FACTORS AFFECTING CAREGIVER OUTCOMES

A thesis

submitted in fulfilment

of the requirements for the degree

of

Master of Social Science in Psychology

at

The University of Waikato

by

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The University of Waikato

2008

Abstract

Research in the area of caregiving has tended to focus on the impact of the caregiving experience itself without consideration of continued psychological distress for caregivers after institutionalisation or death. Seven caregivers of loved ones with Alzheimer's Dementia (mostly spousal) were interviewed about their experiences of caregiving and their emotional well-being after placement of their loved one into a residential care facility or death. The nature of the carers relationship with their loved one (e.g. highly dependent), lack of social supports, inactivity and a poor experience of transition into care seemed to be factors relating to poorer outcomes for these caregivers. Utilisation of social supports, involvement in pleasant events, adequate preparation and information relating to the disease and collaboratively planned transition into care played protective roles for the remaining carers who reported decreased levels of anxiety, guilt, depression and stress post-institutionalisation/death. The implications of the current research for practise, policy change and prevention are extensive and suggest that risk factors may be identifiable and thus poorer mental health outcomes in caregivers preventable. A need for greater support to be made available to caregivers is necessary.

ACKNOWLEDGEMENTS

During this research project I have received help and support from many people whom I would like to acknowledge and thank. Many thanks to my supervisor, Nicola Starkey who has been a great help and support, and my second supervisor, Darrin Hodgetts for his direction. You have been very supportive, and your guidance and patience has been much appreciated. To the support staff and managers at the Alzheimer’s Waikato Foundation and Raeburn Resthome, thank you so much for your input during the recruitment process.

A big thankyou to my boyfriend Noddy, friends and family for taking an interest and encouraging me… not to mention having to listen to me whinge for the past 12 months! I’m sure you are as glad that this is over as I am! A special thankyou to my Grandma, Joan Eyers who was diagnosed with Alzheimer’s Dementia some years ago. You were the inspiration for this research and I won’t stop here.

Finally, thanks to all of the carers of people with Alzheimer’s Dementia that participated in this study who gave up their valuable time to assist me during such an emotionally difficult time in their lives. This study is for future generations of yourselves in the hope of improving the situation faced by all carers of people with AD.

CONTENTS

Abstract ii

Acknowledgements iii

Contents iv

Introduction 1

Alzheimer’s Disease 2
The Caregiving Experience 4
Placement in Long-Term-Care 8
Grief Processes in Dementia Caregiving 14
Factors Affecting Caregiver Outcome 18
Supporting Caregivers 25
Current Research 26

Method 28

Participants 28
Materials 28
Procedure 30
Analysis 31

Results 33

Caregiver Outcomes 34

Shared Experiences of Caregivers after Institutionalisation/Death 36

Themes and Variations Present Within the Poor Outcome Group 38

Themes and Variations Present Within the Good Outcome Group 44

Additional Themes to Emerge From the Discourse 56

-Social and Familial Support 56

-Remaining Involved in Activities and Hobbies 60

-Loss of Relationship 61

Discussion 63

Limitations of the Current Research 74

Implications of the Current Research 77

Suggestions for Future Research 78

Conclusion 80

References 82

Appendix: Information Sheet for Participants 87

Introduction

Recently there has been a shift towards undertaking research that involves caregivers of people with the degenerative disease Alzheimer’s Dementia in the areas of caregiver stress and well-being. Most current literature in this field has focussed on the stress and well-being of a carer during their caregiving experience. Spousal carers, family members and close friends are amongst those caregivers of people with dementia who are taking part in research.

Due to the demographic shift resulting from improvements in health care of the late 20th century, more people are surviving to ages when rates of AD increase. As a result, increasing numbers of elderly require some assistance to manage activities of daily living.

This research will review the current literature in relation to caregiving for a loved one with AD as a means of identifying areas that are in need of more research. Firstly, an overview of the characteristics of AD and its progression will be offered as a means of understanding the role and obligations of the carer of a person with AD. The caregiving process will then be explored in detail, particularly in relation to the emotional and psychological experiences of caregivers of people with AD. Research in this area has at some stages been contradictory, however most researchers report one common theme. That is, that carer’s experiences, at varying stages of the caregiving career, include heightened stress and emotional discomfort. What needs to be clarified however is what factors present within the caregiving experience may be reflective of detrimental long-term outcomes. In obtaining this information, factors that may protect a caregiver against detrimental outcomes will become evident. Also, research in the field of caregiving for relatives with a dementing illness has mainly focussed on the caregiving experience itself, to the neglect of the consequences to the carer when caregiving is terminated either by death or placement into a nursing home.

Alzheimer's Disease.

AD is the most common form of dementia and is more common in women (Nebes, 1992). Initially, difficulty in concentration and in remembering newly learned materials are apparent (Nebes, 1992). Memory deteriorates as the disease progresses and the person may experience delusional thinking as they become increasingly disorientated and irritable (Nebes, 1992).

Research highlights that AD is a degenerative condition that results in a global cognitive impairment involving pre-clinical deficits in episodic memory, executive functioning, verbal memory, attention, visuo-spatial skill, and perceptual speed (Backman, Jones, Berger, Laukka & Small, 2005). With the onset of the disease, deficits in psychomotor speed, memory and intelligence become more evident (Morris, 1996, Nebes, 1992). Such deficits are preceded by physiological changes in the brain, particularly, the deterioration of areas of the cerebral cortex (Nebes, 1992). Research has demonstrated that episodic memory performance (that is, memory relating to personal, factual information) is the first indicator of cognitive dysfunction related to dementia (Grady, 1988). Other deficits at this early stage of AD may include consistent forgetfulness, partial recollection of events, slight impairment in solving problems, in community activities such as shopping, and in home and leisure activities (Morris, 1996). As the disease progresses to the mild stage, moderate memory loss, geographic disorientation, difficulty with time, moderate difficulty in handling problems, inability to function independently in community activities, and a mild but definite impairment of function at home which results in the need for prompting by a carer, are characteristic (Morris, 1996). Moderate AD is characterised by severe memory loss, severe difficulty with time and orientation, severe impairment in handling problems, appearing well enough to be accompanied to functions outside of the home by a carer, preservation of only simple chores, and requiring assistance in dressing and hygiene (Morris, 1996). During the final stages of the disease AD sufferers experience severely fragmented memory, inability to make judgements or solve problems, they appear too ill to be taken to events outside of the family home, have no significant function within the home, are frequently incontinent, and require consistent and extensive help with personal care (Morris, 1996).

Despite this, the rate of decline tends to vary between individuals. For example, in a large-scale study of Alzheimer’s patients it was found that in some instances AD is characterised by a tri-linear pattern of change (Brooks, Kraemer, Tanke & Yesavage, 1993). That is, AD is characterised by an initial period of stability, followed by a period of detectable cognitive decline in the aforementioned areas before returning to a final period of relative stability preceding death (Brooks et al., 1993). Also, depending on co-morbid illnesses and proneness to stroke, other individuals may decline in a different manner. The duration of the disease varies considerably depending on individual variables such as these and can range from as little as three years post-onset to in excess of twenty years until death.

The Caregiving Experience

As AD progresses, significant disturbances in the affected person’s ability to perform daily functions occurs. As a result, the affected person becomes dependent on the help of others. This need is often embraced by relatives or close friends of the person. This section will discuss the caregiving process in relation to the demands on the caregiver’s time by identifying what caregiving for a person with AD involves.

As mentioned earlier, the aging population places greater demands on family members, spouses and professional caregiving services. Zarit, Johannson and Berg (1993) suggested that by age 85, 60% of the population require some form of regular, ongoing assistance due to some degree of disability. With AD being most predominant in people over the age of 75, there is a distinct possibility that extended care will be needed as in over half of cases, people with this diagnosis will be alive at least a decade after onset (Zarit, Davey, Edwards, Femia & Jarrott, 1998). It is for this reason that Zarit et al. (1998) refer to the caregiving experience as a ‘career’.

Much research tends to study caregiving as it occurs during one point in time, to the neglect of what has preceded their current experiences and what is yet to come. This limitation must be taken into account when considering the caregiving career. The caregiving career involves a number of transitions to which the carer must adapt alongside the progression of AD. As the disease progresses, the person requires increasing amounts of support in order to function as effectively as possible in daily life. The caregiver may find themselves increasing the amount of time spent with this person in order to achieve this.

In a small-sampled qualitative study of caregivers, Pearlin (1993) suggested three distinct phases in a caregiver’s career. The time during which carer’s recognise the growing disability in their loved one and assume the caregiving role is considered by Pearlin (1993) to be the first phase. The second phase is characterised by role acquisition during which the caregiver provides assistance of a regular and ongoing nature (Pearlin, 1993). Although limited research involving small participant samples has been conducted in the area, it is generally agreed that caregivers remain in their role and continue to provide care well after the person has been institutionalised (Zarit et al., 1998). It is therefore pertinent to consider the second phase as one in which there are various demands and challenges that a carer may face. The third phase is what Pearlin (1993) describes as disengagement. That is, the termination of the caregiving career as marked by death. Although this transition may mark decreased physical burden for the caregiver, other important psychological factors around grief remain. These increased emotional and psychological impacts of the caregiving experience continue to affect the carer and these phenomena will be discussed in detail in a later section. Typically, during the second phase of the disease caregiver stress is heightened.

Caregiving has typically been viewed in relation to stress theory (Zarit et al., 1998). Aneshensel, Pearlin, Mullan, Zarit & Witlach (1995) propose the stress-process model of caregiving which involves primary and secondary stressors.

Primary stressors arise directly from the needs of the patient (Aneshensel et al., 1995). That is, these stressors can be considered to be the actual caregiving tasks that are carried out, for example, assistance with tasks of daily living such as preparing meals and assistance with bathing. Zarit et al. (1998) consider secondary stressors to have evolved out of primary stressors. Zarit et al. (1998, p.502) describe that "they represent the way in which primary stressors encroach upon and disrupt other areas of the caregivers life, and thus are more variable and individual in their manifestation". Secondary stressors include family conflict, work conflict and financial strain. Secondary stressors also involve psychological dimensions such as feeling a sense of loss for self, diminished self-esteem and emersion in the caregiving role. Consideration of secondary stressors as they relate to carer well-being after their experience has been terminated is also essential. Consideration of this theory as a framework only is essential also because secondary stressors vary so greatly between individuals. In linking stress theory in relation to caregiving, inclusion of specific family contexts is necessary. The roles and functions performed by the carer and care recipient within the family, as well as the quality of this relationship, are important factors to take into consideration (Meuser & Marwit, 2001). Such factors will be explored in detail later.

A variety of negative physical and mental health outcomes have been associated with providing long-term care and are often referred to in the literature as 'caregiver stress' or 'caregiver burden'. Compared to non-caregiving samples using clinically and scientifically sound research designs, carers have been found to report increased physical and emotional distress (Anthony-Bergstone, Zarit &

Gatz, 1988; Robertson, Zarit, Duncan, Rovine & Femia, 2007). In particular, increased feelings of anger, hostility and anxiety symptoms have been found among caregivers of people with AD as compared to the general population, as have increased levels of depression (Zarit et al., 1998). Gallagher, Rose, Rivera, Lovell and Thompson (1989) found depression prevalence rates ranging from 31% for male caregivers to 46% for women caregivers. A vast range of empirically supported diagnostic instruments were used in determining depression prevalence in caregivers across studies however and this may account for varying rates. More recent statistics were unable to be located. Prevalence rates of depression among the general population has ranged from 5.2% to 17.1% in a large scale study of Americans and is two to three times more common in women than in men (Weissman, Bland, Canino, Faravelli, & Greenwald, 1996). Proportionally, it could be assumed therefore that depression among caregivers is much more prevalent than within the general population and that more male caregivers are affected by depression than in the general population. Information regarding depressive symptomology and the disease of the care recipient would have been of benefit in this study. Some research suggests that carers of people with AD are more likely to develop depressive symptomology due to the impact of memory loss on the relationship between caregiver and care recipient (Meuser & Marwit, 2001). This study did not however identify the role that the relationship structure and history may have played in determining well-being.

Carers also display self-reports which are reflective of burden, guilt and inadequacy compared to the general population (Zarit et al., 1998). Care must be taken in interpreting self-reported variables due to the effect of individual perception. As an outcome of such stress caregivers are more likely to develop physical health ailments such as elevated blood pressure and decreased immunity (Zarit et al., 1998). The intensity of these primary and secondary stressors is reflective of detrimental carer outcomes. Increased responsibility for the care recipient may also result in decreased self-care and health behaviour; however research in this area is inconclusive due to small sample sizes (Lieberman & Fisher, 1995).

Although the negative outcomes of caregiving have received substantial research attention, what aspects present within the caregiving career that may lead to these outcomes are unclear. Consideration of the positive aspects of caregiving such as satisfaction, a sense of competency and feeling needed, should be made in relation to the effects on caregiver outcome (Zarit et al., 1998). Another factor that may influence a carer's sense of well-being is the decision and process of placing a loved one into a residential home. Research suggests that this process elicits various responses in caregivers (Daff, Stepien, Wundke, Paterson, Whithead & Crotty, 2006). The importance of this transitional experience during the caregiving career should be considered in relation to the changing expectations and new challenges caregivers experience.

Placement in Long-Term-Care

Researchers have only recently begun to extensively consider the experiences of carers in making the decision to place a loved one into long-term care. Zarit, Anthony and Boutselis (1987) reported that caregivers placing a loved one into a residential care home experience feelings of relief from the emotional and physical stressors of caregiving. More recent research however reflects that this is not a unitary response for many caregivers (Zarit & Witlach, 1992). Contrary to this idealistic approach is that many carers continue to experience varying degrees of emotional distress even after the physical burden of caregiving decreases as a result of placing their loved one into residential care (Zarit & Witlach, 1992). To extend this idea further, consideration of this transitional period and the factors contributing to the decision is necessary. By identifying such factors a more comprehensive understanding of the range of experiences present within the caregiving career may be achieved. It may also be of benefit to consider this period of the caregiving career as it relates to the emotional outcome of the caregiver after placement or death in order to determine any correlational relationships. This link will be discussed in future sections.

Consideration of placement as a coping measure or stressor for the caregiver is pertinent. How this transition affects the care recipient is beyond the scope of this research, however discussion will be made of how this may relate to carer outcome.

In their qualitative study of the process of institutionalising a loved one, Dellasega and Mastrian (1995) found that making the decision involved a singular process for the caregiver that involved “I” (being the caregiver) rather than “we” (being both carer and care recipient). Most often for caregivers guilt and distress were the most predominant responses reported (Dellasega & Mastrian, 1995). This study utilised a very small sample of familial caregivers, however the qualitative approach encouraged flexibility, depth and exploration of various concepts and child, spouse and sibling caregivers were interviewed exhaustively. Zarit & Whitlach (1992) consider the involvement of caregivers in caregiving roles after this transition to remain in varying manifestations. For example, utilising interview and psychometric data collection methods with over 400 participants, carers reported to often visit their relative in the care facility, provide assistance at the care facility in activities of daily living, ensure the care recipients needs are met by interacting with staff, continue to handle the care recipients ‘paperwork’ such as finances and insurance, and provide finance to the care facility itself (Zarit & Witlach, 1992). Therefore instead of giving up the caregiving role, the caregiver’s duties are transformed. Although caregivers time pressures and physical burdens may be alleviated it should be concluded that they continue to experience various challenges. From this perspective it is suggested that;

> ...the consequences of placement will depend on how institutionalisation changes the carer’s situation. To the extent caregivers remain involved with their relative, they will continue to have other responsibilities and concerns, such as the quality of care in the institutional setting, the well-being of their relative, their own feelings of obligation to their relative, and the financial costs of care (Zarit & Witlach, 1992, p.665).

Dellasega and Mastrian (1995) consider placement as a coping strategy because it balances the care needs of the elder and the caregiver’s resources of time, motivation and money. Although Zarit & Witlach (1992) identify with this argument, the effects of placement on caregivers’ well-being are more complicated. The process by which a carer makes the decision to place a loved one into residential care needs consideration as research suggests that it relates to how the caregiver will respond to the transition. For example, in a study of the factors affecting the decision to place a loved one with dementia into a residential care facility, Armstrong (2000) suggested several distinct themes derived from qualitative interviews with a very small sample of caregivers. It was reported by carers that the ultimate reason why caregivers consider placement is related to the challenges of caring for a demented person, including aspects of the experience such as incontinence and physical dependency (Armstrong, 2000). Other themes included the physical and psychological well-being of the carer, support from family and friends, formal help, and the personal needs of caregivers such as personal space, and thirst for knowledge and information (Armstrong, 2000). These results should be interpreted carefully however because the sample size was so small. Dellasega and Mastrian (1995) consider the effects of this process as being related to how caregivers perceive themselves in relation to their loved one and the expectations that are placed on them as a result of this relationship. It is suggested that the pressure to be the "ideal caregiver" becomes increasingly difficult to handle as the needs of the care recipient increase (Dellasega & Mastrian, 1995). Thus, as a result of placement carers may therefore feel that they have not successfully delivered what is expected of them, resulting in feelings of guilt and distress (Dellasega & Mastrian, 1995). At this stage, this conclusion is not grounded in evidence and should be considered a hypothetical possibility.

In considering the continued emotional distress of caregivers it is necessary and productive to consider what factors may contribute to detrimental outcomes, and therefore what factors may protect a caregiver against this. Daff et al., (2006) in their research extended ideas from a previous quantitative randomised-controlled large scale study of caregivers in order to attempt to derive a better understanding of the subjective human experience of caregivers and their experiences. The experience of initially finding a permanent care facility for their loved one was reported by carers to be stressful, confusing and time consuming (Daff et al., 2006). In this study, over 75% of a small sample of participants emphasised this process as being a continuous battle to balance the input of the health care team with the needs and preferences of the elder (Daff et al., 2006). Caregivers in this study identified that they received minimal support with making an informed decision about selecting a facility despite this being considered a protective factor from increased stress (Daff et al., 2006; Armstrong, 2000). The great demand on care facilities and hospitals as a result of the increase in the aging population has lead to caregivers being rushed into decision making and accepting what ever was available at the time, regardless of whether it was considered appropriate for the care recipient and reflective of their wishes (Daff et al., 2006). In addition, Armstrong (2000) emphasised the carer's desire for knowledge and information about the decline progression of AD, as well as highlighting their desire for someone to listen to and understand their experiences. Day care services, that is, services that provide daily care one or more days a week for people with dementia, were reported by caregivers to be of particular assistance in making the transition into full-time care (Armstrong, 2000). Caregivers in this study also displayed a strong desire to ensure the well-being of the care recipient within residential services (Armstrong, 2000). Another theme to emerge involved the carer receiving adequate social support as a protective factor against detrimental outcomes (Armstrong, 2000). These findings should be considered as a starting point for further research only however due to the small participant sample. The implications for practise would be extensive and may include taking into account what the caregivers need as opposed to what practitioners may think they need.

Providing adequate education, counselling services for carers during this time period, and facilitating involvement in care within the institution may be beneficial and crucial starting points therefore, for enhancing carer well-being (Armstrong, 2000). In relation to ensuring the well-being of the care recipient, Dellasega and Mastrian (1995) identified the need to involve the care recipient in decision making while they maintain the mental capacity to do so, in order to minimise resentment, enhance cooperation and preserve the care recipient’s sense of control. Dellasega and Mastrian (1995) also emphasise that planning for future care needs before the time arises is beneficial in providing adequate preparation time to make the decision for both caregiver and care recipient. Experiences of the transition are positively enhanced if the caregiver can work in partnership with care staff as a means of easing the transition for the care recipient (Davies, 2004).

Having considered the factors that may be beneficial in promoting well-being for carers during this time, it is considered necessary now to provide more understanding of the outcomes of caregivers after placing a loved one into residential care as a means of understanding the complications many face during this time, and continue to face throughout bereavement.

Grief Processes in Dementia Caregiving

The argument that carer’s well-being may not be determined by the cessation of the full-time caregiving role was mentioned earlier. The nature and progression of decline in AD and other dementias present various challenges to the well-being of the caregiver. Consideration of how these challenges may affect the carer during, and after, the caregiving experience is essential.

Most research has focussed on the association between providing full-time care, stress and perceived burden. (Sanders & Adams, 2005). This research has tended to neglect the role of grief that is present during and after the caregiving experience. Mace and Rabins (1981, p.209), in relation to the grief experienced by caregivers, wrote:

> As the person’s illness progresses and the person changes, you may experience the loss of a companion and a relationship that was important to you. You may grieve the way she used to be. We usually think of grief as an emotional response to loss and so it is a normal experience for people who love a person with a chronic illness.

In differentiating this form of grief to that related to the actual death of a loved one, Mace and Rabins (1981, p.164) added that “grief associated with a death may be an overwhelming experience in the beginning, and gradually lessen. Grief associated with a chronic illness seems to go on and on”.

Sanders and Corley (2003) report that up to 68% of their small sample of predominantly spousal caregivers demonstrate feelings of grief and loss, and that these feelings are intensified when the care recipient no longer recognises the caregiver. This is important to consider because with AD this failure of recognition often occurs as early as the middle stages of the disease progression (Sanders & Adams, 2005). Therefore, for a number of years leading up to the care recipient’s death, the carer may experience feelings of anticipatory grief (that is, grief related to what will happen in the future). This finding is contradictory however to the results of Ponder and Pomerey’s (1996) study that identified a curvilinear grief course during the disease decline during which grief after the initial diagnosis is high, then declines throughout the mid section of caregiving, and increases again during the final stages of the disease and death. This could perhaps be better understood if grief was quantified during different stages of the disease trajectory in order to determine significant levels of grief at certain points in time. To further complicate the argument, it has also been found that grief is at its most intense during the final stages of the disease process (such as at the time of placement into a residential home) and after death of the care recipient (Rudd, Viney & Preston, 1999). These contradictory findings may be a product of ill-defined grief constructs and small participant samples.

Caregiver grief is characterised by loss of relationships, social interactions and support, previously established social roles, control, intimacy, health status and free time (Loos & Bowd, 1997, Sanders & Corley, 2003). Furthermore, the experience of grief among caregivers varies as a result of several factors (Sanders & Adams, 2005). For example, Gilliland and Fleming (1998) identified heightened despair, anger, loss of control and death anxiety to be characteristics of women’s anticipatory grief. Another example, identified by Meuser and Marwit (2001) suggests differences between grief experiences of adult children carers and spouse caregivers. These factors will be discussed in a later section.

Meuser and Marwit (2002) developed and validated an instrument to measure grief as it relates to caregivers of people with AD called the Meuser and Marwit Caregiver Grief Inventory (MM-CGI). In using this instrument, Meuser and Marwit (2002) identified a number of grief (such as sense of loss) and depression (feelings of hopelessness) reactions in caregivers that could be differentiated from each other. This instrument has provided the possibility to distinguish grief reactions from clinical depressive symptoms during and after caregiving experiences. The implications of such an instrument in practise include the possibility of identifying more specific factors and providing appropriate interventions for troubled carers (Meuser & Marwit, 2002). Future research however needs to examine further whether depression is the main precipitant to grief, or if grief is the predominant response to the losses experienced by caregivers of people with AD (Sanders & Adams, 2005).

Nonetheless, it is suggested that anticipatory grief is a real experience for caregivers and that adequately addressing grief earlier rather than later may positively correlate to carer well-being at death (Burton, Haley & Small, 2006). Interestingly, Gilhooly, Sweeting, Whittick, and McKee (1994) suggest that grief and loss during dementia progression may be more significant than grieving after the death of a loved one. This possibility and other factors present within the caregiving experience that may contribute positively or negatively to caregiver well-being will be identified and discussed in a later section. As mentioned previously, the relationship between the carer and recipient may alter outcomes in relation to caregiver well-being.

In considering well-being outcomes of caregivers it is crucial to determine the nature of the relationship between the carer and the care recipient as this may influence how a carer responds to increasing demands and grief. The theory of communal relationships posited by Clark and Mills (1993) suggests that communal relationships are characterised by behaviours on the part of the friend, spouse or close family member that directly respond to the other's needs. Williamson, Shaffer and Schulz (1998, p.153) suggest that

> in highly communal relationships, partners routinely are concerned about and attend to each other's needs as these needs arise. Less communal relationships are characterised by low levels of feelings of responsibility for the other's welfare and less responsiveness to one another's need.

Therefore it could be assumed that in the context of communal relationships, caregivers may be more inclined to experience more positive affect when helping their partners and poorer affect if the opportunity to help is unavailable. In contrast, those relationships that are not as communal in nature may influence the way in which care is provided and grief is experienced. For example, a carer may feel as though caregiving is more of an obligation rather than being primarily concerned for the well-being of the carer.

To extend this idea further it is worth considering what aspects of a caregivers experience may influence their well-being in relation to Self-Determination Theory (SDT) as suggested by Deci and Ryan (2000). SDT posits that humans achieve psychological well-being when three basic needs are satisfied which include autonomy (making decisions by oneself and behaving accordingly), competence (feeling as though one is capable in their pursuits), and relatedness (feeling connected to others) (Deci & Ryan, 2000). Patrick, Canevello, Knee and Lonsbary (2007) argue that these factors not only affect the well-being of an individual, but also their involvement and motivation in relationships. It could be concluded therefore that a carers perceived level of mastery in these three domains and their motivation in their relationship with the care recipient (i.e. being more communal in nature) could be factors that may ultimately influence the psychological outcome of the carer. Various other factors have also been demonstrated to affect caregiver outcome, including the experience of the transition into care. This will now be discussed.

Factors Affecting Caregiver Outcome

In discussing further the role that residential home placement has on the caregiving experience, consideration of what factors may affect this transition and affect how caregivers cope after this experience is important. As mentioned earlier the transition period into residential care may affect caregiver outcome. Lundh, Sandberg and Nolan (2000) studied these phenomena and concluded that making the decision, making the move, adjusting to the move and reorientation were factors that affected the outcome of carers after placement. If these factors were not adequately prepared for (e.g. in relation to making the decision and move) adjusting to the move and reorientation would be more difficult for the caregiver and vice versa (Lundh et al., 2000). Nolan, Walker, Nolan, Williams, Poland, Curran and Kent (1996) identified four clear themes to emerge from their qualitative research with caregivers that reflect these experiences. One theme that was identified by Nolan et al. (1996) was anticipation of the event. That is, the extent to which the caregiver had proactively planned prior to the transition, and the extent to which the transition has been discussed with the care recipient (Nolan et al., 1996). Another theme to emerge from this study was one of participation (Nolan et al., 1996). That is, participation by both the carer and the care recipient in the decision making process and in the move to a residential home. The third theme to emerge from this study was concerned with information (Nolan et al., 1996). That is, the consideration by both parties based on the relevant facts in exercising a fully informed choice. The final theme to emerge was one of exploration (Nolan et al., 1996). Exploration of available alternatives to placement, of a range of possible residential homes, and of emotional reactions to the move by both the caregiver and care recipient. If across these themes the residential care home was desirable, considered to be of benefit for everyone, an acceptable rationale was provided for the transition, and could incorporate the care recipients personal needs and wishes, the outcome of the caregiver and care recipient would be more positive (Nolan et al., 1996). Nolan et al. (1996) also identified the desire of carers to remain actively involved in their role during residential home placement if accommodated as influencing positive coping methods for the caregiver. By positive coping methods and outcome it is meant that grief is reacted to in a healthy way and can be overcome effectively without prolonged psychological discomfort such as low mood, guilt and loneliness.

The extent to which spouse caregivers were involved in care prior to the death of the recipient is also considered as a factor that affects bereavement outcomes (Shulz, Beach, Lind, Martine, Zdanuik, Hirsch, Jackson & Burton, 2001). In their comprehensive study involving over 1000 caregivers, Shulz et al. (2001) considered outcomes of well-being such as depression, antidepressant medication use, weight loss, and health risk behaviours such as not getting enough rest, and missing doctor appointments, because of their known association with bereavement after caregiving. Shulz et al. (2001) consider two opposing hypotheses to predict the effect of bereavement. Firstly, does exposure to the previously mentioned stressors of caregiving deplete the emotional and social resources of the carer, possibly making them more vulnerable to developing negative coping strategies post-placement or death (Shulz et al., 2001)? Or does death lead to improvement in mental and physical health outcomes of the caregiver due to reduced caregiver stress and burden (Shulz et al., 2001)? It is worth considering here that placement may not necessarily lead to reduced psychological burden despite alleviating physical burden. Shulz et al. (2001) assessed the carer’s involvement in care prior to death in relation to the level of disability of the care recipient, the extent to which the caregiver helped the care recipient with tasks related to this disability and the level of associated strain experienced by the caregiver. It was found that carers who reported caregiving strain had higher levels of depression and showed poorer health practises (Shulz et al., 2001). So following the death of the care recipient, strained caregivers showed improvements in health practises, no further increases in depression/antidepressant medication use or weight loss (Shulz et al., 2001). In the same study, caregivers who reported no strain only exhibited small increases in depressive symptoms while other factors remained stable (Shulz et al., 2001). Suggested are a number of mechanisms to explain their findings:

> First, the death of a spouse often brings with it an end to the decedents suffering as well as an end to caregiving tasks. Second, the fact that death in many cases occurs predictably after a period of disability and decline enables the caregiver to grieve prior to the death, as well as prepare for the death and its aftermath. Third, the need for caregiving is likely to mobilise a family support system that would already be in place when the death occurs Shulz et al. (2001, p.3128).

Shulz et al. (2001) suggest that these mechanisms may act to prepare the carer by decreasing the impact of the loss and promoting adaptive coping responses. The study does not identify however whether depressive symptoms actually decreased after death or if they instead remained stable. For example, were remaining depressive symptoms maintained after death or were there noticeable improvements in mood? Further study to answer these questions would broaden the applicability of these findings, as would a similar study to include non-spousal caregivers in the participant sample, and which identified relationships between these variables during the transition to residential care.

In a further study Shulz, Mendelsohn, Hayley and Mahoney (2003) identified that caregivers whose relatives were placed in a residential home did not show decreases in the previously mentioned domains compared to those who provided end-of-life care themselves. This could possibly be explained by the elderly person’s desire to stay at home for as long as possible and the related guilt experienced by the carer. Whether the caregiver considers the care to be adequate may also be a factor determining guilt and grief reactions of caregivers. Other stressors such as the carer’s sense of obligation to their loved one and the cost of care may also explain these phenomena.

To further understand the effects of caregiving on bereavement, Burton et al. (2006) found that expected death positively correlated with positive outcome. It was also found that spousal caregivers who reported stress during their caregiving experience did not show significant improvements in well-being over time after death (Burton et al., 2006). Inclusion of non-spousal familial caregivers would have been of some use in this study in order to generalise the findings more broadly and eliminate relationship effects. Robertson et al. (2007) also distinguished patterns of positive and negative affect in relation to the caregiving experience of spousal carers. Again, a study which examines this effect on non-spousal caregivers would be beneficial. It would also be interesting to examine this effect with carers who have placed a loved one into a residential home due to the evidence that supports this transition as having similar effects on grief as death.

In contrast, Aneshensel et al. (2004) identified only one in five caregivers to improve in emotional well-being over time after the full-time caregiving career had ceased. These improvements however were only from severe to moderate symptom levels (Aneshensel et al., 2004). Aneshensel et al. (2004) suggested that caregivers who were emotionally distressed during the caregiving experience (meaning high in symptoms related to depression) tended to become more distressed after death and over time afterwards. Therefore it may be worth considering that carer stress and emotional well-being play a significant role in determining caregiver outcome.

In addition to identifying these factors that may promote poorer outcomes in caregivers there is evidence that personal carer characteristics may influence caregiver well-being after placement or death. As mentioned earlier, Meuser and Marwit (2001) studied the different patterns of grieving of spouse caregivers and adult children carers throughout various stages of the caregiving experience. During the early stages of grief in dementia caregiving, that is, during the anticipatory grieving stage, spouse caregivers display attitudes that are more accepting of the care recipients condition, whereas adult children caregivers avoided talking about the future with the care recipient, minimised their own feelings, focussed on the strengths of the care recipient and appeared to be in a state of denial (Meuser & Marwit, 2001). The loss that is experienced by spouse carers is focussed around the losses of the care recipient and the loss of companionship due to their partners decline (Meuser & Marwit, 2001). Adult children caregivers however, display a perceived loss of personal freedom (Meuser & Marwit, 2001). With progression from the early stages to moderate decline of the care recipient, Meuser and Marwit (2001) found that spouse caregivers experience a gradual progression of emotion. That is, they experience pronounced sadness, empathy, compassion and maintain an acceptance of responsibility. Adult children on the other hand become increasingly unable to maintain their denial and produce raw emotions such as anger, frustration and guilt as well as anticipating with enthusiasm the death of their parent (Meuser & Marwit, 2001). The transition to a residential home presents further grief processes for carers. Meuser and Marwit (2001) identify spouse caregivers at this stage to experience grief at the highest level. They become angry, frustrated and sad as the realities of self-care and being un-coupled become real because they experience loss for both themselves and their partner (Meuser & Marwit, 2001). Adult children caregivers however experience a sense of relief, lifted burden, compassion and a decrease in their feelings of anger and frustration (Meuser & Marwit, 2001). It could be assumed therefore that whether a carer is a spouse or child of the care recipient could determine differential outcomes after placement. The study did not identify however how long these grief reactions persisted for after placement and neglects to determine differential grief outcomes after death.

In addition to the nature of the relationship between the caregiver and care recipient, studies also suggest that the gender of the carer plays an important role in influencing caregiver outcomes following death. For example, Rudd et al. (1999) found female spouse caregivers to experience higher levels of perceived anxiety, sadness and anger during their caregiving experience than their male counterparts. Gender may therefore be a factor that produces differential outcomes for caregivers.

Supporting Caregivers

In order to have the most positive outcome for carers, it is recommended that caregivers of people with AD take regular breaks by having other family members and friends provide care. Spending time with a supportive friend or family member may also be helpful. Keeping in touch with the doctor, and other support services such as hired carers, senior day-care programs, support groups, online support networks, respite care providers and residential facilities is encouraged. Professional counselling is also recommended for caregivers because it can greatly relieve the strain of caring for a relative with AD and help the caregiver cope more effectively on an everyday basis.

From the preceding sections it is clear that various factors have been found to contribute to carer outcomes. For example gender, relationship to care recipient, the experience of transition into care, the emotional and physical experience of caregiving itself and carer and care recipient perception of the care facility. Quantitative research designs however have lead to a lack of detailed personal information within carer reports and small and exclusive sample sizes make it necessary to consider the generalisability of some findings and applicability of these findings across all caregiver types. The impact of the relationship between the carer and care recipient has not been a focal point of such research and no studies of this nature have been undertaken with New Zealand participants. The current study aims to fill the existing gaps in the literature by utilising qualitative research methods in order to provide a richness of information, understand the impact of the relationship between the carer and care recipient on outcome, and involve New Zealand participants in the research with a variety of backgrounds, experiences and relationships as a means of understanding the impact of the caring experience after institutionalisation or death has occurred.

Current Research

The aim of the current research is to determine how carers of loved ones with AD fare psychologically when their caregiving obligations have been decreased due to placement into a residential home or after death. The factors present throughout the caregiving experience that may have contributed to the psychological wellbeing of the caregiver will also be identified. It is expected that factors that contribute to poorer mental health outcomes for caregivers of their loved ones with AD after placement or death will include:

-being female

-being a spouse carer

-a poor experience of transition into care (that is, anticipation, participation, information gathering, and exploration)

-not remaining active in care after placement

-caregiving experiences, for example, low stress and low perceived burden

-emotional state during the caregiving experience (that is, emotional involvement and distress)

-not expecting death when it occurred

-poor perception o the care facility

-a close and intertwined relationship history with the care recipient

Factors that are expected to lead to positive psychological outcomes after placement or death for the caregiver of a loved one with AD include:

-being male

-being an adult child carer

-having a good experience of transition to a care home

-remaining active in care after placement

-high stress and high perceived burden caregiving experiences

-low emotional distress during the caregiving experience

-expected death

-positive perception of the care facility

-a detached relationship history with the care recipient

These factors therefore may be assumed to play a protective role.

Method

Participants

Seven participants were recruited through support staff at the Alzheimer's Waikato Foundation in Hamilton and Raeburn Resthome in Cambridge who passed on information sheets to carers who met the inclusion criteria for the research (see appendix). Each participant had been a primary caregiver to a relative or spouse with dementia. Five of the seven participants had placed their relative in a nursing home less then 6 months ago and two of the carers had had their care recipient pass away from dementia less then 6 months ago. The age range was 49 to 81 years of age. The time spent in the full time caring role (post-diagnosis) ranged from 3 years to 9 years. All caregivers were primary caregivers. All seven participants were female, six carers were spouses of the care recipient and one carer was the daughter of the care recipient. All caregivers were of Caucasian ethnicity.

Materials

A list of broad interview domains which covered background and demographic information, the caregiving experience, the reaction to increasing demands and the decision to institutionalise, and the health and well-being of the caregiver after cessation of caregiving was followed during interviews. Interviews were recorded using a Dictaphone. The interview schedule was used to guide questioning and explore pertinent issues further when appropriate (i.e. when more information was needed).

During the background and demographic information section of the interview, participants were asked to describe their relationship history as well as personal factors such as occupation history, personality traits and family. The following questions were asked in relation to the other interview domains:

The caregiving experience:

-What was the relative like before they became ill? E.g. work, interests, role in your life?

-What were the reactions to the recognition of dementia? E.g. by you, relatives, others? What factors affected the decision for you to become primary caregiver?

-How did your life change as a result of caregiving? E.g. what changed, how, when, for what reasons, in what ways? What were the losses/gains?

-Characterise your caregiving experience? E.g. what did you do, what were you responsible for, how did it affect you/your family, describe your duties and how you felt about doing them, how did this change throughout the progression of the disease? What help was received, what help was most useful/unhelpful, how did you feel as the condition deteriorated, duration of caregiving, grief reactions etc.

Reaction to increasing demands and decision to institutionalise:

-What was your reaction to the increasing demands? E.g. losses/gains, feelings?

-What made you consider institutionalisation (or not)? How was the decision made, what factors affected the decision, feelings about the decision, how did you go about making arrangements, what was the reaction of the relative, how did you feel with the lifted burden, how did you deal with the loss, how did you feel about the loss?

-Further contact with the relative (if in a nursing home)?

Health and well-being when the caregiving role is over:

-Grief reactions, feelings after the loss of the relative, coping mechanisms, supports, well-being and acceptance. Reflections of the caregiving experience.

Participants were also asked if they would like to add anything else they considered important to the research and were asked to identify what advice they would give to other carers of loved ones with AD.

Procedures

Ethical approval was obtained from the University of Waikato Psychology Department Ethics Committee. The Alzheimer's Waikato Foundation was then approached and a meeting organised with the acting manager. The purpose of the research was explained to the manager and inclusion criteria were made explicit. Information sheets (see appendix) were then given to the manager who contacted potential participants and passed this information on. Potential participants were requested to provide contact phone numbers that the manager could pass on to the researcher in order to organise a suitable time to undertake the interview. Due to a lack of responses from this organisation another organisation (Raeburn Resthome) was approached and recruitment proceeded in the same manner as mentioned above. Participants were then contacted by phone in order to arrange suitable interview times. Interviews were conducted in the participants' home on all occasions. Participants were informed of their right to have support people present however all participants who were interviewed were alone at the time of the interview. The aims of the research and procedure of the interview were explained to the participant and written consent was obtained from all participants before the commencement of the interview. All interviews were recorded using a Dictaphone so the interviews could later be transcribed and analysed. Semi-structured interviews were conducted and ranged in time between one hour and one and a half hours. The research was comparative and retrospective and used qualitative methodology. Thematic content analysis was utilised as a data analysis technique.

Analysis

Caregiver's reported on their own demographic characteristics such as age, education, general health status, mental health status and duration of caregiving. Caregiver's were also asked to provide information regarding the nature and history of their relationship with the care recipient in order to understand the effects of the caregiving experience in context. Caregiver's also reported their physical and emotional experiences during their time caregiving and provided comparative information of such experiences after the care recipient was placed into residential care or had passed away. All information gathered was self-reported. Interview transcriptions were later analysed for common themes and variations by undertaking thematic content analysis. Individual experiences of positive and negative affect, anxiety, stress, burden, physical and psychological well-being were self-reported.

Results

The purpose of the current research was to determine how carers of loved ones with dementia fare psychologically when their caregiving obligations have been decreased due to placement into a residential home or after death. The factors present throughout the caregiving experience that may have contributed to the outcome of the caregiver were to be identified. For these purposes, the following section has been divided into a series of sub-sections. Firstly, Caregivers were divided into groups based on their psychological well being at the time of interviewing (outcome), and the views of these two groups on the caregiving process is presented. Caregivers were considered to have a poor outcome if they expressed and displayed continued heightened symptoms of grief, guilt, depression, anxiety and stress. Carers were considered to have positive outcomes if they expressed and displayed marked decreases in levels of guilt, grief, depression, anxiety and stress since the cessation of the full-time caregiving role. Secondly, differences and similarities in discourse and the various factors reported to be present during the caregiving experience both within and between these groups is discussed.

The results have been organised in relation to common themes and variations both within and between these groups. Firstly, shared experiences of all caregivers will be discussed. Secondly, themes and variations present among participants in the poor outcome group in relation to the hypothesised factors mentioned earlier will be discussed. Thirdly, themes and variations present within the positive outcome group in relation to the hypothesised factors mentioned earlier will be offered.

Finally, additional themes and variations not present within the existing literature will be described. Names used have been anonymised.

Caregiver Outcomes

Of the seven participants, two had clearly poorer mental health outcomes in relation to continued stress, depression, guilt, grief, anxiety and suicidal ideation. These symptoms were self-reported and also observed during the interaction of the interview. When asked to comment about how she felt emotionally now (post-institutionalisation/death) Susan detailed:

> *"I'm not right. Last week I felt like I could do myself in and make the world a better place. I've become very suicidal. I've got nothing now"*.

Susan was observed to be very anxious (she sat wringing her hands and was constantly concerned that the phone may ring) and was clearly flat in affect. She also reported continued stress in relation to financial matters and guilt in relation to placing her husband into a home. Betty, another spouse caregiver, reported similar feelings of continued guilt over placing her husband into a home saying:

> *"I really have left him after all, after I said I'd cherish him through sickness and health"*.

Betty was frequently tearful during the interview and reported feeling a sense of grief for her loss and the loss of their relationship.

The remaining 5 participants reported some similar feelings however were differentiated because of their acceptance of what has happened and the use of strategies to move forward. The remaining five participants detailed the sense of relief from the pressures (such as physical strain and stress) of caregiving since their primary caregiving role had ceased, heightened mood and decreased anxiety. These caregivers reported a substantial difference in their emotional well-being now compared to when they were caregiving full-time and reported much more beneficial emotional outcomes. Jane reported:

> *"It's only been since he died that I realised I'm not as stressed as I was. I now go to senior citizens indoor bowls. I go and have a good time and have a laugh. I know I care that I've lost my husband but if I'm not laughing I'll cry".*

Similarly, of her experiences now compared to when she was caregiving for her mother full-time at home, Judy said:

> *"Health wise I'm so much better now, I'm off all my medication, I'm much calmer, and I'm much less stressed. I think I've become more philosophical about Mum thinking well, I don't take all the burden on myself anymore, I'm not going to be able to change her condition, she's there getting cared for and we've done the best we can".*

This acceptance appeared to be common among this group. Instead of placing guilt on themselves they have realised that other care options were not available and that their loved ones were therefore receiving the best possible care.

Shared Experiences Of Caregivers After Institutionalisation/Death.

All of the participants reported some sense of loss/grief for their loved ones after placing them into residential care or following their death. Noreen expressed:

> *"I'm beginning to accept what has happened to him but there was years of grief before it came to this. I've got a deep faith so I feel a lot more peaceful".*

Of her experiences, Judy said:

> *"When I realised Mum would have to go into a home, yes I did feel a kind of grief at that time for the fact that this was happening, things were changing, you sort of feel powerless. I definitely think it was a sort of grief process at the time, not exactly the same as when someone dies, but over the situation".*

Similarly, Susan described:

> *"I grieved because our lives together had been ruined and that such an intelligent man had become a baby more or less".*

It was also common for caregivers to experience relieved physical burden however emotional burden was stronger in some cases than others. Betty expressed of her experience of making the decision to place her husband into residential care:

> *"I knew I couldn't manage him on my own and that I needed help lifting him and washing him and things like that. I was becoming very ill all the time, probably something to do with stress. It was the last thing I would ever dream of doing but I really had no choice".*

Jane similarly described:

> *"I've had six minor heart attacks when I was caring for him. But I feel much healthier now. I knew it was the right time and I've accepted that because I need to take care of myself as well. I'm much healthier now".*

Guilt about placing their loved one into a home was reported in all cases however some caregivers were more rational in their reasoning for this. For example, Betty explained:

> *"I felt guilty that I was doing this to him. I used to go in and see him every day to deal with that I think".*

Similarly, Barbara said:

> *"You keep thinking 'why did I do it?' but I knew I couldn't look after him myself, but you really do flog yourself".*

Likewise, Hazel expressed:

> *"He always asked when he was going to be able to come home and I'd feel so much guilt over lying to him".*

Another common theme to arise was that of role confusion and loss of relationships. Every caregiver reported a sense of loss for themselves and their relationships with their loved ones. The difference between the groups however was in how this sense of loss manifested and impacted on their lives. That is, acceptance of this idea rather than ruminating about it. This important concept will be discussed in more detail later. Perceived burden also appeared to remain low among most spouse participants. Subtle differences between perceived burden in spouse caregivers and the adult child caregiver will be described in a later section.

Themes and Variations Present Within the Poor Outcome Group

Both Betty and Susan were primary caregivers for their husbands who had dementia. Both Betty and Susan's husbands were alive at the time of the interview. Betty and Susan reported a close and intertwined relationship history with their husbands. When asked to reflect on her relationship with her husband Susan discussed:

> *"We enjoyed things together. We played golf and danced. He was the loveliest man and never spoke a harsh word to me. Our lives together have been ruined".*

Of her relationship with her husband Betty said:

> *"We were very dependent on each other, it feels as though one person has crumbled and I have gone along with it".*

Both Betty and Susan reported physically and emotionally stressful caregiving experiences. In relation to the physical strain of caregiving and the deterioration of her husband's condition, Susan explained:

> *"I could feel myself breaking down a couple of years ago, I was getting so angry, things were moving at a hundred miles an hour. I was that stressed that I did not want to see anybody, I didn't want the phone to go. If anyone came to the door I would virtually cry because I couldn't cope. My house became very messy".*

Barbara reported:

> *"I used to get very angry but you couldn't show it because that would be the worst thing you could do to them. A man who was so capable then all of a sudden it's all gone".*

What is unique to this group however is the lack of perceived burden on them as a result of the caregiving role. Both Betty and Susan reported a sense of duty and obligation to their husband’s and as a result of this did not consider the experience to be a burden on them, rather it was something they wanted to do. Betty said in relation to burden:

> *“He would have done the same for me. It was never something I thought twice about and although it was difficult at the time I wouldn’t have wanted anyone else to care for him. I never once contemplated not doing it for him. He was my husband after all”.*

These results may therefore suggest that low perceived burden plays a more important role in influencing poorer outcomes than other factors present within the caregiving experience. This may be due to low perception of burden leading to feeling’s that caregiver’s could and should do more for their loved ones, leading to increased feelings of guilt when placing their loved one into residential care.

This factor appeared to be important in terms of impact on the caregiver. For both Susan and Betty, the transition into care was not smooth and was accompanied by severe feelings of guilt and abandonment. Both reported wishing to keep their husbands at home, however due to a lack of resources and support could not do this. Neither Betty nor Susan had ever expected to have to place their husband into a residential care facility and were therefore seemingly ill prepared for the transition. Betty described:

> *“I felt it was my obligation to my husband to care for him at home. You know, through sickness and health. I didn’t realise though how hard it would be to do this by myself”.*

Likewise, Susan reported:

> *“I hadn’t ever considered the idea of putting him into a home. To me that was just not an option because I knew he would have hated it. But when the doctor suggested that this may be inevitable I broke down, right there in the doctor’s office and said I can’t do that!”*

Due to the physical and emotional strain of caregiving and lack of adequate resources to continue caring for their husbands at home the move was inevitable. Of the experience of finding a suitable care facility for her husband (further limited by his needs for a secure unit) Susan explained:

> *“The places that we visited and liked could not handle his wandering so we ended up having very little choice…oh and the wait list made it very limited!”*

This lack of preparation was accompanied by lack of participation on the care recipients behalf in the decision making process, lack of sufficient time to make an informed decision after the process of gathering information and limited exploration opportunities. For example, Betty described:

“The doctor suggested that we should get him in somewhere straight away. The problem with that was the waiting lists. He had to go into the first place that had room and he didn’t particularly like it there”.

In terms of continued caregiving opportunities after they had placed their loved ones into a home, Betty and Susan’s experiences differed. Susan was actively involved in her husband’s care until the disease progressed to the stage where he would sometimes not recognise her when she visited. Of this Susan said

> *“I’ll only go and see him once a fortnight because I find when I come home from seeing him I get really depressed because the day of his is closing in. I’ve seen him go from the top of his tree to a vegetable”.*

Susan does however manage their finances. This burden causes her increased stress as she struggles to meet the costs of the care facility. Betty on the other hand visits her husband every second day and spends mornings reading to him, taking him out, taking him for walks and grooming him, she also manages the finances. In commenting on remaining active in his ongoing care, Betty expressed

> *“I wasn’t going to let them lock him away and I sure wasn’t going to just forget about him. It’s the least I can do for the poor man”.*

It could therefore be assumed that remaining active in care after placement (or not) may depend on the caregiver’s perception of this as a coping mechanism. For example it was less emotionally disturbing for Susan to see her husband and therefore infrequent visits may have served as a protective factor for her. Betty on the other hand seemed to gain strength from her sense of obligation to her husband and remaining active in his care.

As mentioned earlier, Betty and Susan seemed to be insufficiently prepared for the transition into a care facility. Susan displayed a strong aversion to most care facilities and government policies regarding placement. Susan described:

> *"I didn't like the place, it was awful! The care is not good there…I've had to deal with people with no compassion at all".*

In the nursing home available to them at the time, Susan reported that one day:

> *"I walked in and found him, he had noosed himself. He was just sitting there".*

She believed that her husband was not receiving basic care essentials (such as food) and that she felt she had to stand up for his rights. Since that time her husband has been shifted to a secure unit. Susan's report of the new care facility is similar to that of the previous one. Susan said:

> *"I bought a subscription to the herald for him to read. I'd go there and the paper was nowhere to be seen. They would take it and read it themselves. They just treated him like he didn't even exist".*

In contrast, Betty feels as though she was forced to place her husband into a residential home because the doctor had told her there was no other option. His symptoms were severe enough to warrant a secure unit referral. Betty reported feeling that her husband's needs were being taken care of in the secure unit but that he wasn't being treated like a human. Interestingly, both ladies acknowledged that their own opinions may have been influenced by their husband's perception of the care facility. Betty's husband shouted at her one day:

> *"I hate it here! Get out, just get out!"*

This may therefore be important to consider in terms of the impact on the caregiver's perception of the care facility. Feelings of guilt and abandonment may arise when the care recipient has a poor perception of the care facility, thus influencing the reaction of the caregiver and ingraining such feelings of guilt.

Themes and Variations Present Within the Good Outcome Group

Four of the remaining five caregivers were primary caregivers for their husbands. One participant provided care for her mother (Judy). Although it was expected that spouse caregivers would have poorer outcomes overall, there were no significant reported differences in well-being between child and spousal caregivers. It is important to note here that Judy did however report experiencing a strong sense of burden related to her caregiving experience compared with the spousal caregivers who tended to experience a stronger sense of obligation and fulfilment. These finding may suggest that the context in which the relationship takes place and the nature of this relationship may be more important factors to consider.

As mentioned earlier, relationship dynamics may play an important role in determining outcome for a number of reasons and may be more complex than initially presumed. Firstly, the mother-daughter relationship was influenced by feelings of burden as the roles reversed from daughter to carer and mother to care recipient. Spousal relationships on the other hand were often close and interconnected and were accompanied by a sense of obligation and expectation. All caregivers reported a close relationship with their loved one to varying degrees. Some dynamics did vary in relation to the dependence on their loved one for emotional satisfaction. Jane described her husband as a traditional man with controlling tendencies. Of herself after his death she described a sense of freedom:

> *"I've become more relaxed and outgoing, I was never allowed company before…but I get along well with people, so I've started a new life even though I am 81. If you don't you may as well just give up".*

Of her relationship with her husband, Hazel said:

> *"We were never one of those couples that had to do everything together. He had his hobbies and I had mine. We had some together as well. I think that makes it easier to pick your head up and move on".*

So it could be concluded that dependence (as opposed to being detached) on a loved one may influence poorer emotional outcomes by affecting the person's ability to move on and embrace change.

Jane's husband passed away 4 months after he was placed into a care facility. While she reported that she did not expect him to go as fast as he did, Jane found comfort in the fact that he still had his dignity and he could still remember his family.

The impact of a loved ones death may be a more important concept to consider in terms of caregiver well-being. Jane expressed:

> *"I realise now that I've lost him I'm better in myself because I don't have all of the stress of worrying about him. It sounds awfully selfish doesn't it?".*

So while Jane is less stressed, she also considers herself to be lonely and sad but making modest improvements. The experience of the transition into care was reported to be fresh in the carer's minds. For example, Judy expressed

> *"I remember it very well; it was an unpleasant but necessary time…an emotional rollercoaster".*

While most caregivers in this group reported high stress caregiving experiences both physically and emotionally, perceived burden remained low, particularly among the spouse caregivers. For example, Jane described:

> *"I became very unwell. I think it was to do with the stress involved with caring for someone with Alzheimer's. I don't think people realise how stressful it is. He got to the stage where he couldn't bathe himself so I would do it for him. Although it was hard for me at the time I realised that what I was experiencing couldn't have been even close to as bad as he felt".*

Hazel also went on to illustrate this point by saying:

> *"I was always anxious about what he was doing. I wanted to keep him by my side at all times but I couldn't. I was a wreck. I couldn't blame him for that though so I would blame the disease. If I had Alzheimer's I know he would have done all he could for me. So that was the way it was".*

As mentioned earlier, subtle differences were prominent between the spouse caregivers and Judy in this respect. All caregivers described their caregiving experience as emotionally draining and physical exhausting. Barbara reported:

> *"I used to get very angry but you couldn't show it because that would be the worst thing you could do. Here was man who was so capable and then all of a sudden it's all gone".*

Judy however admitted feeling a great sense of burden due to the lack of support from other of her family members and resentment toward her mother. Judy reported:

> *“We used to have big arguments. I used to get frustrated with her and think why can’t she do things for herself, why is she just waiting for someone to help her?”*

This contrasts with the majority of other caregivers feeling obligated to care for their spouses. The nature of the relationship is evidently more relevant in terms of obligations to a partner versus feeling trapped into caring for an elderly parent due to lack of other family members accepting to take on the role of carer. Feeling trapped in the caregiving role and feeling a strong sense of obligation and duty however should be carefully differentiated.

While most caregivers described experiences of feeling a loss of self during their time as a full-time caregiver, it was nonetheless repeatedly described as an experience that had no alternative scenario and was embraced as such. Hazel described an unpleasant experience related to her husband’s physical aggression and continued on to say:

> *“I knew it was the disease. I coped with it as I felt I was here to look after him. I want to be available for him”.*

Very slowly but certainly, Jane acknowledged:

> *"I wanted to do more but I couldn't. I would have done anything to make his suffering go away"*.

It could be assumed therefore the physical and emotional strains of caring for an elderly dementing person are universal, however that the burden associated with this strain is of more relevance in relation to caregiver outcome. High perceived stress and burden may therefore act as protective factors for later mental health outcomes through the process of reminiscence and regaining the lost self after caregiving has ceased.

Spousal caregivers also repeatedly reported the physical strain associated with caregiving as being the hardest to cope with and the deciding factor influencing long-term care placement. Jane highlighted this when she said:

> *"if my body wasn't going to give up I could have looked after him until the end"*.

Similarly, Noreen expressed:

> *"I became so sick that some days I couldn't get out of bed. I was no longer able to lift him into the shower or pull his pants up. I just wasn't strong enough and I knew that trained people could do him more justice than I could"*.

Overall, most of the caregivers in this group reported having a positive experience of the transition into care. Both Judy and her mother came to the decision that being in a residential care facility would be safer. Judy reported that both herself and her mother made decisions together regarding where and when she would go into residential care after 3 months of gathering information about various locations and exploring alternative options (such as respite care and home help). Judy said:

> *"We started looking into it quite early because I wanted mum to have as much say in where she went as possible. I wanted her to choose somewhere that she would be happy. That way I could be happier as well".*

Of the impact of this transition on her families life Judy described:

> *"it's a huge burden lifted off my shoulders. We can now go out to groups, out at night, we feel much freer to plan things".*

While all caregivers in this group experienced a sense of grief at the time of transition, it appeared that adequate time, exploration, involvement by the care recipient and finding a suitable home that met the needs of the care recipient were crucial protective factors. The amount of time caregivers actively engaged in searching for an acceptable care facility varied between 3 weeks and 2.5 years and was in part influenced by the availability of rooms. What seems to be the more important factor however is that they had in some way prepared for, and accepted the inevitability of the transition. Noreen described:

> *"I went to the doctor and he suggested that we start to think about the possibility of a nursing home. We both agreed that the time would come eventually and it would be better to be prepared now".*

Likewise, Barbara explained:

> *"I knew it was going to happen. Although I didn't want it to at the time I am so glad that we had prepared ourselves in advance because some waiting lists are so long and we may have ended up taking him somewhere that he would be unhappy".*

Of the search for an appropriate care facility Jane expressed:

> *"He actually suggested we start looking at nursing homes. I got the feeling he knew I couldn't physically look after him anymore".*

All caregivers described the process as stressful at the time, however reflecting on this process highlighted some key strategies that proved beneficial in the long-term (particularly making the choice with the care recipient to deter resentment). Like Judy, Hazel described:

> *"I wanted him to be happy wherever he was going so I included him in everything I did and made no decisions without asking him what he thought. He would come with me to the rest homes and sometimes he would say 'ooh*

> *no I don't like this place' and so we would keep looking. I think he appreciated that too"*

Likewise, Jane expressed:

> *"I felt that if we made the decision together perhaps it would make it easier on both of us. It wouldn't just be me getting rid of him".*

Timing of placement into the care facility may also have served a protective role, particularly for spousal caregivers. Most of the caregivers in this group reported that by the time a shift was inevitable, their spouses were not lucid enough to realise a change in surroundings, or at least were not cognitively fully aware of the impact of the transition. Barbara said of her husband's first day in residential care,

> *"he just said 'bye bye, I'll see you later, don't be too long".*

Noreen expressed:

> *"He didn't realise that he was to stay there permanently. For the first few months he would ask, 'when can I go home?' I would tell him that this was his home now but he would still ask".*

Of the transition into care for her husband, Hazel described:

> *"He actually didn't seem to realise that this wasn't his home. I think he knew something was different but he couldn't put his finger on it. He really loved being around so many people. He was always a very sociable person".*

Of the caregivers in this group, all reported remaining active in the care of their loved one after placement. Judy describes herself as *"part of the furniture"* at the rest home. Some common care activities maintained described by the caregivers included taking in home cooked food, grooming, reading, and extra physical stimulation. Jane described:

> *"I would take him for walks around the gardens. They have beautiful gardens there. They don't get to go out much because the pressures on the staff are so great. I often made scones or lamingtons to take to him. Those were always his favourites. He never lost his appetite!"*

Noreen chuckled as she said:

> *"The food at the rest home isn't much to rave about. I take him in a lot of fresh fruit. When you are in a rest home food becomes very important!"*

Barbara expressed:

> *“Sometimes I take his good shirts home and starch and press them. He was always a very proud man who liked to look handsome. I didn’t want him to lose that. I’d shave his face and comb his hair every morning”.*

Caregivers in this group described a sense of obligation alongside a sense of realisation that they had done the best they could do in relation to caring for their loved one. This insight may serve to enhance continued involvement in care and minimise feelings of guilt over placing their loved ones into care. Barbara commented:

> *“The one thing I didn’t want to do was just plonk him in there and forget about him. You couldn’t do that after 55 years! And, although he wasn’t the man he’d always been, he was still my husband. He was still the most treasured in our lives”.*

Judy described:

> *“She was my mother. She had cared for me my whole life and now it was time to repay the favour. I resented her at times but this was something that no-one else had offered to do so I did”.*

Noreen became emotional when recalling:

> *"We both knew when it was time for him to go into a home. I was becoming very ill and he could see that. I felt like I had done the best I could and he knew this too which was good".*

As mentioned above, most participants in this group described a positive transitional period into care due to adequate planning and research with the care recipient. Barbara went on to describe:

> *"The fact that he liked it and was happy there made it easier for me. He'd walk into the home and give an enthusiastic hello to whom ever he came across first, which reassured me that I'd done the right thing".*

Most caregivers in this group were generally satisfied with the level of care that their loved one received. For example, Hazel described:

> *"The nurses were so good. They knew what to do and weren't surprised by anything he did. They would read to him and take him for walks. I felt he was safe with them".*

Of her perception of the level of care Judy expressed:

> *"I think there is definitely room for improvement but that has to come from the government. The staff there do the best they can. They are so overworked yet still come to work with a smile on their faces. It must be such a hard job but they do it so well".*

The potential of this finding in relation to positive outcomes for caregivers is vast. Most of the care recipients also had positive reactions to the service and care they received. Judy said:

> *"Mum enjoys having company. She says the food is O.K. and she makes me bring in old recipes to give to the chef (chuckles). She says the nurses are very nice".*

When asked to describe her husband's perception of the care facility, Jane described:

> *"He gets frustrated that he can't just get up and go for a walk. But he always seems relatively happy and still teases the nurses!"*

Food and exercise were repeatedly reported to be the most important attributes influencing their decision to place a loved one into the home and the care recipient's perceptions of the care facility were often influenced by these attributes. A strong link between the level of satisfaction of the care recipient and the level of satisfaction with the caregiver was evident, suggesting this as an important variable in determining a positive perception of a care facility.

Additional Themes to Emerge From the Discourse

Social and Familial Support

Some participants discussed their frustration with the lack of appropriate, government funded support that they and their loved ones received, and the impact that this had on their decision to place their loved one into a care facility, caregiver stress, financial burden, and the contradiction with their desire to care for their loved one at home for as long as possible. Among caregivers in the poorer outcome group, this factor seemed to be particularly relevant and reflective of detrimental outcome in that these caregivers displayed intensely strong desires to care for their loved one's at home, however due to lack of support, could no longer manage to do this. The inability of these caregivers to provide the desired care for their loved ones may therefore have lead to increased frustration, depression, anxiety and stress.

Across the participants in the second group, the utilisation of social support seemed to be an important factor in the improvement of mental health and emotional outcomes for caregivers. For example, caregivers frequently reported having a close social support system, made up of immediate family members, extended family members, friends, church groups and neighbours who would assist not only with caregiving duties such as physical stimulation, cooking etc. but also directly supporting both physically and emotionally the caregivers themselves. For example, Barbara explained:

> *"I realised that I needed to be among family so that I could have help to look after him. I felt very dependent on my son. He has been great. I couldn't have done it without him"*

Barbara continued on to describe the support she received from her son:

> *"It was just knowing that he was on the other end of the phone whenever I needed him. He would come over if I was having a bad day and take Dad out for a while. He used to help us with tidying up the gardens and things like that".*

Of the support she received within her neighbourhood, Hazel described:

> *"Sometimes he would wander out of the house. Because we know all of our neighbours, one would ring me to say 'your husband's over at my place' and so I'd walk down the road and get him. I'd usually stop in for a cup of tea as well".*

This support commonly did not disperse after the care recipient had been placed in a care facility or died, but to the contrary, in some cases support increased. While in some instances support people withdrew as the disease progressed, immediate family members and friends became increasingly concerned and involved with the caregiver. Noreen illustrated this point effectively.

> *"You could easily learn who your friends were. I think it was too hard for some people to see him like that. But that shouldn't matter. When someone needs your help you should be there for them. My family and some friends from bowls have been so patient and caring. They've seen me cry more times than I care to remember".*

The utilisation of support groups for caregivers of people with dementia was also considered by the caregivers themselves to play an important role in supporting them throughout their caregiving career and particularly after institutionalisation/death. Of the Alzheimer's Waikato support group she belonged to, Judy expressed:

> *"To the support group I almost owe my life (chuckling), it's been really good. At that time when I was feeling very alone, especially when you're with that person all the time, you do lose a lot of contact within the community. To go to the meetings and hear about other people and their experiences with the person they are caring for, we'd have a laugh about some of the things they'd do. Yes they were really good. The staff were excellent".*

Jane said of the Alzheimer's Waikato support group:

> *"It was good to be able to share stories and have a giggle about them. It makes you feel more normal when you know others are going through exactly the same thing as you are. They've been really supportive of me and helped me with finding a facility for him".*

Betty found the support groups to be a good way of building a social network:

> *"It's good to be part of a group. I know quite a few people there now so that's really helped".*

Remaining Involved in Activities and Hobbies

A predominant difference between the groups was that of remaining active in social activities and hobbies after the care recipient has been placed in a care facility or passed. While caregivers in the first group involved themselves in some social activities, it seemed as though there was an underlying guilt surrounding taking care of themselves and enjoying life in this respect when their loved one suffered so badly. For example, Susan describes

> *"It feels selfish to me that I would consider going out for lunch when I should be there with him when he needs me most. People say I should take care of myself better but right now my priority is to be there for my husband".*

In contrast, caregivers in the second group differed in this sense and seemed to be more optimistic about taking care of themselves and realised the impact this may have on their well-being. Interestingly, support people of carers in this group often encouraged the carers to start looking after themselves by taking up more social activities and hobbies. Jane expressed:

> *"It's only been since he's died that I've started going out. I now go to senior citizen's indoor bowls. I've made a lot of new friends. My son encouraged me to get out and do things I wanted to".*

When asked to describe what she considered to be important to her managing the grief related to losing her husband to the disease, Barbara described:

> *“You have to keep yourself busy and do things that you enjoy. Join a group and take up offers to go out. It would be easier to sit at home and ruminate but you have to make the effort”.*

Loss of Relationship

Caregivers across all groups reported feeling a sense of a loss of relationship with the care recipient to be the hardest aspect of the disease to handle. Caregivers reported feeling as though their relationship roles had been reversed. For example, Judy reported:

> *“I felt that I was the caregiver and the daughter side was no longer there at all, and Mum related to me as the caregiver, and so there was a lot of conflict within me as to I didn’t really want to be doing this. So now that she’s in a home someone else is doing that physical care and I’m the daughter again”.*

During a day visit back home Jane described of her husband’s visit:

> *“It felt quite strange, he was like a visitor in your home and some how you treated him like a visitor. Although he had lived here for so many years, it didn’t feel like he thought this was his home anymore”.*

It became apparent that caregivers would become more accepting of the loss of relationship over time and begin to move forward with their own lives. Noreen describes:

> *"You have to learn how to live on your own, just making a meal for yourself. It's a new life. It gets lonely at home but you just have to get on with it".*

The difference in outcomes related to this factor seems to be associated with acceptance and the carer's ability to move forward in a constructive manner. Carer's in the first group tended to dwell on the loss of relationship and not take active steps to move forward in a positive direction. More acceptance of the condition and loss was described in the second group. Also the relationship to the care recipient (e.g. mother, spouse) and the nature of the relationship (close and interconnected) may be more important factors to consider in relation to the loss of relationship experienced by caregivers.

Discussion

Much research to date has tended to study caregiving as it occurs during one point in time, to the neglect of what has preceded carer's experiences and the effect of these experiences. This limitation must be taken into account when considering the number of transitions made during the caregiving career to which both the care recipient and provider must adapt as the disease progresses.

The aim of the current research was to determine how carers of people with AD fare after their caring obligations have lessened or ceased, and what factors during their experience may have contributed to a maladaptive or adaptive mental health /emotional outcome.

The current sample of caregivers displayed differing mental health and emotional outcomes. Of the seven participants in the current sample, two distinct groups were identifiable. A good outcome group existed of five of the participants and the two remaining participants were presented as the poor outcome group. The good outcome group displayed decreases on mental health and emotional endpoints such as anxiety, depression, stress, guilt and grief, post-institutionalisation. Available literature suggests that these endpoints are important in determining outcome and improvements within these domains are reflective of good outcomes in caregivers (Zarit et al., 1998; Anthony-Bergstone et al., 1988; Robertson et al., 2007). To the contrary, the poor outcome group was characterised by increased levels of anxiety, depression, stress, guilt and grief post-institutionalisation. While the literature suggests that these endpoints are reflective of detrimental outcomes in caregivers, conclusive results are difficult to determine due to lack of detail and small participant samples. Six of the carers in the present sample were spousal caregivers and one carer cared for her mother. The importance of understanding the impact of the relationship upon carer well-being after placement or death is essential.

The nature of the carer's relationship with the care recipient appears to be an important and influential determinant of outcome and is often overlooked within the research. Meuser and Marwit (2001) suggested several differences in grieving reactions between adult child caregivers and spouse caregivers. During the anticipatory grieving stage however, spousal caregivers in the present study varied in their acceptance of the care recipient's condition. Two of the six spousal caregivers appeared to display low levels of acceptance of their loved ones condition. The adult child caregiver representative also showed a great deal of acceptance of the condition and contrary to what Meuser and Marwit (2001) suggested, did not avoid talking about the future with the care recipient, and tended to show increased concern (compared to spousal caregivers) for her own well-being. Overall, it could be concluded however that spousal caregivers more frequently experience loss as it is related to the losses of the care recipient and the loss of companionship due to their partners decline which varies somewhat from the experience of adult children carers who tend to experience a perceived loss of personal freedom as suggested by Meuser and Marwit (2001). To avoid being overly simplistic and concluding that spouse carers may fare worse post-placement/death, the nature of the relationship in which caregiving took place is essential in consideration of the losses the carer may have faced.

These differences may be better understood in relation to the nature of the relationship with the caregiver as experiences vary considerably within this domain despite the commonality of the relationship. It could be assumed from the current results that caregiver's in highly communal relationships fare worse than their less communal counterparts due to a number of factors including over-dependence on the loved one for happiness, less concern for their own needs and heightened feelings of responsibility for their loved one and internalisation of this ideal. While all caregivers in the present sample reported close and interconnected relationships with their loved ones, carers in the positive outcome group tended to depend less on their loved one for emotional satisfaction. This appeared to influence the caregiver's ability to move forward in a positive direction and accept change. The theory of communal relationships as posited by Clark and Mills (1993) takes into account the role of one relationship member in responding to the other's emotional needs. As suggested by Williamson et al (1998) highly communal relationships and low communal relationships may influence outcomes in caregivers.

The common reports among the present sample of caregivers in relation to their desire to help their loved ones may be reflective of generational values of honour and obligation, considering that the majority of participants were elderly spousal caregivers. The sense of burden experienced by the adult child caregiver may be reflective of this, or may reflect more generally, the nature of this relationship as opposed to intimate relationships.

Carers who fared worse in this sample tended to display decreased autonomy and due to their inability to continue caring for their loved one felt incapable in their caregiving pursuits. To the contrary, caregivers with more positive emotional outcomes expressed feeling as though they had done the best they could do in relation to caring for their loved one. These differences may reflect differing values and internalisation of failure on these domains as opposed to acceptance. Self-Determination Theory as suggested by Deci and Ryan (2000) posits that psychological well-being is achieved when three basic needs are satisfied including autonomy, competence and relatedness. The carer's level of perceived mastery in these three domains and their motivation in their relationship with the care recipient could therefore influence caregiver outcome.

Aneshensel and colleagues (1995) proposed a stress process model of caregiving encompassing both primary stressors (arising directly from the needs of the patient) and secondary stressors (stressors evolving out of primary stressors). As reported in other studies, caregivers in this sample reported a variety of primary and secondary stressors including physical strain, emotional turmoil, financial strain, loss of self, loss of relationship, stress, anger, burden, anxiety, depression, guilt and grief that could be higher than prevalence rates within the general population (Zarit et al., 1998; Anthony-Bergstone et al., 1988; Robertson et al., 2007). Secondary stressors in particular are deserving of consideration as they relate to caregiver well-being in the current context. Also, as suggested by Meuser and Marwit (2001), the impact of memory loss on the relationship between care recipient and caregiver may influence negative emotional symptoms. It was also common for caregivers to report feelings of guilt about placing their loved one into a residential care facility. Zarit et al (1998) concluded that feelings of guilt and burden were more predominant among caregivers than the general population; however the current study suggests that burden may be reflective of the relationship between the care recipient and caregiver, with spouse caregivers reporting less feelings of burden and more feelings of obligation related to their caregiving role. It could therefore be assumed that guilt and burden are very separate constructs that are dependent upon wider variables. Caregivers in the current study also reported a number of positive aspects of caregiving such as fulfilment of obligation and satisfaction. These variables appeared to be of importance when interpreting the relationship between the caregiving experience and caregiver outcome and will be discussed in more detail later.

Carers in the present sample presented responses indicative of grief. It is therefore pertinent to consider how the nature of the relationship may impact on grieving for caregivers. Caregivers commonly reported grieving the loss of their relationship with the care recipient. Carers who tended to have heightened and continued experiences of grief reported close and dependent relationships with their loved ones. Grief in dementia caregiving has been considered in relation to the progression of the disease and the loss of intimate relationships (Mace & Rabins, 1981). Caregiver grief is characterised also by loss of social interactions, support, previously established social roles and intimacy (Loos & Bowd, 1997; Sanders & Corley, 2003).

The decision and process of placing a loved one into a residential care facility is another factor that appears to have affected the present sample of caregiver’s emotional well-being at the present time. As suggested by Daff et al. (2006), this transitional period and the changing expectations and new caregiving experiences that come alongside it, elicited various responses in caregivers. The current sample of caregivers continued to experience varying degrees of emotional distress, and while the majority of caregivers reported improvements in emotional well-being on constructs such as anxiety, depression, and stress, the remaining caregivers did not fare as well within these domains and reported continuing anxiety, guilt, depression and stress. Zarit et al (1987) highlighted the feelings of relief from the emotional and physical stresses of caregiving however more recent research suggests responses to the contrary which may be more relevant to consider in relation to the current research (Zarit & Witlach, 1992). A majority of caregivers reported that the decision to institutionalise their loved one was made and explored with the loved one which is contrary to findings from Dellasega and Mastrian (1995). Caregivers also reported that guilt was the predominant emotion during this transition and appeared to affect the carers in different ways. The internalisation of this guilt however seemed to influence how the caregivers coped emotionally with this transition. For example, carers appeared to develop more detrimental health outcomes if this guilt could not be surpassed. The ability of the caregiver to surpass this guilt appeared to be influenced by the nature of the relationship with the loved one (that is, close, dependent and interconnected) and the sense of obligation, responsibility and duty encroached within this relationship. This difference in finding could in part be due therefore to the variety of caregivers in each sample. That is, the current research obtained information primarily from spouse caregivers who seemed to display higher senses of duty and obligation to their loved ones due to the longstanding history of their relationships as compared to other familial caregivers.

The process by which a carer makes the decision to place a loved one into a residential care facility is important to consider also as it relates to how the caregiver may respond to the transition. The most commonly reported theme to emerge from the current research is that caregivers tended to make this decision only when the physical strain of caregiving (e.g., lifting, dressing, washing) became too difficult to manage. As suggested by Armstrong (2000), this factor and others such as support and encouragement from family and friends influenced the carers' decision to place a loved one into care. Caregivers in this sample who displayed less positive emotional outcomes tended to display higher values of obligation and desire to continue caring for their loved one that overrode their own personal needs and may therefore have contributed to their current state of mind. As a result of placement these carers may therefore feel that they have not successfully delivered what is expected of them, resulting in continued emotional turmoil and a feeling of failure as the "ideal caregiver" as suggested by Dellasega and Mastrian (1995).

Despite the great demand on care facilities as a result of the increase in the aging population, most carers in the current sample identified that the transition into a care facility was less stressful than expected and balancing the needs and preferences of the carer and care recipient was possible with sufficient time and planning. As suggested by Nolan et al. (1996), anticipation of this transition (involving proactive planning and discussion with the care recipient) may influence how the transition is experienced. The detrimental outcome group however seemed to differ dramatically in this respect. Due to their strong sense of obligation and desire to care for their loved one at home, carers in this group were rushed into decision making and were therefore pressured to accept whatever was available at the time regardless of whether it was considered appropriate and reflective of both the care recipients and carers needs and wishes. Daff et al. (2006) considered the wishes of the elder to be pertinent to a successful transition. With lack of preparation however, loved ones often did not have a choice where they ended up and may subsequently have showed a dislike to their new environment. This also seemed to affect the caregiver’s perception of the care facility, resulting in an overall dissatisfaction with the care facility and services provided. Considering the importance of obligation for these caregivers, feelings of guilt over this transition may therefore have been exacerbated. An informed choice due to exploration of alternatives (as suggested by Nolan et al., 1996) may therefore have been unattainable due to lack of preparation.

Carers in the present sample appeared to display improvements on important mental health endpoints when these factors were prepared for. Involving the care recipient in the decision making process and search for a facility tended to influence more positive outcomes in the present sample of caregivers. Dellasega and Mastrian (1995) also highlighted the need to involve the care recipient in decision making while they maintain the mental capacity to do so, in order to minimise resentment and preserve the care recipient’s sense of control. This finding is indicative of previous findings from Nolan et al. (1996) suggesting that if the residential care home was considered desirable, considered to be of benefit to everyone, an acceptable rationale was provided for the move, and could incorporate the care recipients personal needs and wishes, the outcome of the transition would be more positive for the carer and care recipient. To extend this idea, perhaps due to the differential results of the current study, it could be postulated that carers who fared poorly after the transition, more importantly did not accept that the transition would benefit everyone, perhaps mostly themselves.

Most caregivers in the present sample also remained active in care after placement. This may have acted to ease the transition for both the carer and care recipient as suggested by Davies (2004) and Nolan et al. (1996) by fulfilling the caregivers desire to help their loved one and abolish loneliness and guilt over not being able to do this for them full time. However this finding was not unitary. One caregiver in the poorer outcome group also remained active in her husbands care and one became less and less involved. It could therefore be assumed that remaining active in care after placement (or not) may depend on the caregiver's perception of this as a coping mechanism. For example it was less emotionally disturbing for one carer to see her husband and therefore not seeing him has served as a protective factor for her. Another carer on the other hand seemed to gain strength from her sense of obligation to her husband and remaining active in his care. Sander's and Adams (2005) concluded that feelings of grief are more predominant when the care recipient no longer recognises the loved one. This could be another important factor determining coping as the disease progresses to the latter stages as suggested by Ponder and Pomerey (1996) and Rudd et al. (1999).

Another important factor not mentioned in the literature but evident within the results of the current study is that of timing of placement. Although carers in this group tended to make decisions regarding placement with their loved ones, spouses reported that the transition to care was made easier if their loved one was unaware of their surroundings, or at least unaware of the full impact that the transition would have on the care recipient’s life.

All caregivers in the present study reported high levels of emotional and physical strain during their caregiving experience however differential outcomes were present. A possible explanation for this discrepancy may be that caregivers in the poor outcome group, due to their lack of acceptance and understanding of the condition and high levels of obligation to care for their loved ones were ill equipped to grieve throughout the decline process and were not adequately prepared for the decline. Expectation of death may have important implications for these carers. If death is not prepared for and expected, caregivers may display higher levels of depression during bereavement as noted by Burton et al. (2006). Shulz et al. (2001) studied the effects of placement/death on caregiver’s well-being and concluded that caregivers who reported high levels of caregiving strain showed no further increases in depression and improvements in health related practises after placement and those caregivers who reported no strain showed only modest increases in depressive symptoms after placement.

The current sample of poor outcome caregivers maintained strong desires to care for their loved ones at home, however due to physical and emotional decline could not adequately perform the tasks required with caregiving. This conflict between desire and reality may have impacted on levels of guilt, feelings of failure, loss of obligation and financial burden. The transition to a residential home presented the caregivers with further grief processes as for spousal caregivers the realties of self-care and being un-coupled became real in comparison with the adult child caregiver who appeared to experience a sense of relief and lifted burden as suggested by Meuser and Marwit (2001). A later study by Shulz et al. (2003) identified that providing end-of- life care to a loved one lead to improvements on emotional outcomes for caregivers.

Caregivers in the current study who lost their husbands to the disease reported symptoms of grief and loneliness that could be considered healthy and normal responses to the situation. While they reported these feelings, caregivers also reported a general increase in acceptance of what has happened, an increase in activity and pleasurable events, broadened social networks and support from various domains including family, clubs, friends and support groups since the death which is contrary to a finding by Burton et al., (2006) who suggested that caregivers did not show improvements on important emotional outcomes over time after death. This may be a reflection of the strong support surrounding these people in their time of need. Due to evidence that supports the tenet that institutionalisation has similar effects on grief as death, it could be assumed from the results that caregivers do improve emotionally and this may be a function of the support available to them and their ability to surpass feelings of guilt and loneliness.

The mobilisation and utilisation of supports across participants tended to vary. The difference in the amount of support received from family, friends, faith, and neighbours appeared to be a strikingly obvious contributor to differential outcomes. Carers who displayed continued and heightened stress, anxiety, depression and grief reported an overwhelming displeasure with the lack of support they received. On the contrary, carers who displayed better emotional outcomes commented on their utilisation of social supports and concluded that in their opinions this was a crucial protective factor. Social support could therefore be considered as a factor that affects caregiver outcome. The caregivers ability to involve themselves in pleasurable events and remain active during the stages of grieving could be considered a mechanism of social support networks. Another striking difference between the poor and positive outcome groups was that of the carer’s ability to remain active and move forward in life. While carers in the poor outcome group tended to display heightened levels of guilt surrounding involving themselves in pleasurable activities, carers who actively took up and engaged in these activities (such as golf, bowls, social groups) highlighted this as an important factor influencing their current well-being.

Limitations of the Current Research

Discrepancies between overseas studies and the current research findings may be suggestive of a number of limitations of the current research. Firstly, the sample was small (only 7 people) and therefore generalisability is limited. Further, the majority of caregivers were spouse caregivers and therefore the adult children caregivers were represented poorly. All carers were female therefore comparisons and differences related to gender (as suggested by Rudd et al., 1999) could not be made.

The recruitment process involved recruiting people who were readily available to take part in the research. This could have ruled out people who were very active in care, ill or emotionally fragile, busy with activities etc. Also, the sample only consisted of two carers who had lost their husbands to the disease.

It was difficult in some instances to determine healthy grief outcomes vs. poor emotional outcome and while the transition phase and death are characteristic of the cessation of the full-time caregiving role, they appear to be dramatically different phases of the caregiving career. In future research it may be more useful to obtain a participant sample of only carers of people recently placed into a home or only of carers of people who have recently died.

No Maori carers were involved in the study and therefore generalisability of the findings to the Maori population (and other cultures) may be inappropriate. In addition. all participants cared for a loved one with AD. While this study may have important implications for carers of people with AD, generalisability of the findings among other carers would need to be done with caution due to the differing demands and progression of the disease in AD. Further, and perhaps most importantly, carers were mainly recruited through the Alzheimer’s Waikato support group. The results suggest that this may be a potential highly protective factor against poor outcomes for carers. Thus the sample may have been made up of people who are more likely to involve themselves in support activities. The support received through the support group may have already impacted on the well-being of these carers. In order to obtain a more comprehensive sample, these factors would need to be taken into account. A sample may be obtained of carers of people admitted to hospital, or an advertisement placed in a community newspaper.

Despite being aware of trying not to do so, an undeniable amount of personal interpretation is evident within most qualitative studies. This may be a reason for the discrepancies both within and between studies of this nature. Despite this however, qualitative research allows for a richness of information and personal detail that is often surpassed in quantitative research designs. For the information requested of carers in the present study, qualitative research appeared to be the most useful way to obtain it and also proved useful in determining outcome through observation of the participant during the interviews.

Emotional well-being at the time of the study was self-reported by the participants. The information was also retrospective which may have limitations, particularly considering memory deterioration that occurs naturally with old age. Self-reports are often tainted by the persons personality traits and experiences. It may have been more useful to quantify emotional outcome through the use of standardised psychometrics such as the Beck Depression Inventory, the State-Trait Anxiety Inventory, the Meuser and Marwit Caregiver Grief Inventory (to distinguish grief from depressive symptoms) etc.

Implications of the Current Research

Due to the demographic revolution of the late 20th century, more people are surviving to ages when rates of AD increase. As a result, increasing numbers of elderly require some assistance to manage activities of daily living.

The role of the family in providing care for their aging family members has been well documented. Such research suggests that without adequate support, family caregivers may risk negative health and interpersonal consequences such as elevated stress, familial and financial strain, reduced social ties, physical health problems and mental health difficulties. Research around caregiving for relatives with a dementing illness has mainly focussed on the caregiving experience itself, to the neglect of the consequences of caregiving when the caregiving career is terminated (i.e. by death or placement in a nursing home) (Aneshensel et al., 2004). The current study has identified factors of the caregiving experience and relationship history that may have contributed to the carer's outcome. By identifying these factors we will be better equipped to identify protective and detrimental factors of the caregiving experience that may be related to outcomes in the caregiver, and therefore treatments can be adapted to suit individuals with differing circumstances. The current research also takes into account factors related solely to the AD caregiving experience which is multifaceted and rather unique compared to other caring roles due to the impact of memory loss on relationships. On a societal level, protective factors, if enhanced, may provide for opportunity to minimise reliance on residential home care facilities for care recipients. There is also the possibility of using the findings of this research for preventative purposes. There is the potential possibility also that by identifying factors that correlate to detrimental outcomes we may be able to target these factors before their effects are obvious. That is, we may be able to prevent poor outcomes and promote emotionally healthy grief processes and eliminate unnecessary caregiver stress.

The desire of some carers in the present sample to care for their loved one at home until death, or at the very least for as long as possible, highlights the need for greater support to be available so this can be achievable. This may in turn lead to more beneficial outcomes in caregivers as their sense of obligation and willingness to help and protect their loved ones would be honoured and achieved. Support with physical duties of caregiving may be an important factor in the aim of achieving this desire. This would not only serve as a protective factor for caregivers, but also has implications at a societal level. For instance, reliance on residential care facilities would decrease which in turn would make waiting lists shorter and the search or an appropriate facility for a loved one would become less stressful. The demand for mental health services for caregivers would in turn decrease as a result of preventing detrimental outcomes by increasing support and the number of options available for the caregiver.

Suggestions for Future Research

The generalisability of the results of the current research to all New Zealand caregivers of people with AD should be carried out with caution. Firstly it is worth considering the factors that may affect caregivers who are not actively involved in support groups. The majority of the current sample of carers were all involved with the Alzheimer’s Waikato support group to varying degrees. The effect that the support group may have had on these caregivers could be investigated further to determine whether this factor may have influenced the current results. Any common themes and variations apparent with carers who are not involved in support groups would be useful information to compare the current sample against.

Carers of Maori descent were not represented in this sample. This may reflect a lack of knowledge about available support services, a desire to care for a loved one at home, familial values of responsibility and obligation, or extended familial support. The findings would be more generalisable if the reasons for this poor representation were available.

Further studies using groups of carers with a variety of age related disabilities could indicate similarities in needs across participants. If similar needs were to be identified, the findings of the research could be used to assist in the development of a much more politically focussed advocacy platform for carers and their loved ones.

The factors identified in the current study which lead to detrimental and positive outcomes could be included in an information package for not only caregivers of people with AD, but professionals working in services with caregivers. The predictive validity of the aforementioned factors on outcome could then come under scrutiny and the applicability of these findings could be investigated.

Conclusion

The results of this study show that there are a number of identifiable factors that may relate to poorer mental health and emotional outcomes in caregivers and a number of factors that may serve as protective factors for the caregiver. Poorer outcomes seemed to be determined by the nature of the relationship between the carer and care recipient. Carers who experienced poorer outcomes also tended to have few societal and social support systems available to them, were inactive in pleasurable events, and continued to experience feelings of guilt and failure.

Factors that could therefore be considered to protect the caregiver from detrimental emotional outcomes could be long term collaborative planning with the care recipient for the transition to care, availability and utilisation of social support, a less dependent relationship history, good experiences of transition into care, positive perceptions of the care facility and remaining active in pleasurable events throughout the grieving process.

This study has shown that carers need to receive sufficient physical help, information (about the progression of the disease, options available, self-care, what to expect, etc.) financial assistance, respite care and social as well as societal support if they are to have the option of caring for a loved one at home while at this stage there clearly is a lack of options available to them. Services available to carers should incorporate this knowledge into their practise as a means of identifying potentially harmful factors and encouraging more beneficial responses.

The final words should be left with the caregivers who participated in this study.

> *“The grief is ongoing. The grieving is terrible. But I’ve accepted it now; God’s given me peace I really believe. I get a bit upset when I go there and see such sad sights, I’ve got to stop dwelling on it. You think that you grow until the end”.*

> *“At the moment I can’t see anything clear ’cos I’m in no-mans land. I think I’ve adjusted to this and I will adjust to his death you know. I’m very grateful I have a lovely family that are very supportive so I’ll keep involved so I can keep healthy. I’d like to remain positive”.*

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APPENDIX

Information Sheet for Participants

Information Sheet for Participants

What is the research?

The aim of the current research is to determine whether there are any factors present within the caregiving experience (for example, high stress caregiving) that relate to how well a person can deal with grieving a loved one, and how emotionally equipped they are at coping with the post-caregiving experience. By identifying these factors we will be better equipped to provide more appropriate counselling that takes into account individual experiences. There is the potential possibility also that by identifying factors that correlate to detrimental outcomes, we may be able to target these factors before their effects are obvious. That is, we may be able to prevent bad outcomes and promote emotionally healthy grief processes and eliminate unnecessary caregiver stress. This research is supported by a University of Waikato Masters Research Scholarship.

What is expected of you?

You will be expected to partake in one 1 &1/2 interview that will be undertaken either at the University of Waikato or in your home.

During the interview you will be asked questions relating to your caregiving experience. For example, how your life changed as a result of caregiving and how you coped with stressors. You will be asked to describe what your duties were and also how you felt as the disease progresses. You will also be asked to describe your emotional experiences of placing your relative into a nursing home, as well as describing how you felt after this decision was made. If applicable, your grief experiences during this time, or at the time of their death, will also be investigated.

Eligibility

Participants I am looking for will:

-Have been a primary caregiver to a relative or spouse with Alzheimer's disease…**and**

-Placed their relative in a nursing home less then 6 months ago…**or**

-Their relative passed away from Alzheimer's disease less then 6 months ago

What will happen to the information?

The information derived from the interviews will be analysed for recurring themes and obvious differences. The information will be organised into a Masters thesis. All names will be anonymised (by utilising codes) so participants can not be identified and audiotapes will be wiped after transcribing is completed.