiety scores.

Table 7.7 Hierarchical multiple regression predicting anxiety scores

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.21	.21**
Gender	2.88	.42	.32**		
Relationship	.31	.47	.03		
Health rating	-1.34	.19	-.33**		
Hours of care	.53	.45	.06		
Step 2				.26	.05**
Gender	2.59	.42	.28**		
Relationship	.54	.48	.06		
Health rating	-1.19	.19	-.29**		
Hours of care	.53	.45	.06		
Current RQ	-.14	.04	-.17*		
Pre-caregiving RQ	.95	.64	.08		
Meaning	-.05	.03	-.09		
INMECS	.58	.70	.05		
EXMECS	1.80	.65	.14*		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Role captivity

Table 7.8 provides the percentage variance accounted for in role captivity by the independent variables. In the first step of the model, demographic characteristics explained 12% of the variance in role captivity. Gender, relationship and health ratings made significant contributions to the variance (beta = .26, *p* = <.001; beta = -.16, *p* = .003; beta = -.17, *p* = .001). This indicates that being a female caregiver, being an adult child caregiver and having poor health accounted for higher role captivity. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS uniquely explained an additional 25% in variance, increasing the total variance explained to 37%. Current relationship quality (beta = -.28, *p* = <.001), meaning (beta = -.24, *p* = <.001), INMECS (beta = -.13, *p* = .013) and EXMECS (beta = .21, *p* = <.001) significantly explained variance in role captivity. Thus, a poorer current relationship, lower meaning, lower INMECS and higher EXMECS were significant predictors of greater role captivity.

Table 7.8 Hierarchical multiple regression predicting role captivity

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.12	.12**
Gender	.31	.06	.26**		
Relationship	.20	.07	.16*		
Health rating	-.09	.03	-.17*		
Hours of care	.106	.06	.09		
Step 2				.37	.25**
Gender	.20	.05	.17**		
Relationship	.16	.06	.13*		
Health rating	-.05	.02	-.08		
Hours of care	.18	.06	.15*		
Current RQ	-.03	.01	-.28**		
Pre-caregiving RQ	-.11	.08	-.07		
Meaning	-.02	.00	-.24**		
INMECS	-.22	.09	-.13*		
EXMECS	.37	.08	.21**		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Environmental mastery

Table 7.9 provides the percentage variance accounted for in environmental mastery by the independent variables. In the first step of the model, demographic characteristics explained 24% of the variance in environmental mastery. All the variables, gender, relationship, health ratings and hours of care, made significant contributions to the variance (beta = -.23, *p* = <.001; beta = -.16, *p* = .001; beta = .40, *p* = <.001; beta -.12, *p* = .016, respectively). This indicates that being a male caregiver, being a spousal/partner, having good health and providing fewer hours of care accounted for higher environmental mastery. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS only uniquely explained an additional 7% in variance. This indicates that these variables only made a small contribution to the variance in environmental mastery. Adding these variables significantly increased the variance explained to 31%. Only current relationship quality, meaning and EXMECS significantly explained variance in environmental mastery (beta = .10, *p* = .047; beta = .19; *p* = <.001; beta = -.10,

$p = .046$, respectively). Thus, a poorer current relationship, lower meaning and lower EXMECS were significant predictors of greater environmental mastery.

Table 7.9 Hierarchical multiple regression predicting environmental mastery

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.24	.24**
Gender	-2.48	.49	-.23**		
Relationship	-1.85	.56	-.16*		
Health rating	1.97	.22	.40**		
Hours of care	-1.28	.53	-.12*		
Step 2				.31	.07**
Gender	-2.04	.49	-.19**		
Relationship	-1.51	.56	-.13*		
Health rating	1.71	.22	.35**		
Hours of care	-1.61	.52	-.15*		
Current RQ	.10	.05	.10*		
Pre-caregiving RQ	.94	.74	.07		
Meaning	.13	.03	.19**		
INMECS	.18	.81	.01		
EXMECS	-1.50	.75	-.10*		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Competence

Table 7.10 provides the percentage variance accounted for in competence by the independent variables. In the first step of the model, demographic characteristics only explained 3% of the variance in competence. Only hours of care made a significant contribution to the variance (beta = .11 $p = .041$). This indicates that providing greater hours of care accounted for higher competence. The inclusion of pre-caregiving and current relationship quality, meaning, INMECS and EXMECS uniquely explained an additional 24% in variance, significantly increasing the total variance explained to 27%. Only INMECS and meaning significantly explained variance in competence (beta = .21, $p = <.001$; beta = .34, $p = <.001$, respectively). Thus, higher INMECS and higher meaning were significant predictors of greater competence.

Table 7.10 Hierarchical multiple regression predicting competence

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.03	.03*
Gender	-.06	.06	-.05		
Relationship	-.05	.07	-.04		
Health rating	.05	.03	.09		
Hours of care	.13	.06	.11*		
Step 2				.27	.24**
Gender	-.02	.05	-.02		
Relationship	.02	.06	.01		
Health rating	.03	.02	.06		
Hours of care	.09	.06	.08		
Current RQ	.01	.01	.10		
Pre-caregiving RQ	-.13	.08	-.09		
Meaning	.02	.00	.34**		
INMECS	.33	.08	.21**		
EXMECS	.09	.08	.05		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations
*p <.05 **p<.001

Meaning

A hierarchical regression was conducted to explore which factors were predictive of meaning. Religiosity was included as a demographic characteristic as theories suggest that it can be linked to finding meaning (Farran et al., 1999). Given the medium correlations between meaning and role captivity and competence, these were added to the regression. The demographic characteristics were entered in the initial step. Competence and role captivity were entered in the next step, followed by INMECS, EXMECS and pre-caregiving and current relationship quality in the final step. Table 7.11 provides the percentage variance accounted for in meaning by the independent variables. In the first step of the model, demographic characteristics explained 10% of the variance in meaning. Religiosity was the only variable to make a significant contribution to meaning (beta = .22, p = <.001). In the second step the introduction of competence and role captivity uniquely explained 23% of the variance in meaning, significantly increasing the variance explained to 32%. Both role captivity and competence significantly predicted meaning (beta = -.26, p = <.001; beta = .38, p = <.001, respectively). This indicates that caregivers who had low role captivity and higher competence experienced greater meaning. In the final step, the introduction of INMECS, EXMECS, pre-caregiving and current relationship quality, uniquely explained only 6% of the variance in meaning, significantly increasing the variance explained to 39%. Only INMECS made a significant contribution (beta = .21, p = <.001), indicating that higher intrinsic motivations were linked to higher meaning.

Table 7.11 Hierarchical multiple regression predicting meaning

Step Variable	*B*	*SE B*	*Beta*	R^2	ΔR^2
Step 1				.10	.10**
Gender	-1.23	.79	-.08		
Relationship	-2.14	.89	-.13		
Religiosity	1.89	.42	.22**		
Health rating	.70	.35	.10		
Hours of care	.97	.84	.06		
Step 2				.32	.23**
Gender	.26	.72	.02		
Relationship	-1.29	.78	-.08		
Religiosity	1.34	.37	.15**		
Health rating	.22	.31	.03		
Hours of care	.66	.74	.04		
Competence	5.34	.61	.38**		
Role captivity	-3.35	.60	-.26**		
Step 3				.39	.06**
Gender	.32	.69	.02		
Relationship	-.83	.78	-.05		
Religiosity	1.07	.36	.12*		
Health rating	.43	.30	.06		
Hours of care	.34	.73	.02		
Competence	4.01	.63	.28**		
Role captivity	-2.88	.64	-.22**		
INMECS	4.59	1.13	.21**		
EXMECS	2.01	1.07	.09		
Pre-caregiving RQ	1.16	1.03	.06		
Current RQ	-.01	.07	-.00		

Note. RQ = relationship quality, INMECS= Intrinsic Motivations, EXMECS= Extrinsic Motivations

*p <.05 **p<.001

Summary of results

There was a significant difference in ratings of pre-caregiving and current relationship quality. The caregivers' rated their pre-caregiving relationship with the care-recipient as better than their current relationship. Intrinsic motivations, meaning, pre-caregiving and current relationship quality were significantly positively related to each other. Extrinsic motivations were positively related to intrinsic motivations and meaning. Higher meaning was associated with lower burden, depression scores, anxiety scores, and role captivity, and with higher environmental mastery and competence. A better pre-caregiving relationship was associated with lower burden, depression scores, role captivity, and higher environmental mastery and competence. A good current relationship was associated with lower burden, depression scores, anxiety scores, role captivity, and higher environmental mastery and competence. Meaning, intrinsic and extrinsic motivations, and pre-caregiving and current relationship quality significantly explained 17% variance in burden, 25% variance in role captivity, and 24% variance in competence. These variables only made modest contributions to explaining the variance in anxiety (5%), depression (6%), and environmental mastery (7%). Thirty nine percent of the variance in meaning was explained by the predictor variables. Religiosity, role captivity, competence and intrinsic motivators were the only variables that significantly predicted higher meaning.

Discussion

The role of relationship dynamics, motivations to provide care and the meaning caregivers find in caregiving has received little attention in research on dementia caregiving. The findings from two systematic reviews presented in Chapters 2 and 3 indicate that no empirical study has explored how these factors interact and influence wellbeing. Yet findings from studies, which have explored these factors individually suggest that they could have an impact on caregiving. The aim of the current study was to explore how these factors were associated to each other. This study also sought to examine how these factors influenced on caregiver wellbeing, both individually and when combined. In addition, as research indicates that caregiving can influence the caregivers' perceptions of their relationship with the care-recipient, this study also sought to explore whether there was a difference between pre-caregiving and current relationship quality. Lastly, some models of caregiving have identified finding meaning to be a positive outcome of caregiving, this study therefore aimed to identify factors, which predicted finding meaning in caregiving. The findings of the study will be discussed in relation to the aims of the study.

The current study found that there was a significant difference between pre-caregiving and current relationship quality, with the pre-caregiving relationship being rated as better than the current relationship. Other studies have found a similar change in the relationship (de Vugt et al., 2003; Morris et al., 1988b; Wright, 1998). It should also be noted that a small number of the caregivers did report an improvement in their relationship, indicating that for some caregiving brought them closer to the care-recipient. Interestingly, the caregivers' perceptions of these relationships were influenced by the caregivers' gender and kin-relationship to the care-recipient. Being a male caregiver was linked to higher pre-caregiving and current relationship quality. Williamson and Schulz (1990) found that females rated their pre-caregiving relationship less favourably than males. The current study also found that being a spousal/partner caregiver was associated with higher pre-caregiving relationship quality. Spruytte et al. (2002) reported that children and children-in-law caregivers had a better relationship quality with the care-recipient as compared to partner-caregivers. However, that study did not specify whether it was looking at pre-caregiving or current relationship quality.

There were significant associations between meaning, pre-caregiving and current relationship quality, and intrinsic motivations. Extrinsic motivations were only related to intrinsic motivations and meaning. Each of these relationships will be considered in turn. Higher pre-caregiving and current relationship quality was associated with higher meaning. This suggests that a good relationship helped caregivers to derive something positive out of caregiving. Hirschfield (1983) observed that caregiving based on longstanding love and intimacy can lead to a positive construction of meaning. Some studies have found that relationship quality can be linked to positive aspects of providing care; for instance Kramer (1993a) reported that a good pre-caregiving relationship was linked to caregiving satisfactions. Similarly, Lyonette and Yardley (2003) found that a better relationship was linked to higher caregiving satisfaction. However, the measure of relationship quality used in that study contained a mix of questions on pre-caregiving and current relationship quality. In the current study both high pre-caregiving and current relationship quality were associated with high intrinsic motivations. Given that these intrinsic motivations emerge from internal desires for providing care, then it is likely that affection for the care-recipient would be linked to these motives. Lyonette and Yardley (2003) reported a link between a high relationship quality and high intrinsic motivations. They also found a relationship between high relationship quality and low extrinsic motivations. In the current study, there was no significant relationship between extrinsic motivations and pre-caregiving and current relationship quality. Thus, extrinsic motivations, which emerge from self-serving reasons or external factors, were not influenced by the quality of the relationship with the care-recipient and vice versa. Both intrinsic and extrinsic motivations were linked to higher meaning; however, intrinsic motivations had a stronger relationship with meaning. It was expected that given the links to better wellbeing, intrinsic motivations would be linked to meaning. The unexpected finding of the link between extrinsic motivations and meaning indicates that perhaps it is the caregivers' awareness of their reasons for providing care that helps them find meaning in their role.

The findings from correlational analyses indicate that intrinsic and extrinsic motivations, meaning and pre-caregiving and current relationship quality were individually related to caregiver wellbeing. Both a better pre-caregiving and current relationship were linked to higher wellbeing. This suggests that having a good pre-caregiving relationship with the care-recipient is beneficial for the caregivers' wellbeing. Other studies have found that a good pre-caregiving relationship was related to lower burden (Steadman et al., 2007; Williamson & Schulz, 1990), whilst a poor pre-caregiving relationship was linked to higher depression, strain, and lower quality of life (Kramer, 1993a; Morris et al., 1988b). The findings of the current study also indicate that a good relationship can increase feelings of competence in caregiving. A study with adult-child caregivers of older adults found that greater closeness in the current relationship was related to greater subjective effectiveness (Townsend & Franks, 1995). The results of the current study support research which suggests that meaning is linked to higher wellbeing. In the current study, higher meaning was associated with lower burden, depression scores, anxiety scores, and role captivity, and higher environmental mastery and competence. Other studies have found higher meaning is associated with lower depression and lower role strain/overload (Farran et al., 1997; Gallagher et al., 1994). The link between meaning and competence indicates that finding meaning can have a positive effect on influencing how caregivers appraise their role. The findings of the current study indicate that intrinsic and extrinsic motivations can have differential impacts on caregivers' wellbeing. Higher intrinsic motivations were associated with lower burden, role captivity, and higher competence, whilst higher extrinsic motivations were associated with higher burden, anxiety, and competence. Thus, intrinsic motivations were associated with better wellbeing and extrinsic motivations were linked to worse wellbeing. Studies have found this effect with other types of motivations. In a study with adult-child caregivers of older adults, Cicirelli (1993) reported that feelings of obligation to provide care were linked to greater burden and motivations to provide care based on feelings of attachment to the care-recipient were related to lower burden. In the current study, higher extrinsic motivations were linked to higher competence. It is possible that a recognition of the reasons why they were providing care contributed to caregivers feeling positive and competent in their role.

Overall, pre-caregiving and current relationship quality, meaning, INMECS and EXMECS made a significant contribution to the wellbeing measures, even when demographic characteristics were controlled. Meaning and current relationship quality were the main predictors of these variables. Pre-caregiving relationship quality did not significantly predict scores on any of the wellbeing measures. The findings of the current study indicate that theoretical models exploring predictors of wellbeing should incorporate meanings, motivations, and relationship quality. These findings also indicate that both positive and negative aspects of providing care can influence caregiver wellbeing. Meaning significantly explained variance in negative outcomes: burden, depression, and role captivity. It also explained variance in positive outcomes: environmental mastery and competence. These findings suggest that models of caregiving should recognise that positive aspects of providing care can influence both positive and negative affect.

Motivations, meanings and relationship quality were particularly relevant when applied to the aspects of wellbeing directly linked to caregiving: burden, role captivity and competence. Thus, interventions aimed at reducing caregiving stress and promoting feelings of caregiving competence should take into account the role of these factors. Although interventions may not be able to directly influence motivations for caregiving, understanding their influence on caregivers' wellbeing would aid the provision of more effective support. For instance caregivers who have high extrinsic motivations may require more support to help them cope with caregiving. Interventions could address the caregivers' perceptions of relationship quality, for instance through counselling. Caregivers could be provided with support to help them cope with their changing relationship with the care-recipient. Given the implications of a good pre-caregiving relationship for wellbeing, this indicates that caregivers with a poor pre-caregiving relationship with the care-recipient may need additional support with caregiving. Finally, although finding meaning is an individual process, interventions could help caregivers to identify positive aspects of providing care. Psychoeducational interventions have been used to enhance caregivers' competence in their role (e.g. Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001).

The current study sought to identify variables that predicted finding meaning. Overall 39% of the variance in meaning was explained by gender, caregiver relationship to the care-recipient, religiosity, caregiver health, hours of care provided, competence, role captivity, INMECS, EXMECS, and pre-caregiving and current relationship quality. Role captivity and competence made the largest contributions to explaining variance in meaning. Higher meaning was significantly predicted by high religiosity, high competence, high intrinsic motivations and low role captivity. The relevance of role captivity in predicting meaning indicates that positive outcomes of care can be predicted by both positive and negative factors. Some two-factor models do not include these relationships (e.g. Kramer, 1997; Lawton et al., 1991). Rapp and Chao (1990) found that neither caregiving strain nor gain predicted positive affect. However, Cafferata and Stone (1989) found that caregiving role strains and rewards predicted positive affect. The findings of the current study indicate that in order for interventions to be effective in promoting positive aspects of providing care, they also need to address some of the negative aspects of providing care.

In considering the findings it is important to take into account the limitations of the present study. The caregivers were recruited through the Admiral Nurse Service and thus may not be representative of the caregivers who do not have access to this kind of specialist service. Whilst it could be argued that the caregivers in this study should be coping better than other caregivers due to the support they were receiving, it is also possible that the caregivers had been referred to the Admiral Nurse Service because they were having particular difficulty in coping with the role. In this study it was not possible to include the caregivers' ethnicity as a variable in the analyses. Despite identifying participants from twelve areas in England, 91.2% were White British. Thus, there was insufficient ethnic diversity to allow meaningful comparisons. Some studies have found that ethnicity can have an impact on caregiving motives (Kabitsi & Powers, 2002; Lee & Sung, 1997) and the meaning caregivers find in caregiving (Farran et al., 1997). Caregivers' ethnicity may also be linked to their wellbeing (Dilworth-Anderson, Williams, & Gibson, 2002). The current study only had a 37.5% response rate; however, this was higher than a previous study with caregivers from the Admiral Nurse Service, which had a response rate of 33% (Clare et al., 2005).

The current study focused on exploring relationships between the variables; however, the analyses cannot determine the direction of the effects. For instance, high intrinsic motivations could result in higher meaning; alternatively, a high level of meaning may result in greater intrinsic motivations. It is likely that two-way relationships occur between the variables, in which they have an influence on each other. This supports models such as the SPM, which recognise that caregiving is not a static process but a dynamic process, ever changing. These models recognise that a change in one factor can influence other factors. For instance, there is a dynamic relationship between stressors and resources whereby effective resources may decrease the impact of stressors, and ineffective resources may increase stressors (Zarit & Edwards, 2008). A related limitation is the retrospective examination of the quality of the pre-caregiving relationship. It is possible that the caregivers' current mood may have had an impact, as caregivers who are depressed may be more likely to perceive their past relationship with the care-recipient more negatively than caregivers with a more positive current mood. However, the study was primarily concerned with exploring how these ratings of relationship quality influenced wellbeing, regardless of whether or not they were affected by a depressed mood.

This study has illustrated that meaning, motivations and relationship quality do interact and influence caregiver wellbeing. Future studies should build on the relationships identified in this study and incorporate other factors, for instance, the care-recipients' dependency on the caregiver for assistance with activities of daily living or severity of their memory and behavioural problems. These factors have been linked to a perceived poor relationship (Seltzer & Li, 1996; Spruytte et al., 2002). Other types of caregiving motivations could be explored, for instance filial obligation. It is recognised that a limitation of this study is that the participants came from the Admiral Nurse Service and further research is needed to determine whether the findings of this study can be replicated in other samples of caregivers. Similarly research needs to explore the relationships identified in this study with a more ethnically diverse group of caregivers. Longitudinal studies would make it possible to explore how meanings, motivations, and relationship quality change over the caregiving career, and how they continue to influence or be influenced by caregiver wellbeing. Longitudinal studies would also be able to explore how these factors influence nursing home placement; for instance, Wright (1998) found that caregivers who had lower affection for the care-recipient were subsequently more likely to place the care-recipient in a nursing home.

Conclusion

In conclusion, this study sought to explore the interrelationships between caregiving motivations, the quality of the relationship with the care-recipient, and ability to find meaning in caregiving, and the relative contributions of these factors to caregiver wellbeing. There were significant associations between meanings, motivations and relationship quality and, these factors could interact to influence on caregiver wellbeing. In addition, the findings suggest that the caregivers perceived a change in the quality of their relationship with the care-recipient, rating the pre-caregiving relationship higher than the current relationship. The findings of this study have implications for interventions with caregivers. Interventions could help caregivers cope with their changing relationship with the care-recipient, and more support could be provided to those who have had a poor relationship with the care-recipient. Interventions should recognise the impact of caregivers' motivations on their wellbeing, with perhaps more support being offered to those who are egotistically motivated. Caregivers could be helped to identify positive aspects in providing care.

The findings of this study also have implications for theoretical models of caregiving, particularly two factor models. Meaning could influence the negative aspects of providing care, and conversely negative aspects of providing care could predict finding meaning. More longitudinal research is needed to discover how meanings, motivations, and relationship quality change over the caregiving career. The findings of the present study indicate that motivations, meanings and relationship quality have an important role in the caregivers' experience of caregiving.

Chapter 8: Discussion

Introduction

The aim of this thesis was to investigate caregivers' motivations for providing care, their relationship with the care-recipient, and the meaning they found in caregiving. Two systematic reviews were conducted, which explored the impact of these factors on caregivers' wellbeing. The findings from these reviews indicated that the associations between these factors and their combined impact on wellbeing had not previously been examined. Utilising qualitative methodology this thesis explored the influence of meanings, motivations, and relationship dynamics on the subjective experience of caregiving. In addition, the working relationship between caregivers, care-recipients and health care professionals was examined. Quantitative methods were used to explore whether and in what way motivations meanings and relationship quality influence each other and impact on caregivers' wellbeing. Predictors of finding meaning in caregiving were also explored. This chapter will briefly recapitulate the findings of the studies. The limitations of this thesis will be reviewed together with directions for future research. Finally, this chapter will discuss the clinical implications of the findings of this thesis.

Summary of findings

Chapter 2: The impact of the quality of the relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review

This chapter reviewed empirical literature on relationship quality in dementia caregiving. The aim of the review was to examine the impact of caregiving on the quality of the relationship between the caregiver and care-recipient. In addition it explored the impact of the quality of the relationship on both the caregivers' and care-recipients' wellbeing. Fifteen quantitative studies were identified which met the inclusion criteria for the systematic review. Only six studies examined whether caregivers' reported changes in their relationship with the care-recipient. Some studies reported a better pre-caregiving relationship, whilst others reported a better current relationship. Overall, a good pre-caregiving relationship was linked to better outcomes for the caregiver and less reactivity to changes within the care-recipient. A good current relationship also had positive effects on the caregivers' and care-recipients' wellbeing. The care-recipients' abilities and behavioural problems could influence the caregivers' perception of the relationship, as could characteristics of caregivers such as their gender and kin relationship to the care-recipient. In addition to exploring empirical studies, this review discussed the contributions of studies using qualitative methodology, which allowed for a more in-depth examination of the complexity of relationship changes. Some of the methodological limitations of the empirical studies were discussed, primarily that the studies utilised different measures of relationship quality. Many of the studies included in the review had not taken into account the potential impact of the caregivers' gender and kin-relationship to the care-recipient. The main conclusions of this review were that studies should examine both the pre-caregiving and current relationship and consider the perspectives of both the caregiver and care-recipient.

Chapter 3: The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review

This chapter reviewed empirical literature on motivations and meanings in dementia caregiving. The aim of the review was to explore the potential impact of both meaning and motivations on the wellbeing of caregivers of people with dementia. In addition, the review explored individual differences in caregiving motivations. A systematic review of empirical studies identified only four studies exploring motivations for dementia caregiving and six studies examining the meanings found in dementia caregiving. With regard to motivations, the studies reviewed found that cultural norms and the caregivers' kin relationship to the care-recipient could influence their reasons for providing care. Only two studies examined the impact of motivations on caregivers' wellbeing. Motivations were linked to higher scores on measures of depression and positively contributed to variance in the intrinsic rewards of caregiving. Three studies reported that meaning could have a positive impact on caregivers' wellbeing. The findings of this review were integrated with qualitative studies, which allowed further explorations of different caregiving motivations and different conceptualisations of meaning. The methodological limitations of the studies included in the review were discussed. The empirical studies on motivation were limited by not grouping these motives under a theoretical framework, such as intrinsic or extrinsic motivations. The studies on meaning utilised different measures, with often different conceptualisations of meaning, which made comparison of the findings of these studies difficult. This review concluded that the involvement of meanings and motivations in dementia caregiving is an under-researched area, and that more research is needed to explore these factors and address the methodological limitations of existing studies. However, the limited evidence available indicated that both motivations and meanings could impact on caregiver wellbeing.

Chapter 4: Interpretative Phenomenological Analysis

This was a methodology chapter, which critically examined a form of in-depth qualitative analysis, IPA. The theoretical foundations of IPA were discussed in order to explore how IPA is considered to be both phenomenological and interpretative. IPA was viewed as a suitable method for studies that wished to research how people make sense of a particular phenomenon that they are experiencing. This is because IPA is concerned with people's subjective experiences and the meanings ascribed to these. However, it also recognises that access to these experiences involves an element of interpretation on the part of the researcher. Some of the criticisms of the assumptions underlying IPA were discussed as well as the methods used to try to ensure the credibility of IPA. This chapter provided a theoretical framework for analysing an interview using IPA, which described the various stages in the analytic process. The contribution of IPA to health research was discussed and particularly its applicability to research with caregivers and people with dementia.

Chapter 5: Balancing needs: The role of motivations, meanings, and relationship dynamics in the experience of family caregivers of people with dementia

This chapter described a qualitative study which developed the findings from Chapters 2 and 3. This study aimed to explore how motivations, meanings and relationship quality interacted to influence the subjective experience of caregiving. A qualitative methodology was chosen as it allowed for an in-depth examination of this process. Twelve caregivers were identified from the caseload of the Admiral Nurse Service and were interviewed about their reasons for caregiving, their relationship with the care-recipient and any positive aspects of providing care. The findings of the analysis indicated that these factors could be encompassed under an over-arching theme of 'balancing needs', in which the caregivers struggled to balance their needs with those of the care-recipient. The caregivers faced challenges of trying to preserve their relationship, whilst trying to cope with the changes in the care-recipient. Finding meaning was intertwined with the caregivers' relationship with the care-recipient, and motivations to continue caregiving were influenced by the caregiver identifying rewarding aspects of providing care. The relationship with the care-recipient was also one of the primary reasons for providing care. The findings of this study provided a tentative link between meanings, motivations, and relationship quality, and it was suggested that quantitative research was needed to determine the nature of this relationship. In addition, it was recommended that further research include the perspectives of the care-recipients and other key members of the immediate network.

Chapter 6: 'Negotiating the balance': The triadic relationship between spousal caregivers, people with dementia and health care professionals.

The concept of a health care triad was addressed in this chapter, which described a series of qualitative case studies. The aim of this study was to examine the perspectives of members of a triad: the caregiver, the care-recipient and the Admiral Nurse. This study explored the developing triadic relationship and how members worked together. In addition, their perspectives on the effectiveness of this working relationship were explored. Six couples and their Admiral Nurse were interviewed. The analysis of the interviews with the caregivers, described in Chapter 6, was utilised as a framework to which relevant extracts from the Admiral Nurses and care-recipients' accounts were added. The findings of this analysis indicated that the triads were endeavouring to work together in a process of 'negotiating the balance'. Each member of the triad attempted to acknowledge the perspectives of the other members, but had to balance this against their own needs. There were differing perspectives on the caregiving situation and evidence of coalitions occurring between members. There was evidence of coalitions occurring between the Admiral Nurses and caregivers to tackle difficult behaviour. There may be alliances between the caregivers and care-recipients as they decide not to follow the advice of the Admiral Nurses. Finally, there was evidence that the Admiral Nurses and care-recipients can share the same perspective. The findings of this study indicated that the balance of the working relationship could influence its success.

Chapter 7: Relationships, motivations and meanings in dementia caregiving: A cross-sectional study

This chapter described a cross-sectional questionnaire study, which was developed from the findings of the previous chapters. This study sought to explore whether intrinsic and extrinsic motivations, meaning, and pre-caregiving and current relationship quality were associated. This study also examined whether these factors, both individually and combined influenced caregivers' wellbeing. Differences in rating of relationship quality and predictors of finding meaning were examined. This study utilised a cross-sectional questionnaire, the respondents were 447 caregivers in receipt of the Admiral Nurse Service. The findings of this study suggest that there was a significant difference in the caregivers' rating of pre-caregiving and current relationship quality. The caregivers rated their pre-caregiving relationship as higher than their current relationship. Intrinsic motivations, meaning, and pre-caregiving and current relationship quality were significantly positively related to each other, whilst extrinsic motivations were positively linked to intrinsic motivations and meaning. Correlational analyses indicated that these variables were related to the measures of wellbeing. The combined impact of these factors on wellbeing, was examined through hierarchical regression analyses. In these background characteristics such as the gender of the caregiver were controlled. Meaning, intrinsic and extrinsic motivations, and pre-caregiving and current relationship quality significantly explained 17% variance in burden, 25% variance in role captivity, and 24% variance in competence. These variables only made modest contributions to explaining the variance in anxiety (5%), depression (6%), and environmental mastery (7%). An hierarchical regression was performed to identify factors that predicted finding meaning. This included selected background characteristics, pre-caregiving and current relationship quality, intrinsic and extrinsic motivations, competence, role captivity and religiosity. These variables predicted 32% of the variance in meaning, with intrinsic motivations, religiosity, role captivity and competence significantly associated with higher meaning.

Theoretical contributions

This thesis explored the role of meanings, motivations, and relationships in dementia caregiving. The findings from two systematic reviews indicated that no study had explored how meaning, motivation, and relationship dynamics influence each other and caregivers' wellbeing. This thesis found that there could be significant associations between these factors. In addition, there could be association between these factors in terms of how they interact to influence caregiver wellbeing. The thesis also explored the individual contribution of these factors to caregiving, which has extended previous research. There has been little attention paid to relationship quality, motivations, and meanings in theoretical models of caregiving. The role of the relationship between the caregiver and care-recipient is not explicitly stated in the Double ABCX Model. Although the SPM does acknowledge relationship quality, it is seen as a background factor and as a stressor. The findings of this thesis extend these models by suggesting that the relationship between the caregiver and care-recipient can have a mediating role in the experience of caregiving. Having a good pre-caregiving and current relationship had a positive impact on caregivers' wellbeing. Theoretical models have also tended to neglect the caregiver's motivations for providing care. This thesis found that although a person may be motivated to provide care, over time other factors may erode these original motivations, for instance the caregiver's worsening health or pressures from other family members. There has also been little research on the influence of caregiving motivations on wellbeing. The findings of this thesis provided some evidence that intrinsic and extrinsic motivations could have differential impacts on caregiver wellbeing. Only a small number of studies have explored how finding meaning can influence caregiving experience. The findings of this thesis suggest that finding meaning can contribute to the continuation of the caregiving relationship and better wellbeing. This thesis also extended previous research by examining the factors which could predict finding meaning. Meaning was significantly predicted by intrinsic motivations, religiosity, role captivity and competence. This finding challenges two-factor models, which have not allowed for positive caregiving outcomes to be predicted by negative factors (e.g. Kramer, 1997; Lawton et al., 1991). The findings also imply that meaning could be linked to negative aspects of wellbeing.

Methodological considerations

In considering the findings it is necessary to take into account the limitations of the thesis. Firstly, it is acknowledged that the caregivers who participated in the studies were recruited from the Admiral Nurse Service. Thus, they may not be representative of caregivers who are not in receipt of such a service. It has been suggested that having access to this service might explain why the caregivers in the study in Chapter 7 reported reasonably high levels of meaning. However, it should also be noted that some of the caregivers interviewed for the study presented in Chapter 5 struggled to find anything positive in caregiving. It is also possible that the caregivers may have in fact been referred to the Admiral Nurse Service in the first place as they were struggling with their role and needed additional support. Therefore, caregivers in receipt of this service could have been more stressed than other caregivers.

It is acknowledged that the majority of the caregivers who participated in this research were White British. Despite the questionnaire being sent out to caregivers identified from 12 Admiral Nurse teams across England, 91.2% of the respondents were White British. Therefore, the findings of this study may not be applicable to other ethnic groups. Previous research with caregivers in receipt of the Admiral Nurse Service also had a dominance of White-British caregivers (Clare et al., 2005). It is recognised that minority ethnic groups may experience inequalities in the recognition of their mental health needs (Raleigh et al., 2007). They may also be less likely to access support services. Lawrence, Murrary, Samsi and Banerjee (2008) reported that South Asian caregivers who had traditional caregiving ideologies felt that having any professional assistance with care was a failure to fulfil their responsibilities.

The measures used in Chapter 7 also have their limitations. Relationship quality is a broad term, which encompasses many aspects such as affection, reciprocity and communication. The qualitative study presented in Chapter 5 allowed for an in-depth examination of the complexity of the relationship. In the quantitative study presented in Chapter 7, relationship quality was measured with five questions, which assessed the closeness of the relationship, communication, similarity in views, getting along and shared activities. This measure was specifically chosen as it allowed for a comparison between pre-caregiving and current relationship quality. However, it only explored certain elements of relationship quality. Other studies have examined aspects such as a communal relationship, reciprocity, marital satisfaction and marital cohesiveness (Gallagher-Thompson et al., 2001; Rankin et al., 2001; Williamson & Shaffer, 2001). However, some of these measures would not be suitable for non-spousal/partner caregivers. The measure of motivations to provide care also has its limitations as it focuses purely on intrinsic and extrinsic motivations. This measure was chosen because it differentiated between these two types of motivations. There are other caregiving motives which could have been explored, for instance filial obligation or filial attachment. Further research should explore these different types of motivations.

The study presented in Chapter 7 found that religiosity was a significant predictor of finding meaning. It is recognised that in this study religiosity was only measured by one question and this would not have fully encapsulated the multi-dimensional nature of religiosity. Hill and Pargament (2002) examined research on religiosity and concluded that researchers tend to utilise on brief measures of religiosity when it is one of many variables under investigation. In the study presented in Chapter 7 the measure was chosen as it would be suitable for use with caregivers with different religions. The multi-dimensional nature of religiosity has made its measurement difficult (Krause, 1995). Atchley (2005) has argued that measures of spirituality and religiosity need to be sensitive to differences within and across religious groups. Kirby, Coleman and Daley (2004) have argued that there may be cultural differences in the experience of religiosity. For instance, American and British people may differ in how they are affected by religion and spirituality and in how they express their beliefs. Future studies exploring the link between religiosity and finding meaning should use a more extensive measure of religiosity. For instance, Krause (1995) measured three components of religiosity: organisational religiosity, non-organisational religiosity, and religious coping. Kirby et al. (2004) measured spiritual belief using a five-item visual analogue scale.

Lastly, it is acknowledged that although the findings presented in Chapter 7 suggest that meanings, motivations and relationship quality can be linked to caregiver wellbeing, there are many other factors that could also have had an influence. Models of caregiving, such as the SPM, show that many factors can influence the caregiving such as the caregivers' coping resources and level of social support. This thesis did not aim to generate a theoretical model of caregiving from its findings. Rather the aim was to explore how meanings, motivations and relationship quality could influence caregivers' wellbeing. By highlighting the potential influence of these factors this would increase the possibility of these factors being incorporated into theoretical models.

Directions for future research

The limitations identified in this thesis can be addressed in future research. Further research is needed to discover whether the findings of this thesis could be replicated with both a more ethnically diverse sample of caregivers and caregivers who are not in receipt of support services. The majority of the participants in the research presented in this thesis were either spouse/partners or adult-child caregivers. Qureshi and Walker (1989) reported that these are the most common types of caregivers. Future studies should examine whether the findings in this thesis could be replicated with other types of caregivers, for instance caregivers who were friends of the care-recipient. They may different motivations for providing care. The thesis found that relationships, motivations and meanings could interact to influence caregivers' wellbeing. Future studies should incorporate other factors such as the care-recipient's memory and behavioural problems, or the severity of the dementia. Other caregiver characteristics could be explored, such as their resources for coping with their role. Although Chapter 7 found relationships between meaning, motivation, and relationship quality, it could not determine the direction of these relationships. Further studies could utilise statistical methods such as path analysis, which would show the direction of this relationship.

Both interview and questionnaire data were used in this thesis but there are other methods which could be used. In exploring relationship quality, studies could utilise observational methods to observe interactions between the caregivers and the care-recipients. Gallagher-Thompson et al. (2001) observed spousal caregivers and care-recipients during mealtimes and during a task which involved planning an outing. Both non-verbal and verbal communication were examined, and the authors were able to categorise the interactions as supportive, facilitative and rapport-building. Thus, observational methodology would be useful to explore the impact of the quality of the relationship on the care provided. This would allow for a fuller understanding of the changes in relationship between the caregiver and care-recipient. In addition, observational methods could further investigate interactions between health care triads. These observational studies could include quantitative measures which could be used to compare the caregivers' perceptions of the relationship with actual interactions.

Cross-sectional methods were utilised in this thesis, but longitudinal studies would contribute to the further understanding of meanings, motivations and relationship quality. Quantitative studies with caregivers at the time of diagnosis would potentially produce a more accurate rating of the pre-caregiving relationship quality than retrospective accounts. Longitudinal qualitative studies would be able to explore the evolution of a relationship into a caregiving relationship. For instance, Blieszner and Shifflet (1990), utilising qualitative methodology, explored changes in relationship in both adult-child caregivers and spousal caregivers over an 18-month period. Longitudinal qualitative methods would also allow the exploration of how relationships, motivations and meanings develop and change over the caregiving career. The study described in Chapter 5 found that the caregivers' original motivations for providing care may eventually be overpowered by other factors relating to the caregivers' own needs. Longitudinal qualitative studies would allow for a more in depth examination of this process. Finally, given that motivations, meanings, and relationship quality were linked to wellbeing, further studies could examine their role in the prediction of the care-recipient being placed into full-time care.

Implications for clinical practice

Current policy on dementia and caregiving has prioritised earlier diagnosis, which provides the opportunity for earlier intervention and support (Department of Health, 2009). NICE-SCHE (2006) guidelines propose various types of support for caregivers including psychoeducation, psychological therapy and respite breaks. The degenerative nature of dementia means that caregivers often need support through the progression of the illness. However, the National Dementia Strategy (Department of Health, 2008) recognises that most health care services discharge caregivers once the case is stable and appropriate care packages have been put in place. The Strategy has recommended the appointment of dementia advisers who would act as a single point of contact, providing advice and information about other services. These would be different to the Admiral Nurse Service, which offers intensive care management. The Admiral Nurse Service provides support to both the caregiver and care-recipient. Unlike other community health services, the Admiral Nurse Service will work with the caregiver for as long as it is appropriate, even after the care-recipient enters into full-time care or dies (Woods et al., 2003). Chapter 6 explored the working relationship between the caregiver, care-recipient and Admiral Nurse. The findings of this study suggest that for interventions to be successful they should include both members of the dyad. It was also recognised that both caregivers and care-recipients should be provided with opportunities to receive individual support as they may feel uncomfortable discussing their true feelings in the presence of the other member. In order for health care professionals to improve the support they provide to caregivers and care-recipients, the perspectives of all three members of the triad should be taken into account.

Studies have found that early provision of support to caregivers can reduce the number of care-recipients placed in full-time residential care by 22% (Gaugler, Kane, Kane, & Newcomer, 2005). Yet these interventions will only be effective if they meet the needs of the caregivers. The findings of this thesis demonstrate that motivations, meanings and relationship quality can have a significant influence on caregiver wellbeing. This could potentially influence the quality of care provided, yet these factors have tended to be neglected in interventions. The studies in Chapters 5 and 7 show that there can be a relationship between these factors. Thus, it seems plausible that for interventions to be effective they would need to explore all three factors. For instance, interventions promoting finding meaning are unlikely to be successful if the caregiver has a poor relationship with the care-recipient. The implications of each factor for clinical practice will now be considered.

Meaning in caregiving

Both policy and theoretical models of dementia caregiving have focused on the negative impact of providing care. Many of the services offered to caregivers are designed to reduce stress. In the NICE-SCIE guidelines (2006) it is suggested that caregivers should receive support to help combat psychological distress and negative psychological impact. Similarly, theoretical models of the caregiving experience have primarily focused on the negative aspects of caregiving. It is undeniable that, for some, caregiving is a stressful experience, and there are numerous studies that demonstrate that caregiving can have a detrimental impact on caregivers' wellbeing. However, the findings from this thesis indicate that some caregivers can find meaning in caregiving and derive something positive from it. A thematic analysis of interviews with caregivers, presented in Chapter 5, found that the meaning caregivers found in caregiving was intertwined with their motivations to provide care and relationship with the care-recipient. However, not all of the caregivers could find meaning in their role. The study presented in Chapter 7 found that on average, the caregivers were scoring quite highly on the measure of meaning. It is recognised that this high score may have been because they were receiving support from the Admiral Nurse Service. Even so, this does highlight the potential role of support in helping caregivers to derive something positive out of caregiving. Finding meaning is an individual process and it is recognised that interventions may not be able to directly enable caregivers to find meaning. However, interventions could help caregivers to appraise the situation more positively, which could eventually result in them finding meaning.

Acton and Kang (2001) have argued that instead of focusing on negative outcomes of caregiving, interventions should explore the more positive outcomes. The authors argue that interventions are less likely to alter the perceptions of burden, but may be successful in helping caregivers to identify positive aspects of providing care, such as finding meaning. Thus, interventions should focus on positive outcomes which will be more amenable to change. In order for these interventions to be effective they need to be specifically targeted at promoting meaning. The skills training intervention by Martin-Cook et al. (2005) utilised provisional meaning as an outcome measure to discover whether the intervention made caregivers feel more empowered. This intervention had no impact on provisional meaning, primarily because it was focused on helping caregivers to recognise the care-recipients' functional abilities. Thus, effective interventions will need to help caregivers to reappraise their situation and derive something positive out of it. For instance, therapeutic interventions could help caregivers focus on positive aspects of providing care (Nolan et al., 1996). The study presented in Chapter 7 identified that caregiving competence explained significant variance in finding meaning. Kahana and Young (1990) have argued that caregiving uplifts could emerge from seeing an improvement in the wellbeing of care-recipient and from gaining a sense of competence. Therefore, it is possible that interventions which increase competence will help to enable caregivers to find meaning in caregiving. In an intervention designed by Gitlin et al. (2001), occupational therapists worked with caregivers to help them develop greater confidence in their abilities and reframe their appraisals of the caregiving situation. This helped caregivers to feel more competent in their role.

The impact of finding meaning on wellbeing has important implications for the development and delivery of support services. In order for health care professionals and support services to provide more effective support to caregivers there needs to be a better understanding of the positive aspects of providing care (Cohen et. al, 2002). Identifying the ways in which caregivers feel enriched by caregiving will help health care professionals to appropriately validate the caregivers' feelings and experiences (Kramer, 1997). Research on finding meaning can provide pointers on how to enhance positive aspects of care or identify caregivers who are in more need of intervention. Caregivers who cannot find any meaning in their role may be at greater risk of caregiving having a detrimental impact on their wellbeing. Positive experiences may also be important determinants of the quality of care provided (Kramer, 1997). Thus, those caregivers finding little meaning in caregiving may require additional support.

Motivations to provide care

Governmental policy on caregiving has implicitly assumed that people will be willing to provide care. However, this approach fails to recognise that there can be individual differences in caregivers' motivations to provide care. This thesis has explored some of the many different reasons why people provide care. Theories on caregiving motivations imply that these motivations may influence the quality of care provided. Feeney and Collins (2003) have argued that effective caregiving requires the caregiver to be sufficiently motivated to accept the responsibility and effort required in providing care, as caregivers who are not adequately motivated may provide ineffective or low levels of support (Feeney & Collins, 2003). The different types of motivations may influence the provision of care, for instance people who are egotistically motivated may provide poor levels of care (Feeney & Collins, 2003). The study described in Chapter 7 found that caregiving motivations could have differential impacts on caregiver wellbeing. Intrinsic motivations were linked to better wellbeing and extrinsic motivations were linked to poorer wellbeing. These findings indicate that interventions for caregivers need to explore their reasons for providing care. It is recognised that interventions are unlikely to be very effective in altering caregiving motivations. Instead they could focus on identifying those caregivers who may require additional support. Caregivers who are providing care for extrinsic reasons may need more help to cope with caregiving than those who are intrinsically motivated. The study discussed in Chapter 5 found that some of the caregivers were providing care because they had no alternative. This may be because there was no one else available or willing to provide care. These caregivers could be identified as being more at risk of feeling trapped in their role and need additional support.

This thesis has also identified that even where caregivers can be highly motivated to provide care, they may still experience difficulties in their role. Chapter 6 identified some of the problems caregivers experienced and how the Admiral Nurses worked with them to tackle these problems. Nolan and Keady (2001) argue that it is important to assess both willingness and ability to provide care. For instance, some caregivers may feel that they have an obligation to provide care. Conversely, many potential caregivers may be willing to provide care but lack the necessary skills and abilities. Nolan and Keady (2001) recognise that services for caregivers should not support caregivers beyond a point at which their own health suffers. Services should work with caregivers in a way which recognises their existing expertise. Kahana and Young (1990) contend that motivations to care must be coupled with an ability or competence to help in order to sustain a successful caregiving relationship. Therefore, it needs to be recognised that not all caregivers have the necessary abilities or competence to provide care. These caregivers could be encouraged to look at alternative caregiving arrangements. Thus, it is important to differentiate between when it is appropriate to help caregivers to provide care and when interventions should be aimed at helping caregivers to relinquish their role (Nolan et al., 1996).

Finally, this thesis has identified that caregiving motives may eventually be outweighed by other factors. Despite being motivated to provide care, the caregivers described in Chapter 5 discussed turning points, at which it became evident that they might have to give up care. Often this involved the caregivers feeling they needed to prioritise their needs above those of the care-recipient. In addition, two the caregivers in that study had placed the care-recipient into full-time residential care, as they could no longer cope with the caregiving situation. This decision did not ease the caregivers' burden, as they felt guilty about putting the care-recipient into care. Thus, caregivers who want to continue caregiving should be provided with more effective support. The two main types of support on offer to caregivers are financial and psychological/social support. Doty (1986) concluded that support which alleviates the stresses of caregiving would be most effective in postponing institutionalisation. Financial support might erode altruistic motivations for providing care and formalise caregiving (Doty, 1986).

Relationships

Both policy and theoretical models of caregiving have been criticised for ignoring the relational aspects of providing care. Yet this relationship is likely to be one of the main reasons for the caregiver commencing care in the first place. The degenerative nature of dementia means that this relationship will gradually transform, with the reciprocal aspects diminishing. The study in Chapter 5 found that caregivers were trying to preserve and maintain their relationship with the care-recipient. This relationship could determine the way in which the caregiver approaches, responds to and experiences the act of caregiving (Lewis & Meredith, 1988). The studies discussed in Chapter 2 found that the quality of the relationship can impact on the quality of care provided. Williamson and Shaffer (2001) reported that fewer current rewards predicted higher levels of depression and increases in the risk of potentially harmful behaviour. High levels of relationship satisfaction have been linked to less reactivity to memory and behaviour problems, and more effective communication (Steadman et al., 2007). In addition, the quality of the current relationship appears positively related to caregivers' wellbeing and abilities (Burgener & Twigg, 2002). Given the importance of the relationship for caregiving it is recommended that interventions help caregivers cope with this transforming relationship.

It has been proposed that caregivers should be assessed for the quality of the pre-caregiving and current relationship, so as to identify caregivers who are more at risk of negative outcomes (Kramer, 1993a; Nolan et al., 1996). The study presented in Chapter 7 found that both a poor pre-caregiving and current relationship were linked to lower levels of wellbeing. In particular the current relationship was a significant predictor of variance in the measures of wellbeing. Thus, interventions need to tackle both the changing current relationship and also the pre-caregiving relationship. It is acknowledged that caregiving can take place within a poor relationship, and occur in the absence of affection towards the care-recipient (Horowitz & Sindelman, 1983). Nolan et al. (1996) have argued that where there is a existing poor pre-caregiving relationship, there should be caution in encouraging these potential caregivers to provide care. Kramer (1993a) proposes that those with a poor pre-caregiving relationship should be provided with counseling to help them work through their feelings about caregiving in light of this relationship.

Relationship quality is a broad term and numerous factors can result in a perceived good relationship. Interventions have addressed some of the factors that underpin a good relationship. For instance, a psychoeducation intervention by Nobili et al. (2004) included a psychologist visiting caregivers to discuss changes in the relationship and communication with the care-recipient. Interventions have tended to focus on supporting one member of the dyad, when in fact they may be more helpful if they dealt with both members. Whitlatch et al. (2006) found that both people with early stage dementia and their caregivers were able to benefit from a dyadic intervention. Quayhagen et al. (2000) conducted a dyadic counselling intervention which utilised components from couples' therapy such as communication enhancement and conflict resolution. Although this intervention had little impact on reports of relationship satisfaction, the caregivers reported that they benefited from enhanced communication and interaction with the care-recipient.

The relationship between the caregiver and care-recipient may have an important role in the dyad's willingness to accept the support being offered to them. Those who see caregiving as an intrinsic part of the relationship may be resistant to accessing support services. In the study in Chapter 6, one of the female spousal caregivers had been caregiving for many years without receiving any support from formal services. This caregiver only accepted help when her husband's behavioural problems made it difficult for her to care for him. This caregiver seemed to be unwilling to follow the advice of the Admiral Nurse, possibly because she was resistant to changing long-standing patterns of interactions. Caregivers may resist accepting help because their relationship with the care-recipient means that they feel that only they can provide adequate support. There are also caregivers who believe that they are the only ones who can care for the care-recipient properly as the support services available are perceived to be of low quality. Carers UK (2003) found that the formal support services on offer to caregivers were perceived to be of poor quality with a high turnover of staff. Spousal/partner caregivers in particular may be resistant to the care-recipient being placed in respite or full-time residential care as they do not want to be parted from them. This implies that there need to be options for couples to remain together. For some of the couples in the study in Chapter 5, the Admiral Nurse had discussed the option of the couple moving into residential accommodation together.

Conclusions

Caregiving has been conceptualised as a career (Pearlin, 1992), which begins as an individual is introduced to the caregiving role and is marked by transitional events resulting in the gradual restructuring of the caregiver's self-concept. This career continues through the care-recipient being placed into full-time residential care and beyond the death of the care-recipient. Given the potentially longitudinal nature of dementia caregiving, it is important to find ways in which to support the wellbeing of the caregiver. It is recognised that some caregivers will thrive in their role, whilst others will experience a great deal of difficulty adjusting to this role (Montgomery & Williams, 2001). Thus, there needs to be a better understanding of how caregiving can differentially impact on caregivers. Often caregiving takes place within a historical context and the relationship between the caregiver and care-recipient has the potential to either facilitate or impede the caregiving. In addition, caregivers will have their own reasons for providing care. Some caregivers may thrive in their role because they are able to find meaning in it and derive something positive out of providing care. This thesis explored the role of meanings, motivations and relationships in dementia caregiving. The findings from the systematic reviews indicated that no study in dementia caregiving had examined how meaning, motivation, and relationship dynamics influence each other and caregiver wellbeing. This thesis found that there could be significant associations between these factors. In addition, there could be association between these factors in terms of their impact on caregiver wellbeing. This thesis also extended previous research by exploring the predictors of finding meaning, which could be predicted by both positive and negative aspects of providing care. The findings of this thesis suggest that developing a greater understanding of meanings, motivations, and relationships can aid the development of more effective interventions for caregivers.

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Appendix B.1 Extract from a higher-order theme

5. Just trying to find a balance

5.1. Give as much power as I can

You just have to judge
we all as carers do a lot of stonewalling don't we because it's one way of- it's one way of getting through but- it must feel very disempowering to the person whose receiving that treatment
I do try and- um give him as much power as I possibly can
just trying to find a balance
you know the thing is it's always this balance isn't it
I'm not going to stop him from doing things that he would get some sort of satisfaction from doing- you just have to kind of judge whether it's completely unsafe for him
I would not expect or anticipate that he would attempt to cook a meal for himself now- I mean he just couldn't handle that at all
I mean unless I'm actually there- at the time you know it's difficult- but for the most part he- he tends not to erm- he tends not to do really dangerous things

You can't treat him as a child
you can't treat him as a child
Although he is so childlike sometimes
you're trying not to [treat them like a child]
it does seem that way- it does seem like you're treating them like a child
you think well I've got to do this
but you have to do this
you still have to do it
there's lots of things you've got to do
does make it seem like your being bossy- and pushy- and treating them like a kid
most things are not easy for you to make somebody to do
they think you're treating them like a child

I don't want to take away his pride
I've never taken over the- what do they call it- power of attorney
I don't want to take away his pride
he don't want anybody take his bank
he seems to have been putting an [building society] and different things
the statements come and I feel as if I should try and draw it all together
but as yet- as yet I haven't done
I don't know without taking power of attorney
I don't- don't at this stage want to do it
I feel as though I'm robbing him of something
so I'll carry on as we are for a bit longer
I have been to his bank and I have arranged
he went with me and signed that
but he don't remember that

so what I do- every few weeks- I get him to sign a cheque- to my- to me
I pay it into my account
to get housekeeping money every few- that's what I do
he knows he's giving me money
caus that would worry him
he always says have I- have I given you your money this week do you want money
he would care about that

you've got to let him do something
you've got to let him do something
sometimes he'll say I've washed the pans- and all that you know say right- you go there and there not washed properly
it always used to be perfect- but- now when he does it it looks as though somebody's chewed it up with a knife and fork you know [laughs]
he's left the gas on a few times
he'll peel potatoes and put them on and forgotten about them
he has burnt pans and that but there again he cleans them
I suppose you know [laughs] one is against the other aint it- he burns them he cleans them

he's helped me
I don't tell him to do things
I ask him like will you- make a cup of tea please and then he's alright
we just work like that really
this morning he's helped me tidy up and things like that
he's made the bed himself which was alright

we do it together
everyday when I went to work he would duster and hoover
he still does it now but we do it together
I'll do the dusting and then he'll follow around with the cleaner
he can't remember what he's done you see
if I keep doing any… everything then it looks as though I'm not I don't trust him but I do
I mean it's alright just dusting and hoovering and things like that

Appendix B.2: Distribution of themes amongst participants

	We knew each other well	This person is different	I miss the companionship	I miss the help	Just trying to find a balance	You just get on with it	Turning point	I wasn't coping
Tony	X	X	X		X			X
Maureen	X	X	X	X	X	X	X	
Paula	X	X	X	X	X	X		
Angela	X	X	X	X	X	X	X	
Edna	X	X	X	X	X	X	X	
Joan	X	X	X	X	X	X	X	
Jill	X	X	X	X	X	X	X	
Brenan	X	X	X	X	X	X	X	
Judith	X	X				X		
Carol	X	X	X	X	X	X	X	
Deborah	X	X	X	X	X	X		X
Patricia	X	X	X			X	X	

Appendix B.3: Extract from a case study

He doesn't see it as me helping

Doesn't get through to him that he can't do it **(caregiver)**
In fact he can't, it doesn't get through to him that he can't do it
He still thinks that he can, and he starts things, and then it's kaput he can't do it
There's other things I want doing but we would have normally done
That is the biggest problem really, that he can't let go
He can't let go

he sees it as me just wanting these things done **(caregiver)**
He doesn't see it as me helping
he sees it as me just wanting these things done and err trying to take things off him
the attendance allowance- I- for me it's to get the garden done- it's to get things that he would normally do
He still thinks that he can do it
he'll say "why take the garden off me" "I know I can do it"
he can't he hasn't got the strength- he was out there yesterday
within half an hour he's shattered- he wants to come in and sit down
so nothing would really get done
I've got round to him now and said lets get somebody in to do the bulk of the garden

'She's got to stop him from doing all those things that he likes to do, so that probably makes her edgy. She's always there, got to be keeping an eye on what he's doing and preventing him from doing it, which will be stressful because then he'll want to do these things [which] in some way he's quite capable of doing them. She's got to keep stopping him, so she's spending a lot of energy on preventing him from doing things that he's quite capable of doing' **(Admiral Nurse)**

'he doesn't do it right and she's got to- he's got to do it right, no point doing it if you don't do it right. I think that's, I think she's actually said that- and he doesn't do it right' **(Admiral Nurse)**

'I think he is quite frustrated with Joan from stopping him doing stuff that he is actually able to do and jumping in on everything' **(Admiral Nurse)**

'And uh she's all for getting someone in to do the garden I don't know, that's one of the things I can do, why give it away to somebody else' **(care-recipient)**

'she says I'd say I've to do all these things and I don't do them....and I mean other time everything got done....rather quickly, and I went to a timetable....I used to paint the house in three days....All outside....and uh, you get used to it then, so four days is a lot but uh....I don't work to timetables anymore' **(care-recipient)**

Appendix C: Questionnaire

Note: The questionnaire has been minimised so that it would fit into the format of this thesis.

Enhancing the Admiral Nurse Service: Understanding more about the people who receive the service

Confidential Questionnaire

Enquiries to:
Catherine Quinn
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Telephone 01248 388359
Fax 01248 382599

Please return your questionnaire to the above address using the envelope provided.

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Appendix D.1: Correlations

Correlations

		Gender	Age	relationship to PWD	hours of care	Religiosity	Health rating	Total_ role_captiv	Total_ comp	Total_ Burden	Total_ Depress	Total_ Anxiety	Total_ EnvMast
Gender	Pearson Correlation	1.000	-.256**	.179**	-.155**	.101*	.000	.270**	-.077	.287**	.119*	.312**	-.237**
	Sig. (2-tailed)		.000	.000	.001	.033	.987	.000	.108	.000	.013	.000	.000
	N	447.00	440	425	420	442	443	431	432	431	432	429	425
Age	Pearson Correlation	-.256**	1.000	-.696**	.223**	.076	-.179**	-.162**	.022	-.193**	.065	-.033	.088
	Sig. (2-tailed)	.000		.000	.000	.115	.000	.001	.650	.000	.181	.504	.074
	N	440	440.00	420	416	435	436	426	426	425	425	422	419
relationship to PWD	Pearson Correlation	.179**	-.696**	1.000	-.413**	-.066	.104*	.150**	-.091	.137**	-.073	.031	-.112*
	Sig. (2-tailed)	.000	.000		.000	.180	.032	.002	.066	.005	.139	.539	.025
	N	425	420	425.000	400	420	421	409	410	409	410	407	404
hours of care	Pearson Correlation	-.155**	.223**	-.413**	1.000	.014	-.168**	.011	.125*	.072	.249**	.052	-.084
	Sig. (2-tailed)	.001	.000	.000		.779	.001	.823	.011	.143	.000	.294	.092
	N	420	416	400	420.000	415	416	410	412	413	410	409	406
Religiosity	Pearson Correlation	.101*	.076	-.066	.014	1.000	.135**	-.112*	.102*	-.100*	-.161**	-.046	.183**
	Sig. (2-tailed)	.033	.115	.180	.779		.004	.021	.035	.039	.001	.340	.000
	N	442	435	420	415	442.000	440	427	428	426	428	425	421
Health rating	Pearson Correlation	.000	-.179**	.104*	-.168**	.135**	1.000	-.165**	.064	-.269**	-.429**	-.335**	.402**
	Sig. (2-tailed)	.987	.000	.032	.001	.004		.001	.186	.000	.000	.000	.000
	N	443	436	421	416	440	443.00	429	430	429	430	427	424
Total_role_captiv	Pearson Correlation	.270**	-.162**	.150**	.011	-.112*	-.165**	1.000	-.205**	.718**	.412**	.468**	-.472**
	Sig. (2-tailed)	.000	.001	.002	.823	.021	.001		.000	.000	.000	.000	.000
	N	431	426	409	410	427	429	431.000	425	425	426	423	420
Total_ comp	Pearson Correlation	-.077	.022	-.091	.125*	.102*	.064	-.205**	1.000	-.297**	-.104*	-.141**	.296**
	Sig. (2-tailed)	.108	.650	.066	.011	.035	.186	.000		.000	.032	.004	.000
	N	432	426	410	412	428	430	425	432.00	426	425	422	421
Total_ Burden	Pearson Correlation	.287**	-.193**	.137**	.072	-.100*	-.269**	.718**	-.297**	1.000	.584**	.614**	-.647**
	Sig. (2-tailed)	.000	.000	.005	.143	.039	.000	.000	.000		.000	.000	.000
	N	431	425	409	413	426	429	425	426	431.00	426	424	424
Total_ Depress	Pearson Correlation	.119*	.065	-.073	.249**	-.161**	-.429**	.412**	-.104*	.584**	1.000	.626**	-.665**
	Sig. (2-tailed)	.013	.181	.139	.000	.001	.000	.000	.032	.000		.000	.000
	N	432	425	410	410	428	430	426	425	426	432.00	429	422
Total_ Anxiety	Pearson Correlation	.312**	-.033	.031	.052	-.046	-.335**	.468**	-.141**	.614**	.626**	1.000	-.612**
	Sig. (2-tailed)	.000	.504	.539	.294	.340	.000	.000	.004	.000	.000		.000
	N	429	422	407	409	425	427	423	422	424	429	429.00	420
Total_ EnvMast	Pearson Correlation	-.237**	.088	-.112*	-.084	.183**	.402**	-.472**	.296**	-.647**	-.665**	-.612**	1.000
	Sig. (2-tailed)	.000	.074	.025	.092	.000	.000	.000	.000	.000	.000	.000	
	N	425	419	404	406	421	424	420	421	424	422	420	425.000

Correlations

		Gender	Age	relationship to PWD	hours of care	Religiosity	Health rating	Total_ pre_RQ	Total_ Curr_RQ	Total_ In_Motiv	Total_ Ex_Motiv	Total_ Meaning
Gender	Pearson Correlation	1.000	-.256**	.179**	-.155**	.101*	.000	-.179**	-.244**	-.067	-.032	-.087
	Sig. (2-tailed)		.000	.000	.001	.033	.987	.000	.000	.167	.506	.072
	N	447.000	440	425	420	442	443	443	437	433	435	431
Age	Pearson Correlation	-.256**	1.000	-.696**	.223**	.076	-.179**	.143**	.076	.103*	.100*	.079
	Sig. (2-tailed)	.000		.000	.000	.115	.000	.003	.113	.034	.039	.105
	N	440	440.000	420	416	435	436	436	430	426	429	426
relationship to PWD	Pearson Correlation	.179**	-.696**	1.000	-.413**	-.066	.104*	-.282**	-.083	-.118*	-.171**	-.171**
	Sig. (2-tailed)	.000	.000		.000	.180	.032	.000	.089	.017	.000	.001
	N	425	420	425.000	400	420	421	423	416	412	414	409
hours of care	Pearson Correlation	-.155**	.223**	-.413**	1.000	.014	-.168**	.226**	.041	.166**	.020	.113*
	Sig. (2-tailed)	.001	.000	.000		.779	.001	.000	.412	.001	.690	.022
	N	420	416	400	420.000	415	416	417	412	413	413	413
Religiosity	Pearson Correlation	.101*	.076	-.066	.014	1.000	.135**	.084	.084	.132**	.109*	.232**
	Sig. (2-tailed)	.033	.115	.180	.779		.004	.078	.080	.006	.023	.000
	N	442	435	420	415	442.000	440	438	432	428	430	426
Health rating	Pearson Correlation	.000	-.179**	.104*	-.168**	.135**	1.000	.068	.127**	-.076	-.081	.103*
	Sig. (2-tailed)	.987	.000	.032	.001	.004		.155	.008	.117	.091	.034
	N	443	436	421	416	440	443.000	440	434	430	431	429
Total_pre_RQ	Pearson Correlation	-.179**	.143**	-.282**	.226**	.084	.068	1.000	.491**	.372**	.087	.291**
	Sig. (2-tailed)	.000	.003	.000	.000	.078	.155		.000	.000	.072	.000
	N	443	436	423	417	438	440	443.000	436	432	432	429
Total_Curr_RQ	Pearson Correlation	-.244**	.076	-.083	.041	.084	.127**	.491**	1.000	.234**	-.026	.246**
	Sig. (2-tailed)	.000	.113	.089	.412	.080	.008	.000		.000	.599	.000
	N	437	430	416	412	432	434	436	437.000	428	428	424
Total_In_Motiv	Pearson Correlation	-.067	.103*	-.118*	.166**	.132**	-.076	.372**	.234**	1.000	.435**	.448**
	Sig. (2-tailed)	.167	.034	.017	.001	.006	.117	.000	.000		.000	.000
	N	433	426	412	413	428	430	432	428	433.000	427	425
Total_Ex_Motiv	Pearson Correlation	-.032	.100*	-.171**	.020	.109*	-.081	.087	-.026	.435**	1.000	.244**
	Sig. (2-tailed)	.506	.039	.000	.690	.023	.091	.072	.599	.000		.000
	N	435	429	414	413	430	431	432	428	427	435.000	424
Total_Meaning	Pearson Correlation	-.087	.079	-.171**	.113*	.232**	.103*	.291**	.246**	.448**	.244**	1.000
	Sig. (2-tailed)	.072	.105	.001	.022	.000	.034	.000	.000	.000	.000	
	N	431	426	409	413	426	429	429	424	425	424	431.000

Correlations

		Total_ pre_RQ	Total_ Curr_RQ	Total_ In_Motiv	Total_ Ex_Motiv	Total_ Meaning	Total_ role_captiv	Total_ comp	Total_ Burden	Total_ Depress	Total_ Anxiety	Total_ EnvMast
Total_pre_RQ	Pearson Correlation	1.000	.491**	.372**	.087	.291**	-.343**	.160**	-.248**	-.107*	-.072	.228**
	Sig. (2-tailed)		.000	.000	.072	.000	.000	.001	.000	.026	.140	.000
	N	443.000	436	432	432	429	429	430	429	430	427	424
Total_Curr_RQ	Pearson Correlation	.491**	1.000	.234**	-.026	.246**	-.463**	.197**	-.420**	-.259**	-.253**	.279**
	Sig. (2-tailed)	.000		.000	.599	.000	.000	.000	.000	.000	.000	.000
	N	436	437.000	428	428	424	426	425	425	427	424	419
Total_In_Motiv	Pearson Correlation	.372**	.234**	1.000	.435**	.448**	-.230**	.385**	-.112*	.044	.063	.080
	Sig. (2-tailed)	.000	.000		.000	.000	.000	.000	.021	.372	.197	.105
	N	432	428	433.000	427	425	424	425	424	423	421	417
Total_Ex_Motiv	Pearson Correlation	.087	-.026	.435**	1.000	.244**	.083	.213**	.130**	.088	.154**	-.045
	Sig. (2-tailed)	.072	.599	.000		.000	.086	.000	.007	.070	.002	.359
	N	432	428	427	435.000	424	425	424	423	424	421	417
Total_Meaning	Pearson Correlation	.291**	.246**	.448**	.244**	1.000	-.361**	.459**	-.284**	-.175**	-.112*	.272**
	Sig. (2-tailed)	.000	.000	.000	.000		.000	.000	.000	.000	.021	.000
	N	429	424	425	424	431.000	424	425	426	422	420	420
Total_role_captiv	Pearson Correlation	-.343**	-.463**	-.230**	.083	-.361**	1.000	-.205**	.718**	.412**	.468**	-.472**
	Sig. (2-tailed)	.000	.000	.000	.086	.000		.000	.000	.000	.000	.000
	N	429	426	424	425	424	431.000	425	425	426	423	420
Total_comp	Pearson Correlation	.160**	.197**	.385**	.213**	.459**	-.205**	1.000	-.297**	-.104*	-.141**	.296**
	Sig. (2-tailed)	.001	.000	.000	.000	.000	.000		.000	.032	.004	.000
	N	430	425	425	424	425	425	432.000	426	425	422	421
Total_Burden	Pearson Correlation	-.248**	-.420**	-.112*	.130**	-.284**	.718**	-.297**	1.000	.584**	.614**	-.647**
	Sig. (2-tailed)	.000	.000	.021	.007	.000	.000	.000		.000	.000	.000
	N	429	425	424	423	426	425	426	431.000	426	424	424
Total_Depress	Pearson Correlation	-.107*	-.259**	.044	.088	-.175**	.412**	-.104*	.584**	1.000	.626**	-.665**
	Sig. (2-tailed)	.026	.000	.372	.070	.000	.000	.032	.000		.000	.000
	N	430	427	423	424	422	426	425	426	432.000	429	422
Total_Anxiety	Pearson Correlation	-.072	-.253**	.063	.154**	-.112*	.468**	-.141**	.614**	.626**	1.000	-.612**
	Sig. (2-tailed)	.140	.000	.197	.002	.021	.000	.004	.000	.000		.000
	N	427	424	421	421	420	423	422	424	429	429.000	420
Total_EnvMast	Pearson Correlation	.228**	.279**	.080	-.045	.272**	-.472**	.296**	-.647**	-.665**	-.612**	1.000
	Sig. (2-tailed)	.000	.000	.105	.359	.000	.000	.000	.000	.000	.000	
	N	424	419	417	417	420	420	421	424	422	420	425.000

Appendix D.2: Hierarchical regressions

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.489[a]	.239	.231	3.444	.239	31.016	4	395	.000
2	.545[b]	.297	.280	3.332	.058	6.376	5	390	.000

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_Depress

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	9.389	.664		14.131	.000	8.083	10.695			
	Gender	1.222	.374	.147	3.270	.001	.487	1.956	.119	.162	.144
	relationship to PWD	.280	.423	.032	.662	.509	-.552	1.111	-.073	.033	.029
	Health rating	-1.477	.167	-.395	-8.866	.000	-1.805	-1.150	-.429	-.407	-.389
	hours of care	1.795	.401	.219	4.473	.000	1.006	2.584	.249	.220	.196
2	(Constant)	12.600	1.480		8.513	.000	9.690	15.510			
	Gender	838	.372	.101	2.254	.025	.107	1.570	.119	.113	.096
	relationship to PWD	.101	.428	.012	.237	.813	-.740	.943	-.073	.012	.010
	Health rating	-1.277	.166	-.342	-7.706	.000	-1.603	-.951	-.429	-.364	-.327
	hours of care	1.864	.397	.227	4.691	.000	1.083	2.645	.249	.231	.199
	Total_Curr_RQ	-.128	.039	-.167	-3.287	.001	-.205	-.052	-.259	-.164	-.140
	Total_pre_RQ	-.213	.566	-.020	-.377	.707	-1.326	.900	-.107	-.019	-.016
	Total_Meaning	-.082	.026	-.158	-3.211	.001	-.132	-.032	-.175	-.161	-.136
	Total_In_Motiv	882	.621	.078	1.422	.156	-.338	2.102	.044	.072	.060
	Total_Ex_Motiv	.747	.576	.063	1.296	.196	-.386	1.879	.088	.065	.055

a. Dependent Variable: Total_Depress

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.460^{a}	.212	.204	3.838	.212	26.577	4	395	.000
2	.512^{b}	.262	.245	3.738	.050	5.291	5	390	.000

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD
b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_Anxiety

COefficients^{a}

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	10.090	.740		13.627	.000	8.634	11.546			
	Gender	2.876	.416	.315	6.906	.000	2.057	3.694	.312	.328	.308
	Relationship to PWD	.313	.471	.033	.664	.507	-.614	1.239	.031	.033	.030
	Health rating	-1.342	.186	-.328	-7.227	.000	-1.707	-.977	-.335	-.342	-.323
	hours of care	.532	.447	.059	1.189	.235	-.347	1.411	.052	.060	.053
2	(Constant)	9.090	1.660		5.475	.000	5.826	12.354			
	Gender	2.588	.417	.283	6.203	.000	1.768	3.408	.312	.300	.270
	relationship to PWD	543	.480	.057	1.132	.259	-.401	1.487	.031	.057	.049
	Health rating	-1.188	.186	-.290	-6.390	.000	-1.554	-.822	-.335	-.308	-.278
	hours of care	.528	.446	.059	1.185	.237	-.348	1.404	.052	.060	.052
	Total_Curr_RQ	-.142	.044	-.170	-3.253	.001	-.228	-.056	-.253	-.163	-.142
	Total_pre_RQ	.950	.635	.082	1.497	.135	-.298	2.199	-.072	.076	.065
	Total_Meaning	-.052	.029	-.092	-1.818	.070	-.109	.004	-.112	-.092	-.079
	Total_In_Motiv	576	.696	.047	.828	.408	-.792	1.945	.063	.042	.036
	Total_Ex_Motiv	1.795	646	.139	2.778	.006	.525	3.065	.154	.139	.121

a. Dependent Variable: Total_Anxiety

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	430[a]	.185	.176	7.787	.185	22.377	4	395	.000
2	.592[b]	.351	.336	6.994	.166	19.933	5	390	.000

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_Burden

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	22.345	1.502		14.872	.000	19.391	25.299			
	Gender	5.064	.845	.278	5.993	.000	3.403	6.725	.287	.289	.272
	relationship to PWD	3.299	.956	.174	3.450	.001	1.419	5.179	.137	.171	.157
	Health rating	-2.147	.377	-.263	-5.699	.000	-2.888	-1.407	-.269	-.276	-.259
	hours of care	2.560	.908	.143	2.821	.005	.776	4.345	.072	.141	.128
2	(Constant)	32.275	3.107		10.388	.000	26.167	38.383			
	Gender	3.726	.781	.205	4.772	.000	2.191	5.261	.287	.235	.195
	relationship to PWD	3.221	.898	.170	3.586	.000	1.455	4.987	.137	.179	.146
	Health rating	-1.546	.348	-.189	-4.445	.000	-2.230	-.862	-.269	-.220	-.181
	hours of care	3.241	.834	.181	3.887	.000	1.602	4.881	.072	.193	.159
	Total_Curr_RQ	-.457	.082	-.273	-5.582	.000	-.618	-.296	-.420	-.272	-.228
	Total_pre_RQ	141	1.188	.006	.118	.906	-2.195	2.476	-.248	.006	.005
	Total_Meaning	-.221	.054	-.195	-4.124	.000	-.327	-.116	-.284	-.204	-.168
	Total_In_Motiv	-1.670	1.303	-.068	-1.282	.201	-4.231	.891	-.112	-.065	-.052
	Total_Ex_Motiv	5.581	1.209	.217	4.616	.000	3.203	7.958	.130	.228	.188

a. Dependent Variable: Total_Burden

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	348[a]	.121	.113	.54174	.121	13.649	4	395	.000
2	605[b]	.366	.352	.46306	.245	30.130	5	390	.000

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_role_captiv

Coefficientsa

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	2.632	.105		25.183	.000	2.427	2.838			
	Gender	312	.059	.256	5.306	.000	.196	.427	.270	.258	.250
	relationship to PWD	202	.067	.158	3.031	.003	.071	.332	.150	.151	.143
	Health rating	-.091	.026	-.167	-3.480	.001	-.143	-.040	-.165	-.172	-.164
	hours of care	.106	.063	.088	1.676	.095	-.018	.230	.011	.084	.079
2	(Constant)	3.809	.206		18.519	.000	3.405	4.214			
	Gender	204	.052	.167	3.950	.000	.103	.306	.270	.196	.159
	relationship to PWD	163	.059	.128	2.736	.007	.046	.280	.150	.137	.110
	Health rating	-.045	.023	-.081	-1.934	.054	-.090	.001	-.165	-.097	-.078
	hours of care	177	.055	.147	3.203	.001	.068	.285	.011	.160	.129
	Total_Curr_RQ	-.031	.005	-.279	-5.775	.000	-.042	-.021	-.463	-.281	-.233
	Total_pre_RQ	-.106	.079	-.069	-1.347	.179	-.261	.049	-.343	-.068	-.054
	Total_Meaning	-.018	.004	-.238	-5.097	.000	-.025	-.011	-.361	-.250	-.205
	Total_In_Motiv	-.215	.086	-.130	-2.489	.013	-.384	-.045	-.230	-.125	-.100
	Total_Ex_Motiv	.370	.080	.214	4.626	.000	.213	.528	.083	.228	.186

a. Dependent Variable: Total_role_captiv

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.492[a]	.242	.234	4.533	.242	31.483	4	395	.000
2	.557[b]	.310	.294	4.351	.069	7.763	5	390	.000

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_EnvMast

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	28.194	.875		32.235	.000	26.474	29.913			
	Gender	-2.484	.492	-.226	-5.050	.000	-3.451	-1.517	-.237	-.246	-.221
	relationship to PWD	-1.854	.557	-.162	-3.330	.001	-2.948	-.759	-.112	-.165	-.146
	Health rating	1.965	.219	.399	8.960	.000	1.534	2.396	.402	.411	.393
	hours of care	-1.281	.528	-.118	-2.425	.016	-2.320	-.242	-.084	-.121	-.106
2	(Constant)	21.952	1.933		11.359	.000	18.153	25.752			
	Gender	-2.039	.486	-.185	-4.197	.000	-2.994	-1.084	-.237	-.208	-.176
	relationship to PWD	-1.512	.559	-.132	-2.706	.007	-2.610	-.413	-.112	-.136	-.114
	Health rating	1.709	.216	.347	7.899	.000	1.284	2.135	.402	.371	.332
	hours of care	-1.614	.519	-.149	-3.111	.002	-2.634	-.594	-.084	-.156	-.131
	Total_Curr_RQ	.102	.051	.101	1.992	.047	.001	.202	.279	.100	.084
	Total_pre_RQ	.941	.739	.068	1.273	.204	-.512	2.394	.228	.064	.054
	Total_Meaning	.129	.033	.188	3.854	.000	.063	.194	.272	.192	.162
	Total_In_Motiv	.175	.810	.012	.216	.829	-1.418	1.768	.080	.011	.009
	Total_Ex_Motiv	-1.504	.752	-.097	-1.999	.046	-2.982	-.025	-.045	-.101	-.084

a. Dependent Variable: Total_EnvMast

Model Summary^{c}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	$.167^{a}$	.028	.018	.53093	.028	2.821	4	395	.025	
2	$.516^{b}$	.267	.250	.46408	.239	25.397	5	390	.000	1.921

a. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Gender, Health rating, relationship to PWD, Total_In_Motiv, Total_Curr_RQ, Total_Ex_Motiv, Total_Meaning, Total_pre_RQ

c. Dependent Variable: Total_comp

Coefficients^{a}

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B		Correlations		
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	2.058	.102		20.095	.000	1.857	2.260			
	Gender	-.059	.058	-.052	-1.023	.307	-.172	.054	-.077	-.051	-.051
	Relationship to PWD	-.052	.065	-.044	-.798	.425	-.180	.076	-.091	-.040	-.040
	Health rating	.045	.026	.088	1.737	.083	-.006	.095	.064	.087	.086
	hours of care	.127	.062	.114	2.055	.041	.005	.249	.125	.103	.102
2	(Constant)	.371	.206		1.799	.073	-.034	.776			
	Gender	-.017	.052	-.015	-.319	.750	-.118	.085	-.077	-.016	-.014
	Relationship to PWD	.016	.060	.014	.270	.788	-.101	.133	-.091	.014	.012
	Health rating	.028	.023	.055	1.218	.224	-.017	.074	.064	.062	.053
	hours of care	.089	.055	.080	1.612	.108	-.020	.198	.125	.081	.070
	Total_Curr_RQ	.010	.005	.098	1.877	.061	.000	.021	.197	.095	.081
	Total_pre_RQ	-.130	.079	-.090	-1.651	.099	-.285	.025	.160	-.083	-.072
	Total_Meaning	.024	.004	.339	6.746	.000	.017	.031	.459	.323	.293
	Total_In_Motiv	.326	.086	.211	3.769	.000	.156	.496	.385	.187	.163
	Total_Ex_Motiv	.086	.080	.054	1.074	.283	-.072	.244	.213	.054	.047

a. Dependent Variable: Total_comp

Model Summary^{d}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	$.310^{a}$	.096	.084	7.242	.096	8.355	5	394	.000
2	$.566^{b}$	.321	.308	6.294	.225	64.829	2	392	.000
3	$.620^{c}$	.385	.367	6.021	.064	10.096	4	388	.000

a. Predictors: (Constant), hours of care, Religiosity, Gender, Health rating, relationship to PWD

b. Predictors: (Constant), hours of care, Religiosity, Gender, Health rating, relationship to PWD, Total_comp, Total_role_captiv

c. Predictors: (Constant), hours of care, Religiosity, Gender, Health rating, relationship to PWD, Total_comp, Total_role_captiv, Total_Ex_Motiv, Total_pre_RQ, Total_Curr_RQ, Total_In_Motiv

d. Dependent Variable: Total_Meaning

		Unstandardized Coefficients		Standardized Coefficients			95% Confidence Interval for B		Correlations		
Model		B	Std. Error	Beta	T	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	37.950	1.628		23.316	.000	34.750	41.149			
	Gender	-1.228	.792	-.076	-1.551	.122	-2.784	.329	-.087	-.078	-.074
	relationship to PWD	-2.136	.893	-.128	-2.393	.017	-3.891	-.381	-.171	-.120	-.115
	Religiosity	1.890	.424	.218	4.459	.000	1.056	2.723	.232	.219	.214
	Health rating	.696	.354	.097	1.966	.050	.000	1.393	.103	.099	.094
	hours of care	.970	.844	.061	1.149	.251	-.690	2.630	.113	.058	.055
2	(Constant)	36.867	2.617		14.090	.000	31.723	42.012			
	Gender	.256	.715	.016	.358	.721	-1.149	1.661	-.087	.018	.015
	relationship to PWD	-1.285	.784	-.077	-1.639	.102	-2.825	.256	-.171	-.083	-.068
	Religiosity	1.338	.372	.154	3.598	.000	.607	2.068	.232	.179	.150
	Health rating	.221	.312	.031	.708	.480	-.393	.834	.103	.036	.029
	hours of care	.664	.742	.042	.895	.371	-.794	2.122	.113	.045	.037
	Total_comp	5.337	.609	.378	8.769	.000	4.141	6.534	.459	.405	.365
	Total_role_captiv	-3.350	.598	-.255	-5.603	.000	-4.525	-2.174	-.361	-.272	-.233
3	(Constant)	25.765	3.452		7.463	.000	18.978	32.553			
	Gender	.321	.693	.020	.463	.644	-1.041	1.683	-.087	.023	.018
	relationship to PWD	-.826	.780	-.049	-1.059	.290	-2.360	.708	-.171	-.054	-.042
	Religiosity	1.071	.359	.123	2.984	.003	.365	1.776	.232	.150	.119
	Health rating	.434	.303	.060	1.433	.153	-.161	1.030	.103	.073	.057
	hours of care	.336	.730	.021	.460	.646	-1.099	1.770	.113	.023	.018
	Total_comp	4.007	.625	.284	6.411	.000	2.778	5.235	.459	.309	.255
	Total_role_captiv	-2.881	.643	-.219	-4.482	.000	-4.144	-1.617	-.361	-.222	-.178
	Total_In_Motiv	4.586	1.126	.211	4.073	.000	2.372	6.800	.448	.202	.162
	Total_Ex_Motiv	2.013	1.068	.089	1.885	.060	-.087	4.113	.244	.095	.075
	Total_pre_RQ	1.158	1.027	.057	1.127	.260	-.862	3.178	.291	.057	.045
	Total_Curr_RQ	-.007	.074	-.004	-.090	.928	-.152	.138	.246	-.005	-.004

a. Dependent Variable: Total_Meaning