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**RELATIONSHIPS BETWEEN  
COPING STRATEGIES AND MOOD STATES  
IN CAREGIVERS OF PEOPLE WITH DEMENTIA  
IN NEW ZEALAND**

A thesis presented in partial fulfilment of the  
requirements for the degree of  
Master of Science in Psychology  
at Massey University, Albany,  
New Zealand

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2004

## **Abstract**

Alzheimer's dementia is a worldwide concern, as is the growing aging population and demands on services by many elderly people. Caregiving for people with dementia is recognised as one of the most distressing events in any family's life cycle. Many adverse effects among caregivers have been identified, such as increased depression and anxiety, however many questions remain unanswered. New Zealand, in particular, lacks accurate information on caregivers of people with dementia, obviously affecting the programmatic and clinical decisions made about this group.

This study investigates the role of helping attitudes and coping strategies on the mood states (positive and negative affect) of caregivers of people with dementia. A regional sample, recruited through the membership lists of Age Concern and the Alzheimer's Society, consisted of 158 caregivers. A self-report questionnaire was developed for the study using three instruments: Helping Attitude Scale (HAS), Revised Ways of Coping Checklist (RWCCCL), Positive and Negative Affect Scales (PANAS). A range of demographic information was also included in the questionnaire.

The results provide a description of the characteristics of New Zealand caregivers and found that helping attitudes and coping strategies each contribute in different ways to positive and negative mood states, and differentially predict affective outcomes in caregivers of people with dementia. The results may assist practitioners to identify caregivers who may be at risk for developing mood difficulties and allow for the implementation of appropriate psychological intervention and prevention strategies.

## Acknowledgements

My appreciation and thanks go to the many people who have helped and encouraged me during my studies, the research for the project, and the writing of my thesis. Several of them deserve special mention:

Dr. Patrick Dulin, my supervisor, whose guidance, high professional standards, enduring patience, and encouragement assisted me immeasurably. I have tremendous respect for his knowledge in the field of caregiving.

My husband, Clive, for his constant support, understanding, and coping so admirably while I completed my studies and research.

My parents, Beaty and Dave, for their advice, encouragement, and support, without which the task would have been so much more difficult.

The caregivers who participated in this study, and whose expressed effort, time and interest made the research possible.

The Alzheimer's Society and Age Concern, and their staff, whose interest, cooperation, and support of the study, were a source of encouragement for me.

The many friends and neighbours, who through their friendship and encouragement supported me through this long process, especially Wayne, Tessa, Julie, Anne, Gillian, Marae and Vino.

## CONTENTS

Abstract.....	ii
Acknowledgements .....	iii
List of Tables .....	vi
List of Appendices.....	vii
INTRODUCTION.....	1
LITERATURE REVIEW .....	7
Caregiving .....	7
Psychological Impact of Dementia Caregiving.....	9
The Role of Coping Strategies .....	12
Helping Behaviours and Psychological Functioning .....	17
Mood States and Well-being .....	25
Summary .....	29
The Current Study .....	31
METHODOLOGY .....	33
Research Design .....	33
Sample Information.....	33
Measures.....	35
Data Analysis .....	38
RESULTS.....	39
Data Management.....	39
Profiles of Caregivers and People with Dementia.....	40
Measures in Caregiver Sample.....	45
Relationships between Demographic Factors, Helping, Coping and Mood States....	48
Intergroup Differences.....	56
Role of Helping Attitudes and Coping Strategies in Mood States .....	58

Prediction of Positive Affect .....	59
Prediction of Negative Affect.....	61
DISCUSSION.....	64
General Characteristics of Caregivers and People with Dementia.....	64
Role of Demographic and Lifestyle Variables to Positive and Negative Affect.....	64
Role of Helping Attitudes Regarding Positive and Negative Affect.....	68
Role of Coping Strategies Regarding Positive and Negative Affect.....	69
Intergroup Differences .....	70
Applications of Findings .....	73
Limitations of the Study .....	74
Future Research Implications.....	76
REFERENCES .....	79
APPENDICES .....	91

### List of Tables

Table 1. Frequencies of demographic and lifestyle variables relating to caregivers.....	40
Table 2. Means and standard deviations of demographic and lifestyle variables...	43
Table 3. Frequencies of demographic information relating to person with dementia (those cared for) .....	44
Table 4. Descriptive statistics of helping, coping strategies and mood states.....	45
Table 5. Comparison of coping between norm group and caregiver sample.....	46
Table 6. Comparison of positive and negative affect scores between norm group and caregiver sample.....	47
Table 7. Correlations between demographic and lifestyle variables.....	49
Table 8. Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores.....	52
Table 9. Correlations between HAS, RWCCCL, and PANAS scores.....	54
Table 10. Descriptive statistics of study variables according to gender.....	57
Table 11. Stepwise regression analysis for predicting positive affect .....	61
Table 12. Stepwise regression analysis for predicting negative affect.....	63

## List of Appendices

Appendix A. Alzheimer's disease and related dementias .....	92
Appendix B. Request for participants .....	95
Appendix C. Information sheet .....	98
Appendix D. Consent form .....	100
Appendix E. Confidentiality agreement.....	102
Appendix F. Caregiver questionnaire .....	104

## INTRODUCTION

Alzheimer's disease and the related dementias are a significant health concern, not only for people with the diagnosis, but also their families, caregivers and service providers (Gallant & Connell, 1998). Dementias currently affect more elderly people than ever before, with numbers set to increase substantially by 2021. Not only are people living longer than before, but more older people require a wider range of assistance for an increasing number of chronic conditions, including all aspects of dementia service delivery (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Gallager-Thompson, Coon, Rivera, Powers, & Zeiss, 1998; McLeod, 2000; Overman & Stoudemire, 1993; Zarit, & Edwards, 1999). Medical and scientific advances, improved standards of living, and major demographical changes throughout the world have all contributed to the current situation. Unfortunately, many caregivers are struggling with the demands of caring for their older relatives, with increasing numbers requiring assistance from health professionals for a variety of physical and mental health related problems. The situation is a growing cause of concern and focus for research, as health services struggle to meet the needs of an aging population.

Caring for an older person with a disability is one of the most stressful and disruptive events in any family's life (Stuckey, 1998; Zarit & Edwards, 1999), and the responsibilities associated with caring for the elderly are many and varied. Tasks range from basic physical assistance to emotionally challenging tasks, such as dealing with behavioural problems, wandering and personality changes. Many adverse consequences affecting the caregiver's psychological well-being have been identified (Gallager-Thompson, et al., 1998), some lasting long after the elderly person receiving care has died (Doka, 1993; Zarit, & Edwards, 1999).

The existence of a relationship between stressful events and caregiving is well established. There is considerable evidence supporting the role of severe, stressful events or difficulties in the development of depression and other psychological problems (Beck, 1983; Eckenrode, 1994; Brown, Bifulco, & Harris, 1997; Clark & Oates, 1995; Woods & Mitchell, 1997). Stressful events are thought to trigger lasting changes in the function of neurotransmitters in the brain, increasing the risks for future mood disorders (Kaplan & Sadock, 1998). Research has indicated that dementia caregiving in particular is associated with a variety of adverse mental and physical health outcomes including depression (Mellins & Bloom, 1993; Rose, Strauss, Neundorfer, Smyth & Stuckey, 1997).

There is, however, considerable disagreement regarding the nature of the effect of stressful events. Some researchers suggest simplistic links between stressful events and negative outcomes for different individuals (Eckenrode, 1984), while others, such as of DeLongis, Folkman, & Lazarus (1988), see the relationship between mood disturbances, daily problems and life events as more complex.

The work of DeLongis, et al., (1988) in particular, indicates that the negative effects of everyday stress and mood swings are limited to that day, and that many individual differences influence the relationships between stress, health and mood over time. Their findings further suggest that the long-term effects of stressful life events, such as caregiving, posed greater risks for psychological difficulties and negative outcomes, including depression.

Furthermore, some researchers argue that the ongoing stress of long-term life events increase the vulnerability of certain individuals and groups to depression and negative physical and mental health outcomes in general and that maladaptive coping

strategies not only maintain the stress, but reinforce negative affect and helplessness (Nolen-Hoekseman, 1987).

Research indicates that older people experience fewer life events, such as involvement in family, work and community related activities, but more loss related events overall, including loss associated with declining health, work role, spouse, friends and loved ones (Folkman, Lazarus, Pimley, & Novacek, 1987). Considerable variation exists in how individuals experience life and loss events, stress, and psychological distress, meaning that some people are more vulnerable to negative health outcomes than others. Age, gender, and coping have all been identified as variables affecting vulnerability.

It is also important to consider that the mere presence of negative life events do not necessarily lead to negative consequences or depression, but how an individual views the events is crucial in the development of negative outcomes, such as depression (Beck, 1983). Individuals who are more vulnerable to developing negative outcomes are more likely to misinterpret events, and are more sensitive to perceived criticism, rejection, loss, failure, and frustration than less vulnerable individuals. They may also be more responsive to negative life events, use more self-defeating coping strategies (Nietzel & Harris, 1990), and in doing so contribute to their depression and negative outlook on life (Beck, 1983; Hammen, 1995).

Vulnerable people tend to use less adaptive coping strategies in response to life events, and experience longer or more intense depressive reactions as a result (Beck, 1983; Nietzel & Harris, 1990). Independently oriented individuals seem to deal with setbacks more effectively, and increase their positive emotional responses to negative events (Nietzel & Harris, 1990). Vulnerable people are reliant on other

people for support and meeting their needs and their self-worth and confidence depend on their closeness to other people (Beck, 1983).

The differential vulnerability between individuals provides a partial explanation for the contribution of personal, social, and situational factors in explaining the relationship between the variables (Lu, 1995). Evidence for the vulnerability theory suggests that not only do different personalities react differently to stressful events (Hooker, Monahan, Shifren, & Hutchison, 1992; Krohne, 1996), but that differences in coping strategies could be responsible for the relationship between vulnerable personality types and depression (Nietzel & Harris, 1990).

Coping strategies have been found to play a significant mediating role in adaptation to stressful life events, affecting the way people think or act in response to the different demands of these life events (Folkman & Lazarus, 1988, 1991). The work of Folkman and Lazarus provided much needed structure and direction for research with the development of their transactional model for understanding coping processes (Folkman & Lazarus, 1980, 1985, 1986, 1991; Lazarus, 1966; Lazarus & Folkman, 1984, 1991). This model regards coping and stress as a series of transactions in response to the events and situations individuals experience in their daily lives. Their work not only contributed to the development of coping measures, such as the original Ways of Coping scale (Lazarus & Folkman, 1980; Vitaliano, et al., 1990), but assisted with the identification of various coping strategies, such as problem focussed coping, wishful thinking, seeking social support, avoiding, and blaming self or others.

Traditionally, coping strategies have been categorised into problem and cognitive focussed coping strategies, which are used to manage stressors and situations, and emotion focussed coping strategies, which are used to manage

psychological stressors (Nolan, Grant & Keady, 1996; Zarit & Edwards, 1999; Rose, et al., 1997). The reliance of some individuals on specific coping strategies to resolve issues surrounding stressful events has also been described as reflecting a personal coping profile (Vitaliano, et al., 1990).

There is no doubt that ongoing stressful events can have a negative effect on the psychological well-being of an individual (Reynolds & Gilbert, 1991), or that caregiving is stressful. As such, caregivers may experience adverse consequences in the course of their caregiving (Gallagher-Thompson, et al., 1998), however, not all caregivers cope in the same way or to the same extent (Levesque, Cossette, & Laurin, 1995), and many different personal and situational factors influence coping among this group.

In spite of the difficulties and psychological consequences caregivers face, many continue to provide assistance to their needy loved ones. By becoming involved in caring for other people, many caregivers place the well-being of other people ahead of their own, seemingly without counting the cost. This selfless activity, aimed at benefiting another, is considered to reflect altruistic behaviour (Batson & Shaw, 1991).

In conclusion, caregiving is one of the most difficult situations faced by a growing number of individuals, and many adverse consequences have been identified (Gallagher-Thompson, et al., 1998). However, considerable variation exists in how caregivers experience the negative life events and psychological stress associated with caregiving (Levesque, et al., 1995). Some are left more vulnerable to negative health outcomes, such as longer or more intense depressive reactions, and also tend to use fewer adaptive coping strategies in response to life events (Beck, 1983; Nietzel & Harris, 1990).

Coping strategies play a significant mediating role in adaptation to stressful life events, affecting the way people respond to the demands of negative life events (Folkman & Lazarus, 1991). Some caregivers tend to rely on specific coping strategies or personal coping profiles to resolve issues surrounding stressful events (Vitaliano, et al., 1990).

Helping behaviours can be considered to be coping strategies as adaptive helping behaviours have been linked to positive psychological health (Vaillant, 2002). This study investigates the complex relationships between coping strategies and mood states in caregivers of people with dementia in New Zealand. This will both contribute to the current knowledge and theory in the area of helping and coping strategies, and improve delivery of health and support services to caregivers of people with dementia.

## LITERATURE REVIEW

This chapter explores the existing literature regarding the psychological impact of caregiving, the coping mechanisms used by caregivers to manage the stressful life events, the role of helping attitudes and behaviours in this process, and how these variables relate to positive and negative affect among caregivers. Current research relating to these constructs is discussed against the background of underlying theories such as the transactional theory of stress and coping by Folkman and Lazarus (1980; Lazarus & Folkman, 1984), the more recent cognitive phenomenological framework developed by Vitaliano and associates (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985; Vitaliano, Maiuro, Russo & Becker, 1987), and the Broaden-and-Build theory of Frederickson (2001).

It is well established that stressful events do not affect all caregivers equally (Levesque, et al., 1995). Not all caregivers experience negative outcomes as a result of caregiving, in fact a number of positive outcomes have been identified. These include an increased ability to solve problems, better adjustment, an enhanced feeling of self-worth, and enhanced general well-being (Sanders-Dewey, Mullins, & Chaney, 2001; Vaillant, 2002). Both coping strategies and mood states are differentially related to many personal and situational factors that affect helping, coping and mood states that will be discussed in the following section (Bolger, 1990; Reynolds & Gilbert, 1991; Watson & Clark, 1984; Watson, Clark, & Carey, 1988).

### Caregiving

Caring for the elderly is a challenging responsibility that involves a variety of tasks, ranging from physical assistance to emotionally challenging situations. Many

adverse effects for caregivers have been identified; some of which last for long after the elderly person has died (Doka, 1993; Zarit & Edwards, 1999). Caregiving is increasingly being recognised as a complex situation, influenced by many variables, and characterised by individual variation throughout. Not only do individual caregivers bring a variety of characteristics to the caregiving situation, but they also react to and manage stressful life events in different ways (Gallager-Thompson, et al., 1998). Some caregivers adapt to chronic or deteriorating conditions, while others struggle to cope (Levesque, et al., 1995).

It is important to identify both the factors that adversely affect caregivers, and those that limit the harmful effects of caring for others in order to facilitate the development of intervention programmes (Aneshensel, et al., 1995). Cultural and socio-economic factors have been shown to be important influences in caregiving, yet few researchers have investigated their contributions in detail. Research findings suggest possible differences between ethnic groups in their values and beliefs on caring for the elderly, ageing and disability (Aneshensel, et al., 1995; Connell & Gibson, 1997). Some groups, for instance, consider caregiving at home a priority, while others readily accept and use professional assistance.

There have been suggestions that the willingness to use, and availability of services, may offset economic disadvantages for some groups of individuals (such as those in poverty or facing financial difficulties), provided access is not impeded. It has also been noted that members of some cultures tend to share caregiving duties, while others are sole providers (Stommel, Given & Given, 1998). Previous research in this area has indicated that cultural and socio-economic factors have a complex relationship to caregiving and require further investigation.

### **Psychological Impact of Dementia Caregiving**

Caring for an elderly person with dementia is one of the most stressful and disruptive events in a family's life (Stuckey, 1998; Zarit & Edwards, 1999). Most caregivers experience a range of difficulties, such as lack of time for self and family members, high levels of social isolation, disrupted marital and family relationships, career interruptions, financial strain, physical burdens and hard physical work associated with physical injuries, as well as a continuing sense of loss for the person with dementia (Pratt, Schmall, Wright & Cleland, 1985).

The behavioural and emotional problems of people with dementia, and the particular meaning it has for caregivers, tends to have a greater impact on caregivers than routine physical assistance. These factors also add to feelings of captivity and being overloaded or overly burdened (Zarit, & Edwards, 1999; Aneshensel, Pearlin & Schooler, 1993; Aneshensel, et al., 1995; Prushno & Resch, 1989). However, caregivers are not affected equally by the caregiving experience. Psychological distress and negative feelings about the caregiver role are often related to the subjective experiences of the stressor by the caregiver (Levesque, et al., 1995). Some caregivers appear to have a more positive and mature outlook on life, as indicated by their interest in and attitude toward helping other people. They are clearly concerned with the welfare of other people and identify with their needs, without apparent concerns for their own situation or receiving a reward. Vaillant (2002) considers this altruistic approach to helping people to be a psychologically healthy way of dealing with stress, and evidence of maturity. An altruistic approach has been shown to be associated with positive outcomes for caregivers in general, such as increased ability to solve problems, feelings of self-worth and adjustment (Bierhoff, 2002; Zarit & Edwards, 1999).

Family conflict around diagnostic situations and care provision can be very stressful, especially if unsolicited advice is given. It intensifies the difficulties experienced by caregivers, and is associated with poorer outcomes, such as strained familial relationships and emotional difficulties (Zarit & Edwards, 1999).

Research has also identified a range of psychological symptoms associated with caregiver distress, which may assist in identifying “at-risk” caregivers. These include anxiety and irritability; feelings of guilt, loneliness and general demoralisation; high rates of clinical depression; increased use of psychotropic medications; and lasting psychological impairment and distress following the death of the person with dementia (Gallagher-Thompson, et al., 1998; Zarit & Edwards, 1999).

According to Vitaliano, Russo, Weber, and Celum (1993), attempts to relate psychopathology and stress are common but are often considered uni-dimensional. It represents an under utilization of the cognitive-phenomenological model of stress and coping, which supports a reciprocal relationship between coping and distress. According to this approach, a number of factors determine the role of stress (or distress) within an individual. These factors include the potential importance of the event, the personality of the person, the specific properties of the stressful event (novelty value, duration or predictability), available coping responses of the person, the determination of potential value of the event and the interrelationships between these factors (Vitaliano, et al., 1993). Within this framework, an event is considered to be stressful if it is seen as harmful or considered dangerous by an individual caregiver, and specific coping strategies are selected and used by the individual to reduce this harm or distress. It is an ongoing, cognitive process of appraisal and re-appraisal. This framework is useful for investigating the multi-dimensional nature of

the relationships between coping, stress, emotions, and behavioural responses (Vitaliano, et al., 1993).

Research addressing the associations and effectiveness of coping strategies and psychosocial adjustment to chronic illness has identified a variety of coping strategies and emotional behaviours that are reliably associated with negative outcomes. Emotional coping strategies, such as escape or avoidance, seeking information or comfort, wishful thinking and fantasizing, have been shown to be associated with higher levels of distress, uncertainty and diminished adjustment (Bowman & Stern, 1995; Sanders-Dewey, et al., 2001). Research also suggests that emotional coping strategies are more related to psychopathology and negative emotions than problem focussed strategies (Chan & Hui, 1995; Endler & Parker, 1993; Endler, Parker, & Butcher, 1993; Parkhill, 2000). Research suggests that positive appraisal, using a problem focussed approach, and perceived control, all contribute to more favourable outcomes including physical health and well-being of caregivers (Bowman & Stern 1995; Endler & Parker, 1993, 1994; Sanders-Dewey, et al., 2001; Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987; Vitaliano, Maiuro, Russo, et al., 2001). Additionally, predictability and familiarity of events also influence appraisal and the distress experienced by individuals. People cope more successfully with clearly defined, familiar stressors, especially if previously effective coping strategies are known. Caregivers in particular experience less aversion with predictable events (Vitaliano, et al., 1993).

There is also some evidence to suggest that the nature of stressors and effectiveness of coping styles interact with each other. Avoidance strategies are more effective with stressors of short duration, and attention strategies more effective with stress lasting longer than a week (Weidner & Collins, 1993).

It seems reasonable to conclude that the psychological impact of caregiving varies between individuals, and that many different personal, social and environmental factors influence the caregiver's ability to cope with stressful life events. The coping strategies used by caregivers have also been shown to play an important role in determining the outcomes for individual caregivers.

### **The Role of Coping Strategies**

Research has used a range of approaches in exploring the relationship between stressful events, coping and resultant psychological outcomes for individuals. These have included both the nature and effect of the relationships and exploring differences between individuals and groups (Lazarus & DeLongis, 1983). Results from this area of inquiry have increased our knowledge about different aspects of the stress and coping relationships.

Categorising coping strategies has been useful in developing specific interventions (Nolan, et al., 1996; Zarit & Edwards, 1999; Rose, et al., 1997). The three main groups of coping strategies identified include problem focussed coping to manage stressors and situations, cognitive coping to manage the meaning of the stressors through re-labelling, and emotion focussed coping (the management of the associated stress).

Historically, dispositional and contextual approaches have guided coping research. Dispositional coping describes the relatively stable basic coping style an individual uses in different situations, whereas contextual coping, refers to the specific coping behaviours an individual uses in stressful or upsetting situations. Individuals actively select these strategies (Folkman & Lazarus, 1980, 1985; Lazarus & Folkman, 1984). Some support exists for the presence of underlying stable

dispositional coping styles (Heppner, Cook, Wright, & Johnson, 1995). This presents as coping preferences, and the similar, habitual behaviours people use in different situations (Bolger, 1990; Endler & Parker, 1989; Krohne, 1996). What is becoming increasingly clear is that coping is a complex construct, influenced by a range of personal and situational factors, with many interrelationships between coping strategies.

The work of Folkman and Lazarus has been influential in guiding research and providing much needed structure in the field of coping, particularly their transactional model of stress and coping. This model allowed for a more unbiased assessment of the relationships between coping and stress by incorporating a number of factors, processes, and transactions (Folkman & Lazarus, 1980, 1985, 1986; Lazarus, 1966; Lazarus & Folkman, 1984, 1991). Their work also contributed to the identification of two major functions of coping, the regulation of distressing emotions (emotion focussed coping) and addressing a specific problem in order to change it (problem-focussed coping). Both of these functions used cognitive and behavioural ways of managing difficulties, and regard coping as a series of steps (transactions) or specific responses to stressful situations, rather than as personality features or adaptation to distress, as suggested by Vaillant (1977, 2002).

The transactional model views coping as a dynamic, problem oriented approach, responding to the changing demands and appraisals of a situation over time. Appraisals of risks and potential threats to an individual serve as links between stressors and coping responses of individuals. This approach not only acknowledges individual characteristics, but also the ability to respond and change to different situational demands and a preferred, personal way of coping in response to particular demands (Lazarus & Folkman, 1991). In contrast to the problem oriented approaches,

personality or trait approaches to coping were regarded as simplistic, and underestimating of the complexity and variety of coping efforts (Lazarus & Folkman, 1991).

Cognitive appraisal and coping can also be considered as having a reciprocal relationship. Individuals use cognitive appraisal to determine the risk of a situation, and a suitably effective response to manage it. Every aspect of the situation, including the individual thoughts, or feelings, is open to change. More than one re-appraisal or re-assessment of the situation and the coping efforts required is often needed before a resolution occurs. This approach views coping as a series of transactions, which is influenced by many factors such as personal values, beliefs, commitments, and goals. Research has also indicated that personal resources, such as financial means, social or problem-solving skills, health, and energy levels affect the process (Coyne, Aldwin, & Lazarus, 1981).

Appraisals can be either primary or secondary in nature (Lazarus & Folkman, 1984). Primary appraisal refers to the evaluation of personal meaning and perceived level of stress by an individual, such as harm or loss, threat or anticipation of threat, and challenging, or potential for growth. Challenging responses are more likely to occur if a person feels in control of the situation, even partial control. Secondary appraisal requires the assessment of tasks and actions that are needed or available to manage the situation. This complex process takes a number of factors into account, such as coping options, their likely effects, and the expectation of the effectiveness of a particular strategy in resolving a problem (Lazarus & Folkman, 1984).

Research into problem and emotion focussed coping has also highlighted the differential nature of activities involved with each of these strategies (Lazarus & Folkman, 1984). Problem focussed activities are aimed at altering or managing the

problem, while emotion focussed activities are directed at regulating emotional responses and reactions to problem. Coping activities are either approach or avoidant by nature. Approach activities involve cognitions and behaviour, while avoidant activities involve distractions and emotional withdrawal. A person can seek out other people, as in social diversion, or engage in a substitute task when using avoidance (Endler & Parker, 1994).

Research has consistently found problem focussed and emotion focussed coping strategies to be differentially effective (Folkman & Lazarus, 1988; Valliant, 2002). Problem focussed coping (i.e. making a plan to solve a problem) and cognitive strategies, have not only been found to be more effective over time, they are also related to lower levels of distress, and positive mental and physical health outcomes (Sanders-Dewey, et al., 2001; Valliant, 2002). Emotion focussed coping (i.e. just trying to get over it), on the other hand, has been found to be related to higher distress, poorer mental health and negative psychological outcomes for caregivers (Gallagher-Thompson, et al., 1998; Pruchno & Resch, 1989; Rose, et al., 1997). However, there appears to be limited understanding of how coping responses are related to individual emotions (Folkman & Lazarus, 1988). Past research has often been uni-directional and focussed on how emotion and anxiety interfere with cognitions. This underestimated both the complexity of emotion and coping processes, and regarded emotion as motivating or impeding behaviour.

According to Folkman and Lazarus (1988), emotions are dependent on the significance of an individual's cognitive appraisal. The relative value of a stressor depends on the personal meaning it has for an individual, such as the perceived risk and the possible benefit or harm that can occur. It is an active process, and values are

re-considered as changes occur. The relative success of a coping strategy in managing a specific event or situation contributes to the emotions experienced by individuals.

Recent research has found strong positive relationships between emotion focussed behaviours, psychopathology and psychological distress (Endler & Parker, 1993; Endler, Parker, & Butcher, 1993). Specifically, escape-avoidance, accepting responsibility, and behaviours related to self-control are associated with negative emotions (Chan & Hui, 1995; Endler & Parker, 1989, 1990, 1993) whereas problem solving strategies were not only related to lower levels of distress and increased adjustment (Sanders-Dewey, et al., 2001), but also appeared to be unrelated to psychopathology (Endler & Parker, 1990, 1993, 1994).

Extensive research by George Valliant (2002) also supports the changing nature and effectiveness of coping strategies across the life span. Coping strategies that are more social and collaborative in nature, such as altruism, religion, talking to a spouse, children, and friends, tend to become more prominent and effective with age. Longitudinal studies like the Grant and Inner City Youth studies have demonstrated that adaptive coping strategies are the second most important predictor of healthy aging (Valliant, 2002).

The use of a conceptual model of stress and coping, such as the transactional model, and psychometrically sound measures of coping and distress, such as the original Ways of Coping scales, are an improvement on previous structure and theory for research (Vitaliano, Maiuro, et al., 1987). The refinement of the original transactional model led to the current cognitive phenomenological framework for the study of stress and coping, providing additional structure in the field (Vitaliano, et al., 1993; Vitaliano, Maiuro, et al., 1987).

The cognitive phenomenological framework presents distress as a function of a number of factors that determine the role of stress (or distress). These include the potential importance or influence of the event, the personality or experience of the person, the specific properties of the event (novelty value, duration or predictability), the available coping responses an individual has, the determination of potential value of the event, and the interrelationships between these factors (Vitaliano, et al., 1993). According to this framework, an event is considered as stressful, if it is seen as harmful or dangerous to the individual, meanings are assigned to it and specific coping strategies are selected and used by the individual to reduce this harm or distress. It is an ongoing, cognitive process of appraisal and re-appraisal, and reflects the changing nature and reciprocal relationship between coping and stress (distress). The framework is useful for investigating the multi-dimensional nature of the relationships between coping, stress, emotions, and behavioural responses (Vitaliano, et al., 1993).

### **Helping Behaviours and Psychological Functioning**

Social interest has a long history in psychology and is considered related to helping and altruism as well as being indicative of psychological health (Vaillant, 2002). Research has also found positive relationships between social interest and adjustment, feelings of self-worth and a lack of pathology (Endler & Parker, 1990, 1993; Sanders-Dewey, et al., 2001).

Unfortunately, the terms helping behaviour, prosocial behaviour, and altruism, have frequently been used interchangeably, creating some confusion in the field (Bierhoff, 2002). The following descriptions are offered to provide some clarification. Helping is regarded as a general concept and includes all activities and behaviours

directed at providing interpersonal support, whereas prosocial behaviour is a narrower concept directed at improving the situation or welfare of an individual, rather than being the result of professional services (Bierhoff, 2002). Altruistic behaviour is a specialised form of prosocial behaviour, with the additional constraints of perspective taking and empathy characterising the helper's motivation (Bierhoff, 2002; Davis, 1996).

Historically, research has focussed more on antisocial behaviours, such as aggression, than on prosocial behaviours. This is partially due to the perception that helping others has an economic cost and is therefore detrimental to the person performing the behaviour (Bierhoff, 2002; Davis, 1996). Purely altruistic behaviours do not seem to have any logic to them - why would a person perform behaviours that seem to have a cost, but no gain to themselves?

Researchers from a number of theoretical backgrounds have attempted to explain this type of prosocial behaviour, with the empathy-altruism hypothesis and work of Batson on altruistic motivation dominating the field (Batson, 1991; Batson & Shaw, 1991). According to this view, altruistic motivation is based on the goal of increasing the welfare of another person rather than on self-interest or egoistic motivation (Batson, 1991; Bierhoff, 2002). It is a purer motive for helping other people than a motivation of self-gain, and occurs when people experience events and emotions in a similar way to the other person (Batson, 1991; Batson & Shaw, 1991).

Batson equated altruistic motivation with empathic emotion. His model suggests that when a person is perceived to be in need, feelings of sympathy, tenderness, and compassion develop and increase the chances or readiness to become involved in helping others (Batson, 1991; Batson & Shaw, 1991). Critics of this view suggest that these feelings actually narrow the focus or scope of prosocial behaviours,

as the empathic feelings are focussed on those people who elicit compassion rather than larger issues in society (Bierhoff, 2002).

Debates have long raged over the meaning of altruism, egoism, and prosocial behaviour, with some suggesting that altruism is part of a continuum of behaviours in general (Bierhoff, 2002; Cialdini, Brown, Lewis, Luce, & Neuberg, 1997). In particular, the negative state relief theory of Cialdini and his associates consider helping behaviour to be a different version of egoism (Cialdini, et al., 1997; Cialdini & Fultz, 1990).

The negative state relief theory regards helping behaviour as motivated by the individual's desire to reduce negative emotions (Cialdini, et al., 1997; Cialdini & Fultz, 1990). Helping behaviour is seen as self-reinforcing, providing the individual with internal rewards for engaging in helping behaviour, resulting in positive or good feelings about the behaviour. However, very high levels of personal stress and anxiety, and the additional stress from seeing others in need, may influence helping negatively (Bierhoff, 2002; Davis, 1996). As such, proponents of the negative state relief theory question the existence of true altruism, as it can be explained as a version of negative state relief.

Altruistic helping behaviour is increasingly being regarded as a coping strategy, as indicated by the extensive research of Vaillant (1977, 2002). His work views altruistic helping behaviour not only as an indication of increasing maturity, but as a way of managing or coping with the demands of the stresses experienced by individuals. His work provides detail on numerous unexplained examples of altruistic helping behaviours being associated with positive outcomes. Ongoing longitudinal studies have consistently found that adults engaged in altruistic helping behaviour experience more positive psychological outcomes than adults who do not engage in

altruistic helping behaviours, even in the face of serious and ongoing stressful events Vaillant (1977, 2002).

As interest in the underlying motivation and other psychological processes related to human behaviour increased, specifically the prosocial behaviours such as giving, helping, and sharing (Batson & Shaw, 1991), the one sided nature of the more traditional perspectives became apparent. These perspectives attempted to explain complex helping behaviours in relatively simplistic terms. Explanations included behaviour having a genetic or instinctive basis, a behavioural-learning focus involving reinforcements, rewards and punishments, as well as a variety of social theories based on norms, exchanging costs and benefits, or cultural approaches (Knickerbocker, n.d).

In contrast, the more recent approaches appear to hold the view that altruistic helping behaviour includes not only a motivational component, but is also a complex cognitive behavioural process, influenced by many personal and situational factors, and as a process it is open to change with time. It also differs from more general helping behaviour, which refers to providing direct assistance to people in need in situations that do not involve risks or sacrifices for the helper (Reber & Reber, 2001).

Additional support for helping behaviour as a coping strategy comes from a number of theoretical models, such as the cognitive models on coping, the motivational models of Batson (Batson 1991; Batson & Shaw, 1991), Cialdini (Cialdini & Fultz, 1990; Cialdini, et al., 1997), and the more recent Broaden-and-Build theory of Frederickson (2001). The cognitive models include the decision process model of Latane and Darley (1970), the transactional model of coping and stress by Folkman and Lazarus (1980) and the cognitive phenomenological framework for coping of Vitaliano and his associates (Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987; Vitaliano, et al, 1990).

People generally help those who are less fortunate because of altruistic reasons without counting the costs or personal risks or because of self-interest or egoistic reasons. Both altruistic and egoistic behaviours are forms of prosocial behaviours aimed at benefiting an individual. In altruistic behaviour another person benefits, whereas in egoistic behaviour the individual engaged in the behaviour benefits the most, taking benefit from such things as satisfaction from completing a task (Bierhoff, 2002; Reber & Reber, 2001). Research into the many facets surrounding prosocial behaviours such as giving, helping and sharing, is likely to continue.

Latane and Darley developed a five-step model describing decision making in prosocial situations (Bierhoff, 2002; Darley & Latane, 1970) in which people need to notice and interpret a situation before they can assume personal responsibility. They also need to know what to do and decide on a possible effective course of action before finally participating in helping a person (Darley & Latane, 1970).

Schwartz and Howard (1981, cited in Bierhoff, 2002) expanded this model to include the activation of social norms and values, and personal norms in the decision making process. These norms help to determine the moral responsibility of an individual in a specific situation, and provide the linkage between situational demands and internalised values for the individual. Once activated, they serve as standards of conduct and guide the decision making process.

In addition to the above cognitive decision making process, the appraisal process also plays an important role in coping with emergency situations, providing support for altruistic helping behaviour as a coping strategy (Schneider, 1988, cited in Bierhoff, 2002). Appraisals of specific situations allow an individual to evaluate the aspects of each situation and available behavioural alternatives for its significance to the well-being of the individual (Bierhoff, 2002; Lazarus & Folkman, 1984).

Challenging situations are known to contribute to a number of positive outcomes for individuals, such as stress reduction, perceived competence, and social integration (Bierhoff, 2002). This has been demonstrated in a study involving older adults where helping others was positively related to mental health (Midlarsky, 1991, cited in Bierhoff, 2002).

A high degree of helping may well be related to strong personal needs, regardless of whether the helping behaviours are classified as altruistic or egoistic. However, research has shown that altruistic motives appear to be more related to successful outcomes, whereas egoistic motives appear to be related to less successful outcomes (Miller, 2000). The work of Dando and Minty (1987) (cited in Murphy, 1999) also suggests the need for caregivers to come to terms with their own lives and experiences, in order to become more emotionally mature, with the strength and capacity to fill a caregiver role.

Helping behaviours may be motivated by a variety of factors. Negative emotions such as guilt or responsibility may motivate helping, as can positive emotions such as compassion and social approval. Often these emotions are strongly linked to social realms, such as religion or culture. High levels of self-efficacy and modelling, instruction and familiarity also contribute to increasing helping behaviours (Bierhoff, 2002).

Both positive and negative moods affect helping behaviour. According to the negative state relief theory, mildly negative moods more commonly increase helping behaviour and good moods to a lesser extent (Cialdini, et al., 1997; Cialdini & Fultz, 1990). Good moods in particular lead to positive judgements about a potential helping situation and help to sustain the helping behaviour. Several factors contribute to helping behaviour and feeling good about helping. These include direct contact

between the helper and receiver of help, regular participation in helping activities or behaviours, helping people in emergency situations, competent performance of a variety of help related activities, investment of time and effort on a voluntary basis, and being focussed on doing things rather than expecting positive results (Luks & Payne, 1991, cited in Bierhoff, 2002).

It is important to remember that although both positive and mild negative moods can increase helping behaviours; neither will do so if outcomes result in extreme negative consequences for the caregiver. This reflects the complex relationship of the variables and motivational processes involved in helping behaviours. People in high states of personal distress become more anxious and uneasy when seeing others need help, frequently resulting in less help being offered (Bierhoff, 2002; Davis, 1996).

Current research supports the changing nature of helping practices with regard to gender, age, and culture. Research finds that women help both men and women whereas it is unusual for men to help other men. Women are also more likely to seek help from other people (Bierhoff, 2002; Altruism, n.d.). Older women provide more social and emotional support to other people, and are more willing to serve as caretakers for elderly people (Bierhoff, 2002). Vaillant (2002) has highlighted increasing and unexplained altruistic acts by older age groups, along with the changing nature of these acts. Strategies that are more social and collaborative in nature, such as altruism, religion, and talking to a spouse, children, or friends, tend to become more prominent and effective with age, and provide evidence of a growing emotional maturity. Helping in older adulthood seems related to increased feelings of self-efficacy and self-worth (Vaillant, 2002).

Recent research supports the notion that older adults are motivated to remain active in the lives of others, and seem better off when assisting other people. In a study of senior companions and foster grandparents involving a group of low-income elderly adults engaged in helping activities, levels of altruistic motivation was the most important predictor of life satisfaction (Dulin, Hill, & Anderson, 2001). Additionally, levels of altruistic behaviour were equally important in predicting positive affect (Dulin & Hill, 2003).

Results from a longitudinal study looking at the prediction of mortality among older adults indicated that for elderly couples, providing instrumental and social support was more beneficial than receiving it. Providing both instrumental and emotional support to others is significantly related to decreased mortality, whereas receiving instrumental and emotional support was not (Brown, Neese, Vinokur, & Smith, 2003). These results go a long way toward changing current views on older adults as being passive, needy consumers of services. Older people are not only active and engaged people who benefit from helping others, but in doing so, they make valuable contributions to society.

There also appears to be cultural differences in helping behaviour. Groups with a collective approach focus more on interdependence in a social network and the group as a whole, whereas cultures with an individual approach focus more on individual competition and achievement (Bierhoff, 2002). Reciprocal behaviour stayed the same for both approaches, but social responsibility differed, especially for collectivists. Some people may also feel less responsibility for helping people they disliked or felt less empathy for, such as people from different cultural groups (Bierhoff, 2002; Davis, 1996).

Interest in the antecedents and consequences of emotion has also increased, with many psychologists suggesting that they may arise in the context of goal directed action. Empathic emotions are social by nature and have a part in emotional repertoire, and a special significance in social relations in general (Batson, 1991; Davis, 1996; Batson & Shaw, 1991). The emotion-motivation debate presents many challenges and opportunities to researchers (Batson & Shaw, 1991).

The Broaden-and-Build theory of Frederickson (2001), a more recent development in the field of positive psychology, appears to provide some of the strongest links to date of the close connection between emotion, stressful events, coping and mood outcomes, and suggests that the different types of coping strategies as described by the coping models, are differentially related to emotion and outcomes. The Broaden-and-Build theory utilises the concepts of emotional or psychological well-being, different coping strategies, and positive and negative affect, to explain the complex relationship between stressful events, behaviour, coping and mood states in individuals. Positive emotions are considered to not only mark wellbeing, but to act as a means of achieving well-being by increasing resilience and the ability to cope with stress.

### **Mood States and Well-being**

Affect is thought to vary along two main dimensions, pleasantness and activation (Russell & Feldman-Barret, 1999, cited in Frederickson, 2001), or positive and negative emotional activation (Tellegen, Watson, & Clark, 1999). This corresponds with the general view of positive and negative affect being two broad, independent factors representing the major dimensions of mood (Watson, 1988; Watson & Tellegen, 1985). They are often used to assess and study the many facets of

affect over time and are included in descriptions of emotional or psychological well-being, along with some indication of life satisfaction (Huebner & Dew, 1996, cited in Bailey, 1998; Reber & Reber, 2001). Research evidence consistently supports the differential nature of the relationships between positive or negative affect, the different kinds of activities people engage in, and the resultant positive or negative outcomes.

Positive affect refers to levels of pleasurable activity and engagement in the environment, such as enthusiasm, energy, mental alertness, interest, joy, and determination and are more often related to activities that are social by nature (McIntyre, Watson, & Cunningham, 1990; Watson, Clark, McIntyre & Hamaker, 1992). Sadness, loneliness, lethargy and fatigue are features of low positive affect (Kammann & Flett, 1986; Watson & Tellegen, 1985). Positive affect also shows greater variation and fluctuation on a daily basis than negative affect (Watson & Clark, 1984; Watson, Clark, & Tellegen, 1988).

In contrast, subjective distress and unpleasant engagement are features of negative affect, which include feelings of anger, guilt, fear, tension, sadness, scorn, and disgust (Watson & Tellegen, 1985). Negative affect relates to major crises and stressful events involving health matters, evaluations, failure, embarrassment, punishment, and general hassles (Watson & Clark, 1984; Watson, Clark, & Tellegen, 1988).

Research across different samples and age groups provides additional support for the differential relationship of positive and negative affect to anxiety and depression measures (Watson, Clark, & Carey, 1988), with obvious implications for different clinical situations. Positive affect differentiated between anxiety and depression, with low positive scores related to the symptoms and diagnosis of

depression (Watson, Clark, & Tellegen, 1988). Anxiety reflected a state of high negative affect and was not related to positive affect. Whereas depression reflected a mixed state of high negative affect and low positive affect (Clark, Beck, & Stewart, 1990; Lonigan, Cary, & Finch, 1994; Watson & Tellegen, 1985; Watson, Clark, & Carey, 1988). These findings suggest that the mood states of caregivers, as indicated by their positive and negative affect, are clinically important (Watson, Clark, & Carey, 1988; Watson, Clark, & Tellegen, 1988) as they provide information about the psychological or emotional well-being of a caregiver that could be used for intervention and prevention purposes.

Investigation into the effects of coping may clarify the relationships between stressful events, coping and mood in dementia caregivers. This may allow the focus of intervention to change from pathologising, identifying and measuring levels of stress and burden, to working toward ameliorating the adverse consequences of caregiving.

Positive emotions are considered to be non-threatening and as such do not require quick responses. Positive emotions broaden the range of available responses, by facilitating and encouraging alternative options through exploration of new situations, events, and experiences (Frederickson, 2001). The various thought action tendencies triggered by positive emotions, such as to play, explore, savour and integrate, are thought to contribute to durable longer term and indirect adaptive benefits by increasing the range of personal resources available to an individual and building reserves for future use (Frederickson, 2001).

The available evidence further suggests that positive emotions enhance or increase the range of resources, physical, intellectual and social, available to an individual and broaden the scope of available thoughts and actions, whereas negative emotions, such as fear and anger, serve to narrow them (Frederickson, 2001). This is

one of the core propositions of the Broaden-and-Build theory and it has implications for the regulation of emotional experiences. Positive emotions could function to reduce the lingering effects of negative emotions, thus reducing possible harm in situations involving long-term stress, such as dementia caregiving (Frederickson, 2001). Although the precise mechanisms involved are unknown, evidence suggests that positive emotions reduce the effect of negative emotions by dismantling or reducing some of the underlying preparations for specific actions, as can be seen in cardiovascular reactivity returning to more neutral levels and creating a more supportive environment for pursuing positive emotions. Current research supports the differential role of positive and neutral emotions in terms of what they could undo in the system, and suggests that broadening on a cognitive level mediates undoing on a more physiological level, as found within the cardiovascular system (Frederickson, 2001). Research found that during periods of anxiety or stress, physiological reactions such as increased heart rate, palpitations, and increased autonomic responses are evident, but return to baseline levels faster once the stressful period is over for individuals reporting high levels of positive emotions along with high anxiety (Tugade & Frederickson, 2000, cited in Frederickson, 2001).

Existing evidence regarding the undoing effect of positive emotions suggest that positive emotions improve psychological well-being and physical health by enhancing positive emotional experiences at specific moments to help cope with negative emotions (Frederickson, 2001; Frederickson & Levenson, 1998). This provides additional support for the existing findings that positive affect is an important resource for coping with adverse life events (Aspinwall, 2001; Aspinwall & Taylor, 1997; Frederickson, 2001).

The importance of positive emotions to the well-being of caregivers of people with dementia is highlighted by current research involving emotions and coping mechanisms. Three coping mechanisms have been identified as possible contributors to generating positive affect during stressful circumstances. They include positive reappraisal, problem focussed coping, and the infusion of ordinary events with positive meaning (Folkman & Moskowitz, 2000; Frederickson, 2001). However, the nature of their involvement, and whether these strategies can be taught, still need to be determined. The increased psychological resilience following from positive emotions can interact with effective coping strategies to reduce stressful emotional experiences. Together with planning and goal directed activity, they have also been found to predict increased psychological well-being and future positive experiences (Frederickson, 2001). This process has been described as an upward spiral towards emotional well-being.

Finally, it is apparent that emotions, specifically positive emotions, and coping are mutually dependent on each other. By combining research findings from emotional and coping research, the field appears to be moving away from pathologising the difficulties experienced by caregivers of people with dementia to one that emphasizes a more positive approach to caregiver well-being. The Broaden-and-Build theory (Frederickson, 2001) has implications for caregivers of people with dementia, and provides a possible explanation for why some caregivers are able to cope with stressful daily events associated with caregiving.

### **Summary**

Community agencies and health service providers working with elderly clients face increasing challenges to provide appropriate care in a financially shrinking and

politically driven market. This has severe implications for meeting the complex physical and psychological health needs of elderly clients in future years. Many elderly people not only live longer, but also have a greater variety of disabilities that they require assistance with (Doka, 1993; Woods, 1999; Zarit & Edwards, 1999). Healthcare workers increasingly have to not only identify pathology, but also implement preventative strategies and individualise interventions.

The adverse consequences of caring for an elderly person with dementia have been shown to be many and long lasting, affecting most areas of a caregivers life (Doka, 1993; Gallagher-Thompson, et al, 1998; Zarit & Edwards, 1999). Unfortunately, not all caregivers cope effectively with stressful life events, with many personal, situational, and environmental factors influencing their ability to cope effectively (Levesque, et al, 1995).

Research has increasingly highlighted the differential role of emotion focussed and problem focussed coping, and their specific relationships to psychological outcomes and emotional well-being. The literature review suggests that caregivers who struggle to cope make more use of maladaptive coping strategies such as emotional strategies or avoidance, require and use more support, struggle to make decisions, experience more negative outcomes, and are more dependent on other people generally. In contrast, caregivers who cope effectively make more use of a problem focussed approach to dealing with negative life events, experience more positive outcomes, and are more independent, socially active, and psychologically healthy (Endler & Parker, 1993; Endler, et al., 1993; Gallagher-Thompson, et al, 1998; Sanders-Dewey, et al, 2001; Zarit & Edwards, 1999).

However, the relationship between helping behaviour, coping strategies and caregiver mood is complex and influenced by many variables. The theoretical

frameworks proposed by Vitaliano and his associates (Vitaliano, et al., 1993), and the more recent Broaden-and-Build theory (Frederickson, 2001), provide a partial explanation for the relationship between helping behaviour, motivation, coping and mood of caregivers, and how they influence the behaviour of caregivers (Batson, 1991; Batson & Shaw, 1991; Bierhoff, 2002; Davis, 1996).

### **The Current Study**

The current study aims to explore the general characteristics of caregivers of people with dementia within New Zealand; their helping attitudes, the coping strategies they use in problem situations, and how these factors are related to their emotional well-being. The study will also consider differences between genders and participating ethnic or cultural groups. It also hopes to contribute to theory development in this area and identify risk factors for caregivers of people with dementia. This will encourage the implementation of appropriate psychological intervention programmes and prevention strategies for this client group.

The current study has four goals: 1) Identify the general characteristics of both dementia caregivers in New Zealand and the person they are caring for, using a variety of demographics and social attributes. 2) Identify the influence of helping attitudes of caregivers on a measure of emotional well-being (positive and negative affect). 3) Identify the influence of the coping strategies used by caregivers on emotional well-being. 4) Identify possible gender or ethnic differences in caregiver's emotional well-being.

This study conceptualises helping as a coping strategy, and considers coping an active process in determining caregiving outcomes. This study investigates the complex nature of the relationship between helping, coping, and emotion using a large

regional sample of caregivers of people with dementia. The results provide evidence for the differential influence of these variables in the active management of stressful events by caregivers. The results will help to identify caregivers who may be at risk, plan appropriate interventions, and contribute to the increasing body of knowledge in the field of caregiving.

## **METHODOLOGY**

### **Research Design**

The study investigated the various relationships between demographic variables, helping attitude, coping strategies and the outcome variables of positive and negative affect using a self-report methodology. Using a self-report survey method, the study took into account some of the traditional difficulties experienced by caregivers, particularly dementia caregivers. These difficulties included availability of time, making suitable travel and respite arrangements, and specific living conditions and geographical distribution within the wider Bay of Plenty region. This method was previously used successfully with a similar population group in England (Nolan, et al., 1996).

A questionnaire was also developed for the study, incorporating three standardised measures. The questionnaire contained a number of items in four parts that each caregiver completed. It included demographic information, helping attitudes, coping responses, and the mood states of positive and negative affect. The research used correlational and regression methods in order to ascertain relationships between variables.

### **Sample Information**

Participants were recruited from the membership of two community-based organisations, Age Concern and the Alzheimer's Society. These organisations were selected because of their direct link and contacts with caregivers, families, friends, and support networks of people with dementia. Both organisations offer a wide range of services to their members, such as information, counselling, support groups, advice, advocacy, and reading material. Caregivers, organisations, and specific branches of

the organisations were not identified in any way, to maintain confidentiality and anonymity.

Participants were contacted in writing, and information packages were sent out to the members of the participating branches. Some branches also printed information on the study in their newsletters after agreeing to participate. Additionally, committee members and support group coordinators voluntarily discussed the study during meetings with members. Larger branches supplied the researcher with members' contact details (in the form of address labels), whereas some smaller branches contacted members individually or mailed details on the study to members directly. Most Alzheimer's Society branches performed preliminary screening of membership lists to ensure participants met the study's eligibility criteria. Members, or family and friends of people with dementia independently decided on participation. Participation was voluntary, with anonymity and confidentiality of results assured.

The mail-out packages contained a letter requesting participation, an information sheet on the study, a consent form, and the questionnaire. A stamped, self-addressed envelope was included for the return of the questionnaire. Copies of all documentation and forms are included in the appendix section of the study (See Appendices B to F).

Information on the study and questionnaires were mailed to members of the organisations once approval to proceed was received from the Massey Human Ethics Committee. Those who agreed to participate completed and returned the anonymous questionnaire in the self-addressed envelopes provided. Only caregivers who were actively involved in some form of caregiving activities, formal and informal, were included in the study.

Occasional queries were received concerning the general format of the documentation and these were attended to accordingly. Participants were not recruited by way of phone calls or personal contact and no requests for translations or additional forms were received.

One postal mail-out was completed and the majority of forms returned by the due date. The researcher liaised with the organisers of the participating branches by e-mail during the collection phase, and attended to e-mail and telephonic queries as required.

### **Measures**

The study selected three standardised, psychometrically sound measures because of their self-report format, relative brevity, ease of administration, and proven validity and reliability. All the measures, except for the Helping Attitude Scale (HAS) (Nickell, 1998), were developed or standardised using the target population of caregivers or spouses of elderly people with dementias.

The measures and demographic sections together formed a self-report questionnaire in four parts, each with instructions and appropriate examples (copy in appendix F). The demographic section contained personal information relating to both the caregiver and the person with dementia, a helping attitude section with the twenty statements of the HAS, a coping section of forty-one statements relating to the five coping strategies, from the RWCCCL, and an affect or mood section, consisting of ten positive and ten negative affect statements in the PANAS.

The HAS by Nickell (1998) is a multidimensional instrument for measuring beliefs, feelings and behaviours related to helping. The twenty items measure both positive and negative attitudes to helping using a 5-point Likert scale. Research investigating the psychometric properties of the scale obtained an internal consistency

(Cronbach's alpha) of .87, and test-retest reliability of .84 ( $p < .01$ ) (Nickell, 1998).

Research into the normative properties of the scale provided evidence for relationships to empathy, social responsibility, and selfish orientation. The results further indicated that women tend to have a more positive attitude to helping than men (Nickell, 1998). Although this particular measure has not previously been used with this population group, the psychometric results support the suitability of the instrument as a reliable measure for research.

Participants were instructed to indicate the degree of agreement with the helping statements on a scale of one to five. The ratings are 1 (*strongly disagree*), 2 (*disagree*), 3 (*undecided*), 4 (*agree*) and 5 (*strongly agree*). Several items are reversed scored (items 1, 5, 8, 11, 18, 19), prior to adding the totals for the final helping score (Nickell, 1998; See Appendix F, part 2, for a copy of the scale).

The Revised Ways of Coping Checklist (RWCCCL) (Vitaliano, et al., 1985) measures coping in terms of what a person does or thinks in response to the demands of a stressful encounter. The original 68 item Ways of Coping Questionnaire (WCQ) was revised to obtain a shorter but equally valid measure (Vitaliano, et al., 1985). The WCQ has been described previously as the premier means of assessing coping styles and responses, and developed for use with, spouses of patients with Alzheimer's disease (Folkman & Lazarus, 1988).

The RWCCCL, when comparing the internal consistency, reliability, inter-correlations, and factor structure with those of the original WCQ, was found to be more reliable than the original (Burns, Lawlor, & Craig, 1999). The revised scales obtained higher internal reliability coefficient alphas (.82 – .83), lower inter-correlations, and more evidence of construct/concurrent validity than the original scales (Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987).

Additional advantages over the original scale include an independent measure of the coping-distress relationship and rater-reliability of constructs. The scale measures the following coping styles: problem focussed coping, wishful thinking, seeking social support, avoidance and blaming people (self and others). The scale provides both raw and relative effort scores (Folkman & Lazarus, 1980; Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987).

The use of relative effort scores have been encouraged (Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987) in order to observe more clearly relationships of coping and distress, and coping differences across pathological and non-pathological samples. Relative scores are proportional scores for subscales relative to the overall coping efforts made by caregivers.

The improved psychometric properties of the RWCCCL, developmental history involving caregivers of people with dementia clients (Vitaliano, et al., 1985; Vitaliano, Maiuro, et al., 1987), and easy administration support the suitability of the measure for this study. Participants responded to each statement using a 4-point Likert scale, indicating the frequency of use of the strategy in stressful situations. The scale options include 0 (*does not apply or is not used*), 1 (*used somewhat*), 2 (*used quite a bit*), 3 (*used a great deal*) (See Appendix F, part 3, for a copy of the scale).

The Positive and Negative Affect Scales (PANAS) by Watson, Clark, and Tellegen, (1988), consist of twenty words describing various feelings and emotions. The words relate to two scales, positive and negative affect, and are rated on a 5-point scale (Watson, Clark, & Tellegen, 1988).

Each scale of ten items is internally consistent and valid with correlations ranging from .89 to .90, and discriminant validity ranging from  $-.02$  to  $-.18$ . Normative studies (Watson, Clark, & Tellegen, 1988) used factor analysis and

varimax rotation on six data sets of mood ratings from students and community adults of both genders. Regression estimates and factors scores were determined, which correlated highly with PA and NA scales. The results indicated no reliable differences between the adults and students or between genders across all time frames. All of the individual items (mood descriptors) obtained strong primary loadings of .05 and above on either positive or negative mood. The scales also correlate at predicted levels with measures of related constructs. The scales are reliable (with alpha coefficient's ranging from .86 to .90 for PA and .84 to .87 for NA), valid and considered an efficient means for measuring these important dimensions of mood (Watson, Clark, & Carey, 1988). The scales have also been used in several recent samples of elderly community based volunteers (Dulin, & Hill, 2003; Dulin, et al., 2001), further confirming the suitability of the measure for inclusion in the current study.

### **Data Analysis**

A computerised statistical package for social sciences, SPSS for Windows version 11, was used to analyse the information and determine the relationships between the variables (Dickter & Rosnowski, 1996; Yaffee, 1996). A variety of descriptive, inferential, regression, and multivariate statistical techniques were applied, and the results summarised in table format (frequencies, percentages, means, standard deviations, relationships). The alpha level used for hypotheses testing was  $p < .05$  (except where otherwise stated), and were two-tailed.

The study used stepwise regression analysis to investigate the effects of helping and coping strategies of caregivers on their mood states. This allowed for systematic control over the entry of variables, and determining the extent and predictive value of the variables (demographic information, helping attitudes and coping strategies) with regard to the positive and negative affect of caregivers.

## RESULTS

### Data Management

In total, 675 questionnaires were sent out and 283 were returned, reflecting a response rate of 41.9%. Of these, 125 were incomplete or considered unsuitable, as the caregivers did not meet the entry criteria of the study. This was mainly due to the person with dementia having died, or lack of current involvement in dementia caregiving. The final sample size of 158 questionnaires represented a return rate of 28.3%, well within the acceptable limits for postal surveys.

The demographic information included both continuous and categorical variables. These variables are listed in Table 1: Frequencies of demographic and lifestyle variables relating to caregivers, Table 2: Means and standard deviations of the demographic and lifestyle variables, and Table 3: Frequencies of demographic information relating to people with dementia (those cared for).

The independent variables were all continuous and included helping attitude measured by HAS (Nickell, 1998), and the five coping strategies of problem focussed, wishful thinking, seeking social support, avoidance and blame measured by RWCCCL (Vitaliano, et al., 1985; Burns, et al., 1999). The dependent variables were the mood states of positive and negative affect measured by PANAS (Watson, Clark, & Tellegen, 1988).

Caregiver information was entered into a spreadsheet and imported into the SPSS (11.0) programme for statistical analysis. Data screening on a number of levels ensured accuracy of the results. This was done during scoring, after spreadsheet entry, during coding, and preliminary analysis. The sample mean score was substituted for the missing demographic or subscale items on the PANAS and RWCCCL, whereas a

neutral score was substituted with an omitted HAS item. Missing data comprised, on average, 3% or less for most items.

### Profiles of Caregivers and People with Dementia

The demographic and lifestyle information relating to the sample are summarized and presented in table format. Table 1 refers to the frequencies of demographic and lifestyle variables relating to caregivers, Table 2: Means and standard deviations of demographic and lifestyle variables, and Table 3: Frequencies of demographic information relating to the person with dementia (those cared for).

Table 1  
*Frequencies of demographic and lifestyle variables of caregivers.*

Variable name	Category Details	Frequency	Percentage*
Caregiver type <i>n</i> = 155	Main caregiver	101	65
	Alternative caregiver	54	35
Caregiver gender <i>n</i> = 154	Male	49	32
	Female	105	68
Caregiver age <i>n</i> = 158	Under 40 years	6	4
	40 – 49 years	8	5
	50 – 59 years	36	23
	60 – 69 years	26	16
	70 – 79 years	48	30
	80 years and older	34	22
Relationship with person receiving care <i>n</i> = 155	Husband	47	30
	Wife	45	29
	Daughter	44	28
	Son	2	1
	Sister	2	1
	Friend	4	3
	Other	11	7
Marital status <i>n</i> = 157	Married	131	83
	Single	8	5
	Separated	6	4
	Divorced	2	1
	De Facto	6	4
	Other	4	3
Extra family members in home <i>n</i> = 77	Extra Adults	60	78
	Extra Children	7	9
	Mixed	10	13
Smokers <i>n</i> = 153	Smoker	15	10
	Non-Smoker	136	89
Alcohol users <i>n</i> = 148	Alcohol user	101	68
	Non-drinker	47	32
Outside help <i>n</i> = 153	Outside help	123	80
	No help	30	21

Table 1(continued)  
*Frequencies of demographic and lifestyle variables of caregivers.*

Variable name	Category Details	Frequency	Percentage*
Ethnicity of caregiver <i>n</i> = 152	NZ Pakeha/European	121	80
	European	24	16
	Maori	6	4
	Other	1	1
Education of caregiver (years) <i>n</i> = 149	5 – 8 years	15	10
	9 - 12 years	60	40
	13 – 15 years	38	26
	16 years plus	36	24
Employment <i>n</i> = 154	Employed	42	27
	Unemployed	112	73
Breadwinner <i>n</i> = 153	Breadwinner	45	29
	Not breadwinner	106	69
Employment (hours/week) <i>n</i> = 121 Only 40 indicated hrs worked/week = 875.3, 21.9 hrs/week	Retiree	81	68
	7.5 hours/week	7	6
	13 hours/week	4	3
	20 hours/week	10	8
	27.2 hours/week	14	12
Financial help <i>n</i> = 158	Yes, receives help	79	50
	No help	79	50
Source of financial help <i>n</i> = 79	Government sources	65	82
	ACC funded	1	1
	Private funds	8	10
	Multiple sources	5	6
Income per annum (household) <i>n</i> = 157	9,000	8	5
	12,500	19	12
	18,000	22	14
	21,400	14	9
	23,000	35	22
	28,000	25	16
Caregiver residential arrangements <i>n</i> = 153	35,000	34	22
	Rental accommodation	4	3
	Private home	78	51
	Share with recipient of care/Stay with family	2	2
	5	3	
Geographical area of caregiver <i>n</i> = 155	Living retirement complex	64	42
	Multiple categories		
	Rural area	24	16
	Country town/village	37	24
	Regional Centre	93	60
Problems experienced by caregivers <i>n</i> = 148	Larger city	1	1
	Memory and attention span	2	1
	Personality changes	2	1
	Physical functions	7	5
	Behavioural/affect difficulties	2	1
	Other socio-emotional difficulties	10	7
	Multiple difficulties: all of above	125	85

\* Percentages may not add up to 100% due to rounding

The range of demographic information and the size of the regional caregiver sample (N = 158) facilitate the description of both general caregiver characteristics and of the person with dementia within the sample. This can be used to develop a profile of caregivers within the New Zealand context.

The mean duration of caregiving was 4.5 years, and care was provided for an average of 9.7 hours each day. The majority of caregivers were female (68%). Most caregivers were married (83%), 59% were spouses of the person receiving care, and 28% were daughters of the person with dementia. The caregivers averaged 12.3 years of education, 10% smoked 0.5 packs per day on average, 68% used alcohol (approximately 4.3 drinks per week), 80% identified themselves as New Zealand Pakeha / Europeans, 16% identified as European and 4% as Maori. There were no caregivers of Asian or Pacific Island descent in the study.

Most caregivers listed a multiple range of difficulties related to caregiving (85%). These included a combination of supervision, wandering, nocturnal habits, medical needs, difficulties with physical functions such as incontinence, cognitive problems such as loss of memory and limited attention, personality changes and behavioural or affect difficulties. In addition to this, some caregivers also listed socio-emotional difficulties, which referred to difficulties they were personally experiencing, such as accepting the change in mother-daughter relationships, or mourning the loss of a parent or partner.

The average household income of caregivers was \$23,400, 27% were employed, 68% retired and 33% were employed on a part-time basis. A substantial proportion utilised or received additional financial assistance (50%) from a variety of sources. The majority came from larger regional centres (60%) and used a range of residential

arrangements such as living with family, short stays in rest homes or nursing homes (42%).

Table 2  
*Means and standard deviations for demographic and lifestyle variables.*

<i>N</i> = 158 Caregivers	<i>M</i>	<i>SD</i>
Duration Of Care (Years)	4.5	2.7
Daily Hours Of Care	9.7	8.9
Age Of Caregiver	67.3	14.0
Smoking Amount (Packs/day)	0.5	1.9
Alcohol Amount (Drinks/Week)	4.3	6.2
Additional Help (Hours/Week)	16.8	40.2
Education (Years)	12.3	2.9
Employed (Hours/Week)	6.3	10.9
Income (\$ Per Annum)	23,400	8,100
Age Of Recipient Of Care	79.4	7.1
Severity Of Dementia	3.4	1.1
Daily Living Difficulties	3.8	1.1

The information provided by the caregivers also describes the characteristics of the people receiving care, the details of which can be found in Table 3: Frequencies of demographic information relating to people with dementia (those cared for). The mean age of the people being cared for in the study was 79.4 years, most were female (59%) and of New Zealand Pakeha / European origin (81%). The most common form of dementia was moderately severe Alzheimer's dementia (3.4 on a 5 point scale), experiencing moderate to severe difficulties with activities of daily living (3.8 on 5 point scale). Around 54% also have other general medical conditions, and 48% are receiving treatment or being monitored for these conditions. Thirty-four percent of the people with dementia utilise multiple residential arrangements, 31% live in nursing homes, and 25% live in private homes. A further 14% of people with dementia were of European origin, and 5% identified as Maori. No other ethnic groups were identified.

Table 3  
*Frequencies of demographic information relating to people with dementia (those cared for).*

Variable	Details	Frequency	Percentage*
Age of person with dementia <i>n</i> = 158	Under 60 years	3	2
	60 – 69 years	7	4
	70 – 79 years	65	41
	80 – 89 years	74	47
	90 years and older	9	6
Gender of person with dementia <i>n</i> = 133	Male	54	41
	Female	79	59
Ethnicity of person with dementia <i>n</i> = 154	NZ Pakeha/European	124	81
	European	21	14
	Maori	7	5
	Other	2	1
Type of dementia <i>n</i> = 93	Alzheimer's	76	82
	Multi-infarct	8	9
	Vascular	6	7
	Parkinson's related	3	3
Severity of dementia <i>n</i> = 158	1, very mild	10	6
	2, mild	17	11
	3, moderately severe	65	41
	4, severe	38	24
	5, very severe	28	18
Difficulty with daily living activities <i>n</i> = 158	1, not at all	4	3
	2, very mild	17	11
	3, somewhat	50	32
	4, moderately severe	32	20
	5, very much/great deal	55	35
Presence of other conditions <i>n</i> = 154	Yes, other medical conditions	83	54
	No other conditions	71	46
Receiving Rx for other conditions <i>n</i> = 153	Yes, receiving treatment	73	48
	Not receiving treatment	80	52
Residential details for person with dementia <i>n</i> = 154	Rental accommodation	1	1
	Private home	38	25
	Staying with caregiver	5	3
	Staying with family	3	2
	Living in retirement complex	8	5
	Nursing home resident	47	31
	Multiple arrangements	52	34

\* Percentages may not add up to 100% due to rounding

### Measures in Caregiver Sample

The psychometric information for the measures is discussed and compared to the caregiver sample. The descriptive statistics for the study variables of helping attitudes, coping strategies (problem focussed, wishful thinking, seeking social support, avoidance and blame), and caregiver mood states (positive and negative affect) for the sample are presented in Table 4.

Table 4  
*Descriptive statistics of helping, coping strategies, and mood states.*

<i>N</i> = 158	Actual Range	<i>M</i>	<i>SD</i>	Cronbach's Alpha
Helping Attitude	52 – 97	78.7	8.6	.83
Helping Attitude (Females) ( <i>n</i> = 105)	58 – 97	79.7	8.0	.79
Helping Attitude (Males) ( <i>n</i> = 49)	52 – 94	76.8	8.8	.88
Problem Focussed Coping	0 – 3	1.9	0.6	.75/.85*
Wishful Thinking	0 – 3	1.4	0.9	.75/.86*
Seeking Social Support	0 – 3	2.1	0.8	.75/.79*
Avoidance	0 – 2.7	0.9	0.6	.75/.73*
Blame	0 – 2.8	0.9	0.7	.75/.80*
Positive Affect	0 – 48	29.5	8.4	.88
Negative Affect	0 – 46	22.0	8.6	.88

\* Original reliability analysis used subscales, .75 refers to Cronbach's alpha for the complete RWCCCL scale in the current sample.

The norm group obtained a mean score on the *Helping Attitude Scale (HAS)* of 79.6 (*SD* 8.7), ranging from 32 – 97 (*N* = 407). Females in the norm group were more positive towards helping than the males ( $t = 6.546, p < .00$ ). In one sub-sample females obtained a mean score of 81.5, compared to the males, with a mean of 75.2 (Nickell, 1998). The mean helping attitude score for all caregivers (*N* = 158) was 78.7, with a standard deviation of 8.6. Scores ranged from 52 – 97.

In the norm group, female caregivers tended to have a more positive helping attitude, however in this study, the gender differences were not statistically significant (female caregivers, *n* = 105, obtained a mean score of 79.7 with a standard deviation of 8.0, while male caregivers, *n* = 49, obtained a mean of 76.8, with a standard deviation of 8.8). The HAS obtained a Cronbach's alpha coefficient of .83,

confirming the reliability and use of the scale in this sample of caregivers. HAS appears to be a reliable measure of helping attitudes or pro-social tendencies in this sample.

The RWCCCL (Vitaliano, et al., 1985), measures the coping strategies of caregivers. The RWCCCL has satisfactory psychometric properties (internal consistency, intercorrelations) (Vitaliano, et al., 1985). The norm group included psychiatric outpatients, students and spouses of clients with dementia.

This study followed the same general format for analysing scores as the original RWCCCL, and used the raw scores of each coping strategy, which allows for direct comparisons between the scores on the different instruments. The RWCCCL obtained a combined scale reliability of .75 (Cronbach's alpha), confirming it as a reliable instrument with the caregiver sample.

Comparisons of coping between the norm group and caregiver sample are summarised in Table 5. The caregiver sample obtained higher mean scores for all the coping strategies and showed greater variation than the norm group.

Table 5  
*Comparison of coping between norm group and caregiver sample.*

	Norm Group (relative scores)		Caregiver Sample (relative scores)		Caregiver Sample (raw scores)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Problem Focus	20.7	9.5	27.9	11.4	1.9	0.6
Wishful Thinking	9.4	5.9	17.2	9.3	1.4	0.9
Seeking Social Support	8.7	4.8	29.1	10.9	2.1	0.8
Avoidance	8.5	5.2	12.6	8.3	0.9	0.6
Blame	2.1	2.4	11.8	8.9	0.9	0.7
Caregiver Age	65.8	9.2	67.3	14.0	67.3	14.0
Education	23.5% over 16 yrs (60%, 12 years)		24% (36) over 16 yrs 12.3 years (mean)			
Males	22 (36.8%)		49 (32%)			
Females	39 (63.2%)		105 (68%)			
Married	62 (100%)		131 (83%)			
Relationship to Person with Dementia	62 (100%) spouse		92 (59%) spouse 44 (28%) daughter			

The PANAS was used to reflect and rate caregiver's feelings over the last month on a scale of 1 (*very slightly/not at all*) to 5 (*extremely*). This is comparable to

the “last few weeks” timeframe of the norm group (Watson, Clark, & Tellegen, 1988), and provided a positive and negative affect score for each caregiver.

The Pearson correlation between the positive and negative affect scales of the caregiver sample was  $-.16$  ( $p < .05$ ), indicating the relative independence of the two scales. Cronbach’s alpha coefficients of  $.88$  were obtained for both scales, supporting their inclusion and use in the current caregiver sample (See table 6). This is similar to the norm group, where the positive affect score was also greater than the negative affect score, and no gender differences were found (Watson, Clark, & Tellegen, 1988).

Table 6

*Comparison of positive and negative affect scores between norm group and caregiver sample.*

	Norm Group		Caregiver Sample	
	Positive Affect (PA)	Negative Affect (NA)	Positive Affect (PA)	Negative Affect (NA)
Actual Range	-	-	0 – 48	0 – 46
Mean	32.0	19.5	29.9	22.2
SD	7.0	7.0	7.7	8.4
Cronbach’s Alpha	.87	.87	.88	.88
Correlation of PA – NA scales	-.22	-.22	-.16	-.16
Sample size	586	586	158	158
Population	Primarily students, some adults		Caregivers of dementia clients	
Time frame	Past few weeks		During last month	

However, in contrast to the norm group, the caregiver sample evidenced differences between the gender groups. The mean positive affect score for the 49 male caregivers ( $M = 27.3$ ,  $SD = 7.4$ ) was significantly lower than the 105 female caregivers’ score ( $M = 31.1$ ,  $SD = 7.7$ ) at the  $p < .01$  level. Male caregivers showed greater variation in their positive mood states, and female caregivers greater variation in negative mood states. Thus, both the positive and negative affect scales appear

stable and reliable indications of caregiver affect in the current sample. In conclusion, the selected measures of the study are all considered reliable and suitable for inclusion in the current caregiver sample.

### **Relationships between Demographic Factors, Helping, Coping and Mood States**

Pearson product-moment correlations indicated the strength and direction of relationships among the study variables. The significant correlations are summarised in Table 7: Correlations between demographic and lifestyle variables, Table 8: Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores, and Table 9: Correlations between HAS, RWCCCL, and PANAS scores. Of particular interest were the demographic characteristics of both caregivers and the people with dementia that are significantly related to positive and negative affect, as well as the independent variables of helping and coping.

A number of significant relationships were identified between the general demographic and lifestyle factors, however not all were significantly related to helping, coping and mood states of caregivers, or contributed to the prediction of positive and negative affect of caregivers. The correlations among these factors are summarised in Table 7: Correlations between demographic and lifestyle variables.

Table 7  
Correlations between demographic and lifestyle variables.

	N = 158	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Gender (caregiver)		1													
2 Daily hours (caregiving)		-.009	1												
3 Ethnicity (caregiver)		.074	.076	1											
4 Relation		.421**	.330**	-.096	1										
5 Age (caregiver)		-.368**	.348**	-.066	-.527**	1									
6 Employed		.001	-.291**	-.222**	.342**	-.464**	1								
7 Hours/week Employed		.097	-.336**	-.075	.350**	-.550**	.832**	1							
8 Income (household)		.128	-.111	.031	.164*	-.272**	.261**	.334**	1						
9 Age (dementia)		.140	-.056	-.083	.203*	.041	-.047	-.003	.101	1					
10 Gender (dementia)		-.284**	.023	-.075	-.256**	.309**	-.068	-.043	.001	-.009	1				
11 Ethnicity (dementia)		.137	.046	.258**	.197*	-.066	-.016	-.030	.008	.088	-.113	1			
12 Education (carer, years)		.038	-.100	-.093	.062	-.072	.086	.066	.208**	.134	-.028	.065	1		
13 Residence (caregiver)		-.122	.121	-.040	-.048	.081	-.064	-.079	-.084	.053	-.029	.134	-.011	1	
14 Attorney (P.O.A.)		-.157*	.007	-.139	-.204*	.009	.190*	.135	.114	.053	.001	-.300**	-.091	-.089	1

\*  $p < .05$  level (2 tailed), \*\*  $p < .01$  level (2 tailed)

The relationships among the different demographic and lifestyle variables are grouped into personal factors, condition factors, and economic factors for discussion purposes.

*Personal factors* include the relationships between the caregiver and person with dementia, as well as age and gender of both parties. These personal factors seem to indicate that older caregivers are more likely to be spouses of the person being cared for, work fewer hours (formally), and have a lower income. Caregivers are also more often of the opposite gender to the person with dementia (See Table 7: Correlations between demographic and lifestyle variables).

*Condition factors* refer to the type of dementia, severity, and activities of daily living difficulties. They are frequently positively related to caregiving and practical factors, such as daily hours spent caregiving, and duration of caregiving in years. It is not surprising that the more severe the dementia and higher the level of daily living difficulties, the greater the extent and duration of assistance required by the person with dementia. In most instances this referred to a person with Alzheimer's dementia (See Table 7: Correlations between demographic and lifestyle variables).

*Economic factors* include being employed, hours worked per week, and household income. These factors indicate that older spousal caregivers work fewer hours and have a lower income than other caregivers (See Table 7: Correlations between demographic and lifestyle variables).

The other caregivers (family, friends or formal caregivers) are younger and more economically active (employed for more hours on a weekly basis). Not surprisingly, their income is higher and they are on the average spending fewer hours caregiving each day. Caregivers reporting higher income and fewer average daily hours caregiving also report that the person they are caring for is less severely affected

by their condition (See Table 7: Correlations between demographic and lifestyle variables).

The demographic and lifestyle variables are differently related to the psychometrically measured variables. The significant correlations between these variables are summarised in Table 8: Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores.

Of particular interest is the relationship of personal factors with positive and negative affect. In general, the personal factors related to positive affect, whereas the economic factors related to negative affect. The results indicate that being female and younger, and not caring for a spouse with dementia, are positively related to positive affect, whereas hours spent providing care, being unemployed, and having a low income, are positively related to negative affect of caregivers caring for a male person with dementia (See Table 8: Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores).

Gender of the person with dementia is the only factor relating to both positive and negative affect. In both cases the relationship is negative (males coded 1, females coded 2; to PA  $r = -.209, p < .01$ ; to NA  $r = -.179, p < .05; n = 133$ ). This indicates that caregivers caring for males with dementia report experiencing less positive affect and more negative affect.

In contrast, both personal and economic factors relate to helping attitudes. The economic factors relate positively to helping indicating that as income increases so do the reported levels of helping attitudes. The factors relating to helping attitudes are caregiver gender ( $r = .16, p < .05, n = 154$ ), relationship with person with dementia ( $r = .18, p < .05, n = 155$ ), being employed ( $r = .18, p < .05, n = 154$ ), weekly hours worked ( $r = .16, p < .05, n = 121$ ) and income ( $r = .16, p < .05, n = 157$ ).

Table 8

Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores.

\*  $p < 0.05$  level (2 tailed), \*\*  $p < 0.01$  level (2 tailed)

N = 158	1	2	3	4	5	6	7	8	9	10	11	12	13	14
15 HAS Score	.157*	-.101	-.164*	.176*	-.149	.176*	.162*	.158*	.147	.007	-.059	.162*	-.076	.021
16 Problem focused	.090	-.083	-.116	.163*	-.233**	.088	.082	-.033	-.055	-.056	-.161*	.027	-.089	.033
17 Wishful thinking	.169*	.099	-.044	.025	-.133	-.020	-.031	-.243**	-.185*	-.152	.041	.005	-.112	.054
18 Seeking social support	.182*	.026	-.068	.118	-.109	.055	.078	-.009	.023	-.029	-.105	-.035	-.180*	.107
19 Avoidance	-.024	.057	-.008	.016	-.035	-.043	-.022	-.188*	-.079	-.043	.011	.008	-.081	.044
20 Blaming	.020	-.068	-.064	.035	-.018	-.018	-.019	-.074	.132	.050	.027	.113	-.092	.161*
21 Positive affect	.215**	-.064	.002	.246**	-.253**	.119	.150	.060	.039	-.209**	-.049	.090	-.013	.009
22 Negative affect	.097	.267**	.117	-.126	-.027	-.208*	-.134	-.188*	-.177	-.179*	.043	-.062	.088	-.039

1 - Gender (caregiver), 2 - Daily hours (caregiving), 3 - Ethnicity (caregiver), 4 - Relationship, 5 - Age (caregiver), 6 - Employed, 7 - Hours/week employed, 8 - Income (household), 9 - Age (dementia), 10 - Gender (dementia), 11 - Ethnicity (dementia), 12 - Education (carer, years), 13 - Residence (caregiver), 14 - Attorney (P.O.A).

Differences in the relationships between coping strategies and the demographic factors are again evident (See Table 8: Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores). A number of coping strategies relate significantly to demographic factors. Problem focussed coping relates negatively to caregiver age ( $r = -.23, p < .01, n = 158$ ) and ethnicity of the person with dementia ( $r = -.16, p < .05, n = 154$ ), but positively with relationship ( $r = .16, p < .05, n = 155$ ) indicating that when the relationship between the caregiver and the person they are caring for is more of a professional relationship than a close family relationship, the reported use of problem focussed coping increases.

Wishful thinking relates negatively to household income ( $r = -.24, p < .01, n = 157$ ) and age of person with dementia ( $r = -.19, p < .05, n = 158$ ), but correlates positively to caregiver gender ( $r = .17, p < .05, n = 154$ ) indicating that the women in the caregiver sample reported more use of wishful thinking than the men (See Table 8: Correlations between demographic and lifestyle variables, HAS, RWCCCL, and PANAS scores). Seeking social support relates positively to caregiver gender ( $r = .18, p < .05, n = 154$ ), and negatively to residence of caregiver ( $r = -.18, p < .05, n = 153$ ), whereas avoidance relates negatively to household income ( $r = -.19, p < .05, n = 157$ ).

In addition, both helping and coping strategies relate to positive and negative affect differently. These correlations are summarized in Table 9: Correlations between HAS, RWCCCL, and PANAS scores.

Table 9  
Correlations between HAS, RWCCCL, and PANAS scores.

	N = 158	15	16	17	18	19	20	21	22
15 Has Score		1							
16 Problem Focus		.193*	1						
17 Wishful Thinking		-.052	.399**	1					
18 Seeking Social Support		.192*	.587**	.431**	1				
19 Avoidance		-.193*	.323**	.593**	.224*	1			
20 Blame		.044	.253**	.356**	.296**	.376**	1		
21 Positive Affect		.307**	.254**	-.079	.163*	-.031	-.165*	1	
22 Negative Affect		-.139	.045	.494**	.179*	.307**	.264**	-.160	1

\*  $p < .05$  level (2 tailed), \*\*  $p < .01$  level (2 tailed)

Helping attitudes, overall, are related to positive affect ( $r = .31, p < .01, N = 158$ ), but are not related to negative affect. The helping attitudes of male caregivers are highly significantly related to positive affect ( $r = .41, p < .01, N = 158$ ). The helping attitudes of female caregivers are related to positive affect ( $r = .25, p < .05, N = 158$ ) and to negative affect ( $r = -.25, p < .05, N = 158$ ).

The coping strategies also relate differentially to positive and negative affect. Problem focussed coping ( $r = .25, p < .01, N = 158$ ) and seeking social support ( $r = .16, p < .05, N = 158$ ) relate positively to positive affect, while blame related negatively to positive affect ( $r = -.17, p < .05, N = 158$ ). Caregivers who use problem focussed coping and make less use of blame as a means of coping, are more likely report higher levels of positive affect (See Table 9: Correlations between HAS, RWCCCL, and PANAS scores).

In contrast, wishful thinking ( $r = .50, p < .01, N = 158$ ), seeking social support ( $r = .18, p < .05, N = 158$ ), avoidance ( $r = 0.31, p < .01, N = 158$ ), and blame ( $r = .26, p < .01, N = 158$ ), relate to negative affect.

Blame is related to both positive affect and negative affect, but the direction and strength of the relationship differs. Less use of blame is related to positive affect, whereas increased use of blame is related to negative affect (See Table 9: Correlations between HAS, RWCCCL, and PANAS scores).

Seeking social support is the only coping strategy the study found to be significantly related to both positive affect ( $r = .16, p < .05, N = 158$ ) and negative affect ( $r = .18, p < .05, N = 158$ ). This could be explained as caregivers with a positive outlook making more appropriate decisions regarding obtaining appropriate assistance, whereas caregivers who are more negative possibly being more dependent and requesting assistance (See Table 9: Correlations between HAS, RWCCCL, and PANAS scores).

Helping attitudes and coping strategies are also related. Helping is positively related to problem focussed coping ( $r = .19, p < .05, N = 158$ ) and seeking support ( $r = .19, p < .05, N = 158$ ). Avoidance is negatively related to helping ( $r = -.19, p < .05, N = 158$ ). Caregivers with higher scores on helping attitudes appear to make more use of problem focussed coping, do not use avoidance strategies, and tend to ask for help.

It seems reasonable to conclude that not only are different demographic factors related to the mood states, helping, and coping, but the nature and direction of the relationships also differ. Helping and coping strategies relate differently to each other, as well as to positive and negative affect of caregivers. At the zero-order level, positive affect is related to helping attitudes, problem focussed coping and positive affect are related, whereas negative affect is related to emotional coping strategies.

### Intergroup Differences

The study intended to investigate possible differences between caregivers who identified with specific ethnic or cultural groups living in New Zealand. Unfortunately due to a high degree of variability in ethnic group sizes and low group number in some groups, such as Maori participants, reliable comparisons between the groups could not be made between the cultural groups participating in the study. The available data suggests that there may be differences in the way caregivers of NZ Pakeha/European, European, and Maori descent use coping strategies. This would need to be investigated in more detail in future studies.

The study was, however, able to identify differences between male and female caregivers. Information relating to gender groups is presented in Table 10: Descriptive statistics of study variables according to gender. A one-way between groups analysis of variance was conducted to explore differences between male and female caregivers of people with dementia in helping attitudes, coping strategies, or mood states (positive and negative affect). The sample was divided into three groups based on gender: Male, Female, and Other, which included unspecified or missing information.

Significant differences between the gender groups were obtained involving wishful thinking as a coping strategy,  $F(2,155) = 3.0, p < .05$ , and positive affect  $F(2,155) = 4.4, p < .05$ . Despite reaching statistical significance, the actual mean score difference for wishful thinking between the groups was small, 0.36, with a small effect size of 0.04. The mean difference for positive affect was larger, 3.8, with a more moderate effect size of 0.05. Effect sizes were calculated using eta squared.

The mean wishful thinking score for the 49 male caregivers ( $M = 1.1, SD = 0.8$ ) was significantly different from the 105 female caregivers' score ( $M = 1.5, SD = 0.9$ ) at the  $p < .05$  level. The mean positive affect score for the 49 male caregivers ( $M =$

27.3,  $SD = 7.4$ ) was significantly different from the 105 female caregivers' score ( $M = 31.1$ ,  $SD = 7.7$ ) at the  $p < .01$  level. Bonferoni adjustment was selected over the Tukey HSD test, as it was more robust with unequal groups, smaller samples, and minor infringements of assumptions regarding homogeneity of variances (Coakes & Steed, 2001, 2003; Cronk, 2002; Pallant, 2001).

In both situations, male caregivers appear to make less use of wishful thinking as a coping strategy, and reported lower levels of positive affect than the female caregivers, who were more positive in affect and tended to use more wishful thinking in their coping. No other significant differences involving the other variables were identified at the  $p < .05$  level.

Table 10  
*Descriptive statistics of study variables according to gender.*

$N = 158^*$	Gender	$M^{**}$	$SD^{**}$
HAS Score	Male	76.7	8.7
	Female	79.7	8.0
	Other***	76.8	18.3
Problem Focus	Male	1.9	0.6
	Female	1.9	0.7
	Other***	1.6	1.0
Wishful Thinking	Male	1.1	0.8
	Female	1.5	0.9
	Other***	1.4	1.1
Seeking Social Support	Male	1.9	0.8
	Female	2.1	0.7
	Other***	1.7	1.2
Avoidance	Male	1.0	0.7
	Female	0.9	0.6
	Other***	0.9	0.7
Blame	Male	0.9	0.7
	Female	0.9	0.8
	Other***	0.8	0.6
Positive Affect	Male	26.1	9.2
	Female	31.1	7.7
	Other***	28.3	5.0
Negative Affect	Male	21.1	8.0
	Female	22.6	8.8
	Other***	19.2	7.6

\* Group sizes: 49 Male and 105 Female caregivers, 4 Other caregivers.

\*\* Rounded to 1 decimal

\*\*\* *Other* refers to missing or unspecified gender information.

### **Role of Helping Attitudes and Coping Strategies in Mood States**

In this section the relationships between the independent variables of helping attitude and coping strategies, and the dependent variables, positive and negative affect, are explored through stepwise regression analysis. Stepwise regression analysis allows for control over the variables entered, the stage of entry and examination of the change in variance specific to each variable.

The variables were entered in a series of steps, and a regression equation was obtained in which the variables contributed significantly to the prediction of the dependent variables (Gardner, 2001). The stepwise process reflects variables being added as possible predictors for the dependent variables of positive and negative affect.

The independent variables were entered in the following order, based on theoretical significance and relationship to the study variables. Caregiver gender, relationship between caregiver and person with dementia, caregiver age, and gender of the person with dementia were entered first, followed by daily hours of caregiving, employment of caregiver, income of household, and gender of the person with dementia.

Coping strategy scores for caregivers were entered on the second step of the model and included problem focused coping, wishful thinking, seeking social support, avoidance and blame, followed by the HAS scores on the third step of the model. This was done in order to control for the influence of demographic and lifestyle variables, and other forms of coping, when examining the unique variance of helping attitudes.

Current research and multidimensional theories discussed in the literature review also provide support for the influence of personal and situational factors, such as age, gender, employment, geographical location, and active social participation in

managing life events (Endler & Parker, 1993, 1994; Folkman & Lazarus, 1988; Vaillant, 1977, 2001; Vitaliano, Maiuro, et.al., 1987, Vitaliano, Russo, et al., 1993). As such, the variables were entered in the order mentioned previously when determining the nature and extent of the relationships of both positive and negative affect.

The data meets or exceeds each of the essential assumptions for stepwise regression analysis, with the ratio of cases to independent variables with 26 cases per variable, scatter plots of residuals against the predicted values of positive and negative affect scores were normally distributed, with no clear indication of a relationship. Multicollinearity, singularity and outliers were also absent (Coakes & Steed, 2001, 2003; Gardner, 2001; Tabachnick & Fidell, 2001). The critical Mahalanobis value of 22.46 ( $p < .001$ ) for 6 independent variables (helping attitude and five coping strategies) was not exceeded (Coakes & Steed, 2001, 2003; Palant, 2001).

### *Prediction of Positive Affect*

Multiple stepwise regression was used to determine the role of coping strategies and helping attitudes on the positive affect of caregivers of people with dementia. Demographic and lifestyle variables were entered first, followed by the coping strategies and finally the helping behaviour score as measured by RWCCCL and HAS, respectively.

The multiple regression procedure allowed for the examination of helping behaviour and coping while controlling for the other independent variables. The analysis also indicated the nature and degree of the relationship of helping attitudes and coping with regard to positive and negative affect of caregivers.

A significant result was found,  $F(6,149) = 9.21, p < .00$ , with an overall  $R$  squared ( $R^2$ ) of .30. The amount of variation explained by the predictor variables and

the predictive power of the equation increased with each successive step as additional variables were entered into the equation (See Table 11: Stepwise regression analysis for variables predicting positive affect).

Caregiver age, duration of caregiving, and difficulties experienced with activities of daily living by the person with dementia accounted for 12% of the overall variance in positive affect. The addition of problem focussed coping increased the amount of variance accounted for by the predictor variables to 20%. The strategy of blaming people accounted for a small increase in the amount of variation in positive affect of caregivers to 22% of the overall variance. The final predictor variable that was included in the regression was helping attitude (HAS score), which accounted for another 8% of the variance in positive affect and together with the other predictor variables accounted for 30% of the variance in positive affect of caregivers of people with dementia.

The final six variables were all significant and unique predictors of positive affect of caregivers. Caregiver age ( $\beta = -0.20, p < .01$ ), experiencing activity of daily living difficulties ( $\beta = -0.20, p < .05$ ), and blaming people ( $\beta = -0.24; p < .01$ ), were negatively related to positive affect of caregivers, whereas duration of caregiving ( $\beta = 0.23, p < .01$ ), using a problem focussed approach in dealing with events ( $\beta = 0.24, p < .01$ ), and helping attitudes ( $\beta = 0.23, p < .01$ ) were positively related to positive affect of caregivers within this study.

Table 11  
 Stepwise regression analysis for variables predicting positive affect ( $N = 158$ ).

Variable	$R$	$R^2$	Adj. $R^2$	$F$	B	SE B	Beta	T
Step 1	0.30	0.10	0.10	10.60***				
Carer age					-0.14	0.04	-0.30	-3.30**
Step 2	0.31	0.10	0.10	8.30***				
Carer age					-0.15	0.04	-0.30	-3.60***
Duration					0.52	0.22	0.20	2.40*
Step 3	0.40	0.12	0.11	7.12***				
Carer age					-0.15	0.04	-0.30	-3.60***
Duration					0.70	0.23	0.30	3.01**
ADL difficulties					-1.20	0.60	-0.20	-2.12*
Step 4	0.41	0.20	0.20	7.70***				
Carer age					-0.12	0.01	-0.23	-2.94**
Duration					0.72	0.23	0.30	3.20**
ADL difficulties					-1.30	0.60	-0.20	-2.33*
Problem focus					2.70	0.93	0.22	2.90**
Step 5	0.50	0.22	0.20	8.50***				
Carer age					-0.12	0.04	-0.22	-2.90**
Duration					0.73	0.22	0.30	3.30**
ADL difficulties					-1.30	0.54	-0.20	-2.34*
Problem focus					3.40	0.93	0.30	3.70***
Blame					-2.51	0.80	-0.24	-3.20**
Step 6	0.52	0.30	0.24	9.21***				
Carer age					-0.10	0.04	-0.20	-2.60**
Duration					0.70	0.22	0.23	3.02**
ADL difficulties					-1.14	0.53	-0.20	-2.20*
Problem focus					2.93	0.92	0.24	3.21**
Blame					-2.51	0.80	-0.24	-3.30**
HAS score					0.21	0.10	0.23	3.20**

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

### **Prediction of Negative Affect**

Multiple stepwise regression was also utilised to determine the role of coping strategies and helping behaviour with regard to negative affect of caregivers of people with dementia. It used the scores obtained from caregivers with regard to their demographic and lifestyle information, and replies on the RWCCCL, HAS, and PANAS measures. These variables included in this analysis were correlated at the zero order level with positive and negative affect.

A significant result was found,  $F(6,149) = 13.30$ ,  $p < .000$ , with an overall  $R$  squared ( $R^2$ ) of .40. The amount of variation explained by the predictor variables and

the predictive power of the equation increased with each successive step as additional variables were entered into the equation (See Table 12: Stepwise regression analysis for variables predicting negative affect).

The initial amount of variance accounted for by daily hours spent caregiving was 10%. Daily hours spent caregiving, caring for a male with dementia, and income together accounted for 13% of the overall variance in negative affect. The addition of the coping strategy wishful thinking increased the amount of variance accounted for by the predictor variables to 31%. Using a problem focussed approach to dealing with life events increased the proportion of variance accounted for to 33% of the overall variation in negative affect. Gender, income, and using a problem focused approach, were negatively related to negative affect.

The final four variables that significantly predicted the negative affect of caregivers were daily hours of caregiving, wishful thinking, blaming people (self or others), and not using a problem focused approach. However, the demographic variables of gender of the person with dementia (male), and income (low) were no longer significant with the other variables controlled for (See Table 12: Stepwise regression analysis for variables predicting negative affect).

The beta values confirmed that wishful thinking ( $\beta = 0.50, p < 0.001$ ) as strongest predictor of negative affect of caregivers, followed by daily hours of caregiving ( $\beta = 0.22, p < .01$ ), blaming people ( $\beta = 0.20, p < .05$ ) and problem focussed coping ( $\beta = -0.20, p < .05$ ).

Table 12  
 Stepwise regression analysis for variables predicting negative affect ( $N = 158$ ).

Variable	$R$	$R^2$	Adj. $R^2$	$F$	B	SE B	Beta	T
Step 1	0.30	0.10	0.10	12.30**				
Daily hours caring					0.30	0.10	0.30	3.51**
Step 2	0.33	0.11	0.10	9.10***				
Daily hours caring					0.30	0.10	0.30	3.61***
Gender of ALZ					-2.02	0.90	-0.20	-2.40*
Step 3	0.40	0.13	0.12	7.80***				
Daily hours caring					0.24	0.10	0.30	3.40**
Gender of ALZ					-2.01	0.90	-0.20	-2.40*
Income					-0.20	0.10	-0.20	-2.20*
Step 4	0.60	0.31	0.30	16.70***				
Daily hours caring					0.21	0.10	0.22	3.30**
Gender of ALZ					-1.30	0.80	-0.11	-1.70
Income					-0.10	0.10	-0.10	-0.90
Wishful thinking					4.22	0.70	0.44	6.20***
Step 5	0.60	0.33	0.31	14.62***				
Daily hours caring					0.20	0.10	0.21	3.01**
Gender of ALZ					-1.30	0.80	-0.11	-1.64
Income					-0.10	0.10	-0.10	-0.80
Wishful thinking					4.90	0.74	0.50	6.60***
Problem focus					-2.10	1.00	-0.20	-2.20*
Step 6	0.60	0.40	0.32	13.30***				
Daily hours caring					0.20	0.10	0.22	3.24**
Gender of ALZ					-1.44	0.80	-0.13	-1.91
Income					-0.10	0.10	-0.10	-0.80
Wishful thinking					4.40	0.80	0.50	5.70***
Problem focus					-2.31	1.00	-0.20	-2.42*
Blame					1.80	0.83	0.20	2.20*

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .000$ .

## DISCUSSION

### **General Characteristics of Caregivers and People with Dementia**

The large number of caregivers who participated in the study provided a substantial amount of information regarding the demographic and lifestyle features of caregivers in New Zealand. The results provide characteristics of both the caregivers and the person with dementia they care for.

### **Role of Demographic and Lifestyle Variables to Positive and Negative Affect**

This study found that demographic and lifestyle variables are differentially related to the mood states of caregivers (positive and negative affect) in terms of the extent and nature of relationship, as well as in their role in the prediction of positive and negative affect of caregivers of dementia.

Demographic and lifestyle variables that related significantly to positive affect in caregivers include being female, being younger, caring for a male with dementia and being related to the person with dementia, but not necessarily in a marital relationship. Interestingly, different variables were related to negative affect. These include spending long hours each day caring for the person with dementia, being unemployed, coming from a low income household, and caring for a female with dementia. Caregivers from low income groups are unlikely to have sufficient funds for alternative sources of providing care, and may be forced to spend many hours each day providing the required care themselves. It comes as no surprise that caregivers on low incomes are also often those who are unemployed and report higher levels of negative affect, particularly if they are caring for a male with dementia, who may have been the breadwinner.

Gender of the person with dementia was the only variable related to both positive and negative affect of caregivers. Caring for a male with dementia is more likely to be related to positive affect, whereas caring for a female with dementia is more likely to be related to negative affect in caregivers.

Demographic and lifestyle variables also differ in their contribution in predicting both positive and negative affect. Significant demographic variables in the prediction of positive affect include younger caregivers (age), caring for someone with relatively fewer problems in daily living or personal care activities and caring for longer periods overall (duration in years). However, different demographic and lifestyle variables contribute to the prediction of negative affect in caregivers. They are hours spent each day caregiving, caring for a male with dementia, and coming from a lower income group.

It may be that being motivated to provide care and empathetically identifying with the person with dementia (Batson, 1991; Batson & Shaw, 1991) combine with problem solving and not using blame as a coping strategy, to make some caregivers more resilient to the many difficult events they face during their caregiving experiences. This seems to be the case even if the caregiving continues for a number of years.

This would seem to support both the research findings of Vaillant (1977, 2002), and supporters of the cognitive-phenomenological frameworks for coping with stressful events (Endler & Parker, 1993, 1994; Vitaliano, et al., 1985; Vitaliano, et al., 1990), as well as the more recent Broaden-and-Build theory regarding the relationship between positive affect and the specific broadening of action repertoires (Frederickson, 2001). According to these theories, helping is regarded as a cognitive process that involves determining the risks and benefits, as well as available effective

strategies, to manage the demands of the situation (Vitaliano, et al., 1985; Vitaliano, et al., 1990). Evidence supporting these theories suggests that resilient individuals recover faster from stressful situations, and that this is related to the level of positive emotions they experienced (Frederickson, 2001; Frederickson & Levenson, 1998). It seems that these individuals are not only able to assess life events and determine which strategies to use most effectively to solve problems, but that they have a wider range of strategies readily available for use, thus increasing their flexibility and adaptability in difficult situations (Endler & Parker, 1993, 1994; Vitaliano, et al., 1990; Vaillant, 2002). Achieving success results in helping outcomes that are beneficial for the caregiver and the person being care for, and feeling good about it encourages the helping behaviour to continue (Batson, 1991; Batson & Shaw, 1991; Frederickson, 2001). This is also seen as a sign of emotional maturity and adaptability (Vaillant, 1977, 2002). Managing the demands of caregiving effectively likely contributes to positive emotions in caregivers and in turn enhances long term physical and mental health.

The ability to solve caregiving problems effectively is a likely contributor to positive feelings within the caregiver, which in turn maintains the helping or caregiving behaviour according to the negative state relief theory. According to this theory, caregivers receive their reward from two sources, assisting someone in distress while reducing their own levels of distress (Cialdini & Fultz, 1990; Cialdini, et al., 1997). However, the community also provides additional reinforcement as it is deemed socially desirable to provide assistance to people in need (Bierhoff, 2002; Davis, 1996).

It is not unexpected to find caregivers experiencing positive feelings when the person with dementia is experiencing fewer problems with daily living or personal

care tasks. This likely occurs in the early stages of dementia when the person with dementia is more likely to be physically able and participating independently in personal care tasks. It would require less direct input and be less stressful for caregivers who may well be providing only general assistance of a supervisory nature.

When problems become more complex, as in the latter stages of dementia, more negative affect is reported. Previously employed coping strategies also seem to be less effective, and caregiving becomes more emotionally and physically demanding. Additional assistance and support is highly likely to be required in many situations, and caregivers are likely to find selection of effective coping strategies more difficult, with more unpredictable results.

Different demographic and lifestyle variables are related to negative affect. Negative affect is more related to longer term stressful events and problems related to health matters (Watson, Clark, & Carey, 1988). Caregivers may be more anxious about the caregiving situation and if this is combined with less positive affect, then they are at higher risk for depression (Watson, Clark, Carey, 1988; Watson & Tellegen, 1985). It is likely that they will not be enjoying the situation, experience distress, and generally be involved reluctantly.

The above information would suggest the need for additional support and information being made available to caregivers during stressful times as well as respite and time-out for caregivers to avoid the negative effects of being involved with long term stressful events such as dementia caregiving.

The involvement of income in the prediction of negative affect highlights the difficulties caregivers of limited financial means face in providing care to people with dementia. Caregivers may have difficulty arranging for alternate, effective care if they have limited financial means at their disposal, creating additional stress within an

already difficult situation. Providing long hours of care each day necessarily prevents caregivers from being breadwinners and the subsequent loss of income could increase the risk of negative outcomes to caregivers, people with dementias, and their families.

Given the increased risk of psychopathology associated with negative affect (Chan & Hui, 1995; Endler & Parker, 1993; Endler, et al., 1993), stress, and adjustment problems of providing long-term care (Bowman & Stern, 1995; Sanders-Dewey, et al., 2001), this is undoubtedly an area of importance in our aging society. Appropriate intervention would include making available knowledge of the condition, what the caregivers could expect at each stage, appropriate strategies to deal with the problems in each stage of the dementia, and support systems that are available that caregivers could access when required. It would also be important for the caregivers to maintain the control in this process as this has been found to contribute to more favourable physical and mental health outcomes for caregivers (Bowman & Stern 1995; Endler & Parker, 1993, 1994; Sanders-Dewey, et al., 2001; Vitaliano, et al., 1990).

### **Role of Helping Attitudes Regarding Positive and Negative Affect**

The results indicate that helping attitudes are differentially related to the prediction of positive and negative affect of caregivers. Interestingly, helping attitudes played a more prominent role in the prediction of positive affect than demographic and lifestyle variables, but were not involved in the prediction of negative affect. This is not surprising, as helping has a long association with positive affect and psychological well-being. This has been well documented in the literature (Batson & Shaw, 1991; Endler & Parker, 1993, 1994). Vaillant (2002), for instance, regards altruism as one of the most psychologically healthy ways of reducing the impact of stressful events, and a sign of emotional maturity and adaptation.

According to the empathy-altruism hypothesis (Batson, 1991; Batson & Shaw, 1991), caregivers with a strong helping attitude are likely to identify strongly with the person with dementia, show empathy and concern, and feel good about helping the other person, which is likely to motivate the behaviour to continue. The results of this study support the previous research regarding helping behaviour as motivational, and having a direct influence on positive emotions among caregivers of people with dementia.

The results of past research also offer partial explanations for why helping was not associated with negative affect of caregivers. Caregivers who have had limited exposure to adequate role models and social learning experiences (Bierhoff, 2002; Davis, 1996) may be less able to be socially responsive, and experience caregiving tasks as unpleasant or stressful (Endler & Parker, 1993, 1994; Sanders-Dewey, et al., 2001), along with a perceived loss of control (Bowman & Stern, 1995). Additionally, their reduced resilience may have increased their vulnerability for negative outcomes, as suggested by the Broaden-and-Build theory (Frederickson, 2001).

All of these would have resulted in less favourable and negative outcomes for caregivers, and reduced their motivation to participate in helping related activities (Batson, 1991; Batson & Shaw, 1991).

### **Role of Coping Strategies Regarding Positive and Negative Affect**

The study found that coping strategies are differentially related to positive and negative affect. Coping strategies in general played a more prominent role in predicting positive affect, in contrast to negative affect.

Both problem focussed coping, and not blaming people for situations or stressful events, emerged as significant predictors of positive affect. The use of these coping strategies, especially having a problem focussed approach, support previous

research involving coping as having a strong, direct relationship with positive outcomes and good mental health (Endler & Parker, 1990, 1993, 1994; Gallagher-Thompson, et al., 1998; Lazarus & Folkman, 1988; Sanders-Dewey, et al., 2001; Vaillant, 2002; Watson, Clark, & Carey, 1988). Caregivers who manifest this type of coping are also likely to be more involved in variety of social activities or support networks, which further enhances their positive feelings and well-being (Endler & Parker, 1993; Lu, 1995; McIntyre, et al., 1990).

The results of the study support past research suggesting that caregivers actively try to manage the stressful events they experience during caregiving. This may have contributed to positive mood functioning among caregivers, and assisted them in reducing the negative mood commonly associated with long-term stressful events by increasing the strategies or repertoires at their disposal for dealing with situations and life events (Frederickson, 2001). This supports the work by Vitaliano and associates (Vitaliano, Katon, et al., 1987; Vitaliano, et al., 1989, 1990), who found that caregivers of people with dementia also tended to use less social support services, perhaps because of additional psychological difficulties such as low self-esteem, a lack of confidence or adjustment problems (Sanders-Dewey, et al., 2001; Endler & Parker, 1993; Endler, et al., 1993). These factors offer a partial explanation for their use of emotional coping strategies and negative outcomes generally.

### **Intergroup Differences**

The following section discusses the significant differences in helping attitude, coping strategies, and positive and negative affect between participating groups within the study, specifically those between male and female caregivers, and caregivers belonging to different ethnic or cultural groups within New Zealand.

Few significant differences were identified between the male and female caregivers in the study. The only differences in the study variables related to the coping strategy of wishful thinking, and the mood state of positive affect.

Female caregivers used more emotional coping strategies than the male caregivers, and had slightly higher positive affect scores. Research indicates that using emotional strategies are related to higher levels of stress, poorer mental health, and negative psychological outcomes (Gallagher-Thompson, et al., 1998; Pruschno & Resch, 1989; Rose, et al., 1997) and that high positive affect is related to better psychological outcomes (Sanders-Dewey, et al., 2001; Watson, Clark & Carey, 1988). Female caregiver may then be at higher risk of negative psychological outcomes due to the use of emotional coping strategies (Vaillant, 2002) but may be afforded some protection in the form of positive affect. This supports the Broaden-and-Build theory of positive emotion that suggests positive emotions increase psychological resilience and ability to cope with stress (Frederickson, 2001).

It may be that the male caregivers do not find caregiving tasks pleasurable, and that the socialisation patterns in society may have contributed to the situation and their negative caregiving experiences. It seems highly likely that they will be experiencing some sadness, loneliness, social isolation, and see providing the assistance as unpleasant. All of these offer partial explanations for the reduced positive affect experience by male caregivers (McIntyre, et al., 1990; Watson & Clark, 1984; Watson, et al., 1992).

These results provide additional support for findings suggested by Vaillant (2002) who found that older female caregivers provided more social and emotional support for others. Female caregivers also tend to seek help more from other people (Bierhoff, 2002), which would work in their favour by offering them more supportive

networks in general. It may be that men are less inclined to request assistance from others, possibly for fear of appearing less knowledgeable or losing face or losing control over a situation, preferring instead to suffer in silence (Bierhoff, 2002; Davis, 1996.).

However Prentice-Dunn (n.d.) suggests that their lower scores may also be the result of wanting to escape a difficult situation, that the male caregivers may in fact be more focussed on their own feelings, thus relatively inattentive to a person with dementia. They may also feel compelled to participate in caregiving, and feel less rewarded or positive about caregiving in general.

In contrast, having more supportive networks available through their participation, female caregivers, are not only likely to increase their knowledge and ability to cope with difficulties, but also to experience a greater degree of control and support (or perceived control and support), all of which are likely to contribute to their increased adjustment, lower stress, and improved positive affect (Gallagher-Thompson, et al., 1998; Sanders-Dewey, et al., 2001; Vaillant, 2002; Watson, Clark, & Carey, 1988).

It may just be that norms, regulations, and socialisation patterns for females have increased their ability to be emotional and socially more responsive (Bierhoff, 2002; Davis, 1996), and continued involvement may reduce their negative feelings, along with empathic concern and identification with the person with dementia (Batson & Shaw, 1991).

The study was unable to make comparisons between caregivers who belong to different ethnic groups due to small numbers participating in the study. Future research would need to investigate the possible existence of differences between caregivers who belong to different ethnic groups.

### **Applications of Findings**

The findings of this study have some immediate practical implications for caregivers, and the agencies and organisations that employ and support caregivers and their families. As the number of older adults and hence the number of people with dementia and requiring care increases, so too will the impetus on providing a psychologically safe environment for caregivers to work. This is not only for the good of caregivers, but for the good of the people they are caring for, because the people with dementia are likely to get a better quality and continuity of service if caregivers have positive outcomes associated with their caregiving activities.

In our society, employers are increasingly being held responsible for the well being of employees. For organisations employing and supporting caregivers, these results have direct implications for staff selection. The results suggests that people who use problem focussed coping strategies and those that have high helping attitudes would potentially be better suited to employment as a caregiver, as they are at less risk of negative psychological outcomes. Human resource agencies might consider using measures of helping attitudes and problem focussed coping in the caregiver selection process. Similarly, employers and supporters of caregivers might utilise these results by training caregivers in the use of effective strategies to help them cope more effectively with their caregiving tasks. Within the framework of cognitive behavioural therapy, caregivers could be taught to reframe negative beliefs, identify skills and abilities that they already have and improve helping attitudes and problem solving skills. Such skill training could be particularly useful for caregivers who are already struggling with the demands of their caregiving role. The results also suggest that as groups, men and women bring different skills and strengths to the caregiving situation. Women report higher levels of positive affect and make more use of social

contacts than men, whereas men tend to use more problem focussed coping. Agencies and organisations that employ and support caregivers can use this information to be aware of particular differences that might be pertinent to one gender (although caution must be taken here as the results relate to the congregate tendencies of these groups and individual variation must not be overlooked) and to use the strengths each bring to caregiving situations. Promoting strengths and minimising weaknesses through support programmes that encourage both male and female caregivers to build personal, social and community networks might be a valuable practical application to come out of this research. This would provide caregivers with a holistic approach to their caregiving, in which they are encouraged to take care of themselves as well as the person with dementia.

### **Limitations of the Study**

This study provides valuable information about caregivers and people with dementia in New Zealand. However, there are some limitations to the current study, which has implications for the utility of the results.

The majority of sample came from the membership of two regional community based organisations working with people with dementia and their families (Alzheimer's Society), and elderly clients in general (Age Concern). The non-random nature of the sample makes it difficult to generalise to other populations. Because the sample was limited to a particular region, the sample group may have a more homogenous experience of social support than, for example, a sample that also contained participants from larger urban areas. With a larger sample, although it was a specific population group, random selection of caregivers could have been used to increase the ability to generalise the finding across all caregivers of people with dementia.

The different ethnic or cultural groups in New Zealand were not equally represented, making it difficult to identify trends and compare results for these groups. It may be that the different groups do not belong to the organisations approached to participate in this study, or that they use other means to assist or support caregivers. Alternatively, the method of investigation may not be appropriate for all cultural groups. Some groups may prefer a more consultative, interview or discussion style approach, rather than answering formal questions in writing. Language or educational difficulties may have created barriers to some caregivers' participation.

It would also have been helpful to explore the possibility of whether results were different for formal and informal caregivers. The study made no distinction between formal (agency care) or informal caregiving (family, friends).

The study did not obtain information on the health status of caregivers. Caregivers who were themselves experiencing health problems may hold different views and their health problems could affect their ability to provide care, or use support services. Lack of collaborative information regarding personal health, or support services/medical information for the caregiver meant that this potentially moderating variable was not controlled for. Caregivers were the only source of information, and many caregivers were unable to complete all the items on the questionnaire due to the position they were in. While having this information would have enhanced the study, the additional questions may have lead to more incomplete forms. Caregiver burden is well-known and documented (see literature review), and many participants indicated that they had difficulty finding time for many activities, and for themselves. As such, many may have had difficulties finding time to complete the questionnaire, even though it was made clear that they could complete the sections

in stages. Some may simply have felt it to be too long. Some age-related health factors of an elderly population tend to limit participation in similar research, such as difficulties with vision (struggled to read), and hearing (struggled to hear if read). This may have affected the level of participation in the study, and the number of incomplete items overall.

The formal format and layout appeared to have caused difficulty for some caregivers. Many wrote additional comments in the margins, highlighting their need or desire to discuss many aspects of the questionnaire and their personal situations in more detail. A more personal, consultative and qualitative approach or style would have allowed for the collection of this information to take place.

### **Future Research Implications**

Information on caregiving within New Zealand is severely limited. This study provides basic knowledge regarding caregiving for people with dementia in New Zealand. The study highlighted a number of important psychological implications that need to be addressed in future studies. Future studies also need to explore the role and possible beneficial effects of stress, and a more holistic approach to caregiving problems (Nolan, et al., 1996), rather than a one sided or pathologising approach that has been used previously. Holistic aspects of caregiving include spirituality; cultural factors; degree of family involvement and support; the availability, appropriateness and access to support services for caregivers and people with dementia; more specific needs of caregivers and people with dementia such as respite care; and policy issues relating to caregiving services. The present study did not investigate these aspects of caregiving, which would likely provide substantial information on caregiving for use

in assessment, intervention, and prevention of negative outcomes for caregivers of people with dementia in a New Zealand perspective.

Studying the complex relationships that are known to exist between the many variables involved in combining quantitative and qualitative approaches, also longitudinally, would further enhance our knowledge of caregiving in dementia. It is necessary to go further than just identifying problems or levels of stress, and to look also at how caregivers appraise situations, determine their state of vulnerability, how they use the social resources available, how the caregiving situation and the caregivers themselves change over time, and what interventions are most effective for what stages. All of these aspects need to be investigated (Vitaliano, Maiuro, et al., 1990; Folkman, Schaefer, & Lazarus (1979), cited in Folkman, et al., 1987).

It is important to investigate what differences exist between particular groups, and to see what skills are more important for caregivers from different backgrounds (Gallagher-Thompson, et al., 1998). Many questions remain about cultural, ethnic and gender differences, especially within the New Zealand context, the study was too limited to identify other than the possibility of differences between cultural and groups, male and female caregivers. Some of these questions include the degree of culturalisation, cultural differences in approaches to caregiving, service provision and access to services, family involvement and support networks in caregiving, urbanisation and its relation to caregiving in different cultures.

It is also necessary to do more than just identify risk factors for caregivers; the appropriateness and effectiveness of intervention strategies also needs to be investigated. It would be advantageous for health professionals to be able to identify whether the use of specific coping strategies, such as problem focussed coping and wishful thinking, and the conditions under which they contribute to caregiver well-

being are responsible for positive or negative outcomes. The role of emotional coping strategies and the relationship this has with known diagnostic groups and outcomes for caregivers needs to be explored for the New Zealand population groups in general.

In addition to identifying stress levels of caregivers, health professionals also need to be able to identify the risk to caregivers of experiencing difficulties, the factors that may influence the different stages of caregiving, and the type and levels of support services required. These are all prerequisites for the development of more effective intervention strategies for caregivers.

By identifying the many varied facets of caregiving, and the factors that influence it, the well-being of caregivers and people with dementia are enhanced. The availability of accurate information is likely to contribute and improve policy and service development in variety of organizations, locally and nationally by basing decisions on accurate information regarding caregivers, and people with dementia.

Clinicians face tremendous challenges, identifying, diagnosing, and providing treatment to a variety of people with a variety of physical and mental health problems (Vitaliano, et al., 1990). Many factors complicate this process, and affect the nature of the interventions offered. These are related not only to the individual, but also the situation, the nature of the condition, and the nature and availability of services in general. This study provides a strong framework for future research in this important area.

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**APPENDICES**

Appendix A. Alzheimer's disease and related dementias .....	92
Appendix B. Request for participants .....	95
Appendix C. Information sheet .....	97
Appendix D. Consent form .....	100
Appendix E. Confidentiality agreement.....	102
Appendix F. Caregiver questionnaire .....	109

**Appendix A: Alzheimer's disease and related dementias**

## **Alzheimer's Disease and Related Dementias**

Alzheimer's disease can briefly be described as a progressive form of dementia characterised by the gradual deterioration of intellectual abilities such as memory, judgement, abstract thought, a variety of other higher level functions (planning, organisation, problem solving, sequencing), language and physical/motor disturbances, as well as changes in personality and behaviour (Kaplan & Sadock, 1998; Reber & Reber, 2001).

It has an insidious onset, commonly occurs after age 65, and was previously referred to as senile dementia. Onset before age 50 is rare, but known to have a genetic basis and occur in families. Memory impairments and subtle personality changes are frequently the only indications of the illness, that eventually progress to the debilitating cognitive and behavioural changes seen during the later stages, which include muteness and complete inability to self-care (Kaplan & Sadock, 1998; Reber & Reber, 2001).

The related dementias are generally described as dementias with similar symptoms, but a different disease progression or origin, such as vascular dementia's with evidence of vascular disease, or dementias due to other medical conditions such as head trauma, Parkinson's, Huntington's, Pick's or Creutzfeldt-Jacob disease. Dementias may also be substance induced (Kaplan & Sadock, 1998).

The characteristic brain atrophy and amyloid plaques of Alzheimer's disease are diagnosed by exclusion, using computer axial tomography (CAT scan) or magnetic resonance imaging (MRI scan).

Practical indications of clinical features of Alzheimer's may include (Kaplan & Sadock, 1998):

- Early prominent memory impairment is common, especially for recent events such as phone numbers, events of the day and general conversations. These impairments become progressively more severe.
- Orientation can be progressively affected for person, place, and time, but level of consciousness is seldom impaired. They do not know who or where they are. Memory plays a role as well, e.g. they may forget how to get back to their rooms at night after going to the bathroom.

- Language difficulties become noticeable with cortex involvement, and may include vague, imprecise, stereotyped language or difficulty in naming objects.

- Personality changes frequently occur, and very disturbing for friends and family. Pre-existing traits may become more marked, or even decrease in intensity.

- Paranoid delusions and hallucinations are common, and people with dementia may become hostile to or suspicious of others. Physical aggression and violent reactions are common in some people who also have psychotic symptoms. If the frontal or temporal areas of the brain are involved, these changes can be marked, with the person with dementia becoming very irritable and quick to react emotionally or angrily to situations. The hallucinations and delusions are mostly unsystematic by nature, but not always.

- Anxiety, depression and neurological signs, e.g. seizures may also be present. Additional neurological symptoms in vascular dementias may include headaches, dizziness, faintness, weakness, focal signs, sleep disturbances, dysarthria and dysphagia.

**Appendix B: Request for participants**



## Caregiver Research Project 2003

My name is Jean Dominy. I am a student in the School of Psychology at Massey University undertaking research to complete a Masters degree in Psychology. My supervisor is Dr. Patrick Dulin, Clinical Psychologist and lecturer at Massey University. My research is looking at the role of coping strategies in predicting the emotional well-being of caregivers of people with Alzheimer's and related dementias.

My interest in the topic comes from my awareness of the many difficulties facing caregivers of people with disabilities, and concern for the well-being of all elderly people. Many overseas studies cover a range of difficulties faced by caregivers in general, and specifically caregivers of people with dementias. Unfortunately little is known about the situation in New Zealand, how different caregivers cope or feel, or what can be done to help them. It is my hope that this study will extend our knowledge about caregiving, and make a difference for all caregivers, and the many people with dementia.

I would like to invite you, as a caregiver, or other members of your family (if they are involved in caring for a person with dementia), to participate in the project. An information sheet (with more details of the project) and questionnaires are available through the branches of the Alzheimer's Society or Age Concern in Tauranga and the wider Bay of Plenty (Whakatane, Rotorua, Taupo), the Researcher or School of Psychology. If you are willing to participate after reading this, you are invited to complete the consent form and questionnaire. All the forms have to be returned to the researcher on completion in the stamped, addressed envelope provided for this purpose by the return dates listed.

You do not have to be a member of any organisation to participate in the project, but you do need to be (or have been) directly involved in caring for someone with dementia. No names are required, your participation would be completely anonymous. You are however requested to code your own forms to help us keep the pages of each questionnaire together. Details on how to do this are provided in the Project Information sheet.

Thank you for considering participating in this project. It is much appreciated.

Yours sincerely,

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c/o School of Psychology, Massey University, Private Bag 11222, Palmerston North. Phone: (06) 356 9099.

This project has been reviewed and approved by the Massey University Human Ethics Committee, (PN Protocol 6 June 2003).

If you have any concerns about the conduct of this research, please contact:  
Prof. Sylvia V. Rumball, Chair, Massey University Campus Human Ethics Committee:  
Palmerston North, 06 801 2794, e-mail: [s.v.rumball@massey.ac.nz](mailto:s.v.rumball@massey.ac.nz)

**Appendix C: Information sheet**



## CAREGIVING RESEARCH PROJECT 2003

### *“The Role Of Coping Strategies In Predicting Emotional Well-Being Of Caregivers Of Alzheimer’s And Related Dementias”.*

#### **What is this project about?**

The research is being undertaken for an MSc thesis. This study aims to investigate the effects of caring for elderly people with Alzheimer’s and related dementias on their caregivers. It will specifically look at the experiences of caregivers and the coping strategies they use to maintain their emotional well-being, and gain an understanding of the process of caregiving. It hopes to identify some differences between the major cultural groups living within New Zealand.

Overseas research on caregiving has highlighted the many difficulties and stresses faced by caregivers, and some of how they cope. Unfortunately little is known about caregiving in New Zealand, and how best to provide assistance. This study aims to remedy this situation by identifying possible risk factors, how people cope and what influences their emotional well-being, and help professionals plan more effective interventions. A self-completed questionnaire will be used, requiring mainly YES/NO, or multiple-choice type answers to questions covering many aspects of caregiving.

#### **How are people going to get to know about the project and get involved?**

- Caregivers will be recruited by a mail-out to the members of the Alzheimer’s Society and Age Concern in Tauranga, and the wider Bay of Plenty Region (Whakatane, Rotorua and Taupo). Advertisements will also be placed in their newsletters. If additional participants are needed, additional branches of the organisations will be contacted (e.g. Waikato, Manawatu, Wanganui), also related community based organisations (e.g. Grey Power, Medical Practitioner groups, Rest Homes).
- No names are required and no lists of participants will be kept. This assures your anonymity, protects your identity, and keeps information private and confidential. No one will be able to identify you or your answers. Forms are available from the listed organisations, researcher, supervisor, or the School of Psychology.
- The numbers of participants depend on the number of returned questionnaires. Large numbers strengthen the findings.

#### **Who can participate in the project?**

- Any adult over 18 years that is caring or have recently cared directly for someone with Alzheimer’s or a related dementia. The severity of the condition, the kind of help or where you stay does not matter. You also do not have to live in the same home or town.
- The person with dementia must preferably not have a major physical or mental health condition diagnosed before the dementia diagnosis. This includes the misuse of medication, drugs, or other substances. These problems are likely to confuse the effects of the dementia and the results of the study.

### **What will happen to the information?**

- Information from the anonymous questionnaires will be collected, summarised, statistically analysed and interpreted by the researcher.
- This will allow us to describe caregivers in general, especially those that may be at risk or need some help during caregiving, and help health professionals plan more appropriate interventions. Specifically, caregiver's helping behaviours and ways of coping, and how this influences emotional well-being will be studied.
- A summary of the findings will be sent to the organisations, and published in their newsletters, once the project has been completed. Additional copies can also be obtained from the Researcher or the School of Psychology (free of charge). The results may also be presented at a conference or published in professional journals.

### **What will you need to do?**

- Answer a range of mainly multiple choice type questions about different aspects of your personal caregiving experiences. It may take about 45 minutes. The sections can be completed in one session, or at different times, if this is more convenient.
- You need to be able to complete the forms in writing, or tell someone which answers to write down for you. Completing all the questions will be appreciated. Completed questionnaires need to be returned to the Researcher in the supplied pre-paid envelopes by 15 July 2003 (1<sup>st</sup> mail-out) or 15 August July 2003 (2<sup>nd</sup> mail-out).
- There will be no payment for completing the questionnaires, but your participation will be appreciated.

### **You need to be aware of the following:**

- Participation is voluntarily, you can ask questions or withdraw at any stage.
- Completion and return of the anonymous questionnaire without a consent form implies consent. You can decline to answer any particular question, but fully completed forms will be appreciated. To help keep your forms together, please choose any 5 letters or numbers as a code (or combination) and write it on each page of your forms, e.g.CJD23.

### **If you need some help during the project:**

It is unlikely that participants will experience any discomfort or come to any harm during the project. Please do not hesitate to contact us at any stage, if you have any concerns, queries or need another form. Unfortunately we cannot deal with personal matters directly, but can refer you to someone who may be able to help you.

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 Telephone: 06 350 5799 Ext.: 2060

C/o School of Psychology, Massey University, Private Bag 11222, Palmerston North.

This project has been reviewed and approved by the Massey University Human Ethics Committee, (PN Protocol 6 June 2003).

If you have any concerns about the conduct of this research, please contact:  
 Prof. Sylvia V.Rumball, Chair, Massey University Campus Human Ethics Committee:  
 Palmerston North, 06 801 2794, e-mail: [s.v.rumball@massey.ac.nz](mailto:s.v.rumball@massey.ac.nz)

**Appendix D: Consent form**

### CAREGIVER RESEARCH PROJECT 2003

*This consent form will be held for a period of five (5) years.*

**“The Role Of Coping Strategies In Predicting Emotional Well-Being Of  
Caregivers Of Alzheimer’s And Related Dementias.”**

I have read the Information Sheet and understand the nature, purpose and details of the study. My questions have been answered to my satisfaction, and I understand that I may ask further questions or withdraw at any stage during the project. I agree to participate in this study under the conditions set out in the Information Sheet. This form will be stored separately to the caregiver questionnaire.

Signature: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix E: Confidentiality agreement**

## CAREGIVER RESEARCH PROJECT 2003

*This confidentiality form will be held for a period of five (5) years.*

I, \_\_\_\_\_,

Understand the nature and purpose of the project and agree to keep confidential all information concerning the project:

**“The Role Of Coping Strategies In Predicting Emotional Well-Being Of Caregivers Of Alzheimer’s And Related Dementias ”**

as explained in the Information Sheet on the project.

Signature: \_\_\_\_\_

Full-name (please print): \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix F: Caregiver questionnaire**

## Caregiver Research Project 2003 Questionnaire

**This questionnaire is strictly confidential and anonymous. Names and addresses are not required. It should take approximately 45 minutes to complete, and can be done in stages.**

Part 1: A range of general questions about yourself and the person you care for to provide background information about your situation. Fill in or tick the answer that best applies to you.

Part 2: These statements address beliefs and behaviors about your interactions with others. You will be asked to indicate how much you agree or disagree on a scale of 1 to 5.

Part 3: This section asks you to consider specific experiences and problems related to caregiving and indicate how often you have performed a certain behaviour.

Part 4: In this section you will be asked to rate 20 words which describe how you generally feel on a scale from 1 to 5.

If you require a copy of the questionnaire in Te Reo Maori, please contact us, and one will be forwarded to you. Please note that the original English version has to be completed and returned.

**Please return as soon as possible or by 15 July 2003 in the freepost envelope provided.**

**Thank You for Your Cooperation, It is Much Appreciated.**

**Researcher:**

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**Supervisor:**

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[p.l.dulin@massey.ac.nz](mailto:p.l.dulin@massey.ac.nz)

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Phone: (06) 356 9099.

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Palmerston North, 06 801 2794, e-mail: [s.v.rumball@massey.ac.nz](mailto:s.v.rumball@massey.ac.nz)

## Part One: General information.

Please consider each question carefully before answering. Please answer all the questions if possible, and check both sides of the page.

1. Are you the only or main caregiver? (circle one) Yes / No

2. How long have you been involved in caregiving? (indicate one)

\_\_\_\_\_ less than 1 (one) year      \_\_\_\_\_ 8 (eight) to 10 (ten) years

\_\_\_\_\_ 2 (two) to 4 (four) years      \_\_\_\_\_ more than (ten) years

\_\_\_\_\_ 5 (five) to 7 (seven) years

3. How many hours a day (on average) do you spend providing direct care? (indicate one)

\_\_\_\_\_ up to 3 (three) hours      \_\_\_\_\_ 10 (ten) to 12 (twelve) hours

\_\_\_\_\_ 4 (four) to 6 (six) hours      \_\_\_\_\_ night care only

\_\_\_\_\_ 7 (seven) to 9 (nine) hours      \_\_\_\_\_ other: please specify \_\_\_\_\_

4. What is your relationship to the person receiving care? (indicate one)

\_\_\_\_\_ husband      \_\_\_\_\_ brother

\_\_\_\_\_ wife      \_\_\_\_\_ sister

\_\_\_\_\_ daughter      \_\_\_\_\_ friend

\_\_\_\_\_ son      \_\_\_\_\_ other: please specify \_\_\_\_\_

5. What is your age? (indicate one)

\_\_\_\_\_ 18 to 29 years      \_\_\_\_\_ 60 to 69 years

\_\_\_\_\_ 30 to 39 years      \_\_\_\_\_ 70 to 79 years

\_\_\_\_\_ 40 to 49 years      \_\_\_\_\_ 80 years and older

\_\_\_\_\_ 50 to 59 years

6. What is your personal relationship status? (indicate one)

\_\_\_\_\_ single      \_\_\_\_\_ divorced

\_\_\_\_\_ married      \_\_\_\_\_ involved in a committed /de facto relationship

\_\_\_\_\_ separated

7. How many adults and children live in the home with you?

\_\_\_\_\_ adult males                      \_\_\_\_\_ boys under 18 years

\_\_\_\_\_ adult females                      \_\_\_\_\_ girls under 18 years

8. Do any of them have any difficulties that also need help? (circle one) Yes / No

9. Do you smoke? (circle one) Yes / No If Yes, how many packs per day? \_\_\_\_\_

10. Do you drink alcohol? (circle one) Yes / No If yes, how many drinks per week? \_\_\_\_\_

11. Do you receive any outside help with caregiving tasks? (circle one) Yes / No

12. Where does this help come from? (indicate e.g. family, friends, organisations)

---

13. How many hours per week do they help?

\_\_\_\_\_ 0 to 3 hours                      \_\_\_\_\_ 13 to 18 hours

\_\_\_\_\_ 4 to 8 hours                      \_\_\_\_\_ more than 18 hours

\_\_\_\_\_ 9 to 12 hours                      \_\_\_\_\_ other: please specify \_\_\_\_\_

14. Which ethnic/cultural group do you personally most identify with? (indicate one)

\_\_\_\_\_ NZ Pakeha/European                      \_\_\_\_\_ Asian

\_\_\_\_\_ European                      \_\_\_\_\_ Pacific Islander

\_\_\_\_\_ Maori                      \_\_\_\_\_ Other (specify): \_\_\_\_\_

15. How many years of education (school and other training) have you had? (mark one)

\_\_\_\_\_ 5 to 8 years                      \_\_\_\_\_ 13 to 15 years

\_\_\_\_\_ 9 to 12 years                      \_\_\_\_\_ 16 years or more

16. Are you currently employed? (circle one) Yes / No

17. Are you the main breadwinner? (circle one) Yes / No

18. How many hours per week (on average) do you spend at work? (indicate one)

\_\_\_\_\_ 5 to 10 hours                      \_\_\_\_\_ 16 to 24 hours

\_\_\_\_\_ 11 to 15 hours                      \_\_\_\_\_ 25 to 30 hours

19. Do you receive any financial assistance (other than salary/wages)? (circle one)

Yes / No If Yes, please specify from who and how much:

20. What is your average annual household income (approximately)? (indicate one)

\_\_\_\_\_ under \$10, 000 \_\_\_\_\_ \$ 21,000 to \$25,000

\_\_\_\_\_ \$10,000 to \$15,000 \_\_\_\_\_ \$ 26,000 to \$30,000

\_\_\_\_\_ \$ 16,000 to \$20,000 \_\_\_\_\_ more than \$30,000

21. Please indicate your residential arrangements: (mark all that apply)

\_\_\_\_\_ rented state house/flat

\_\_\_\_\_ privately owned home

\_\_\_\_\_ share home with person receiving care

\_\_\_\_\_ staying with family (e.g. daughter/son)

\_\_\_\_\_ living in retirement complex/village

\_\_\_\_\_ only person receiving care staying in rest home / nursing home

22. Describe the geographical placement of your home: (indicate one)

\_\_\_\_\_ rural district, e.g. farm, small village (Waimana).

\_\_\_\_\_ country town, e.g. Whakatane, Wanganui, Levin, Waihi.

\_\_\_\_\_ regional town/main centre, e.g. Tauranga, Palmerston North, Hamilton.

\_\_\_\_\_ large city, e.g Auckland, Wellington.

**We also would like to learn about the person you are caring for:**

23. How old is the person with dementia (receiving the care)? \_\_\_\_\_ years

24. Please indicate where the person with dementia is currently staying (mark all that apply):

\_\_\_\_\_ rented state house/flat \_\_\_\_\_ living in retirement village

\_\_\_\_\_ privately owned home \_\_\_\_\_ in rest home / nursing home

\_\_\_\_\_ sharing home with caregiver \_\_\_\_\_ other: \_\_\_\_\_

\_\_\_\_\_ with family (e.g. daughter/son)

Please check both sides.

25. Which ethnic/cultural group is the person with dementia most likely to identify with? (indicate one)

\_\_\_\_\_ NZ Pakeha/European      \_\_\_\_\_ Asian  
 \_\_\_\_\_ European      \_\_\_\_\_ Pacific Islander  
 \_\_\_\_\_ Maori      \_\_\_\_\_ Other (specify): \_\_\_\_\_

26. Specify type of dementia (if known) \_\_\_\_\_

27. How severe is this dementia? (indicate one)

1                      2                      3                      4                      5  
 very mild                      moderately severe                      very severe

28. To what extent do they have difficulties with performing their daily activities?

1                      2                      3                      4                      5  
 not at all                      somewhat                      very much/great deal

29. Do they have any other major medical or psychiatric conditions? Yes / No

If yes, please specify briefly \_\_\_\_\_

\_\_\_\_\_

30. When were these conditions diagnosed? (indicate date) \_\_\_\_\_

31. Are they receiving any treatment for these additional conditions? Yes / No

32. What has been the three most difficult tasks/behaviours/problems you have personally had to deal with during caregiving? \_\_\_\_\_

\_\_\_\_\_

33. Have you (or they) made any plans for their future living arrangements? Yes / No

34. Are they still able to make their own financial and legal decisions? Yes / No

35. Do you (or anyone else) have a Power of Attorney to help with their affairs?  
 Yes / No

**Part 2:**

The following statements measure your feelings, beliefs, and behaviours about your interactions with others. It is not a test, there are no right or wrong answers. Please answer all the questions as honestly as possible. Please indicate your level of agreement or disagreement with each statement in the space next to each statement using this scale:

1	2	3	4	5
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

**Example:**       4      I prefer to give than to receive

- \_\_\_\_\_ Helping others is usually a waste of time.
- \_\_\_\_\_ When given the opportunity, I enjoy aiding others who are in need.
- \_\_\_\_\_ If possible, I would return lost money to the rightful owner.
- \_\_\_\_\_ Helping friends and family is one of the great joys in life.
- \_\_\_\_\_ I would avoid aiding someone in a medical emergency if I could.
- \_\_\_\_\_ It feels wonderful to assist others in need.
- \_\_\_\_\_ Volunteering to help someone is very rewarding.
- \_\_\_\_\_ I dislike giving directions to strangers who are lost.
- \_\_\_\_\_ Doing volunteer work makes me feel happy.
- \_\_\_\_\_ I donate time or money to charities every month.
- \_\_\_\_\_ Unless they are part of my family, helping the elderly isn't my responsibility.
- \_\_\_\_\_ Children should be taught about the importance of helping others.
- \_\_\_\_\_ I plan to donate my organs when I die with the hope that they will help someone else live.
- \_\_\_\_\_ I try to offer my help with any activities my community or school groups are carrying out.
- \_\_\_\_\_ I feel at peace with myself when I have helped others.
- \_\_\_\_\_ If the person in front of me in the check-out line at a store was a few cents short, I would pay the difference.
- \_\_\_\_\_ I feel proud when I know that my generosity has benefited a needy person.
- \_\_\_\_\_ Helping people does more harm than good because they come to rely on others and not themselves.
- \_\_\_\_\_ I rarely contribute money to a worthy cause.
- \_\_\_\_\_ Giving aid to the poor is the right thing to do.

Please check both sides.

**Part 3:**

Please consider all the experiences and problems you have had during caregiving, and list your major problem:

Then carefully read each statement before considering how often you used this way of dealing with the major problem. Mark or circle one option to indicate your choice for each statement, using the following scale:

0	1	2	3	N/A
Never Used	Rarely Used	Sometimes Used	Regularly Used (4-5 x per week or more)	Does Not Apply

**Example:** I left the room to avoid an argument.

0	1	<u>2</u>	3	N/A
---	---	----------	---	-----

1. I bargained or compromised to get something positive from the situation.  
0    1    2    3    N/A
2. I concentrated on something good that could come out of the whole thing.  
0    1    2    3    N/A
3. I tried not to burn my bridges behind me, but left things open somewhat.  
0    1    2    3    N/A
4. I changed or grew as a person in a good way.  
0    1    2    3    N/A
5. I made a plan of action and followed it.  
0    1    2    3    N/A
6. I accepted the next best thing to what I wanted.  
0    1    2    3    N/A
7. I came out of the experience better than when I went in.  
0    1    2    3    N/A
8. I tried not to act too hastily or follow my own hunch.  
0    1    2    3    N/A
9. I changed something so things would turn out all right.  
0    1    2    3    N/A
10. I just took things one step at a time.  
0    1    2    3    N/A
11. I knew what had to be done, I doubled my efforts, tried harder to make it work.  
0    1    2    3    N/A
12. I accepted my strong feelings, didn't let them interfere with other things too much.  
0    1    2    3    N/A

13. I changed something about myself so I could deal with the situation better.

0    1    2    3    N/A

14. I stood my ground and fought for what I wanted.

0    1    2    3    N/A

15. I talked to someone to find out about the situation.

0    1    2    3    N/A

16. I accepted sympathy and understanding from someone.

0    1    2    3    N/A

17. I got professional help and did what they recommended.

0    1    2    3    N/A

18. I talked to someone who could do something about the problem.

0    1    2    3    N/A

19. I asked someone I respected for advice and followed it.

0    1    2    3    N/A

20. I talked to someone about how I was feeling.

0    1    2    3    N/A

21. I blamed myself.

0    1    2    3    N/A

22. I criticized myself.

0    1    2    3    N/A

23. I realized I brought the problem on myself.

0    1    2    3    N/A

24. I hoped a miracle would happen.

0    1    2    3    N/A

25. I wished I was a stronger person – more optimistic and forceful.

0    1    2    3    N/A

26. I wished that I could change what had happened.

0    1    2    3    N/A

27. I wished that I could change the way that I felt.

0    1    2    3    N/A

28. I daydreamed or imagined a better time or place than the one I was in.

0    1    2    3    N/A

Please check both sides.

29. I had fantasies or wishes about how things might turn out.

0      1      2      3      N/A

30. I thought about fantastic or unreal things that made me feel better (like perfect revenge or finding a million dollars).

0      1      2      3      N/A

31. I wished the situation would go away or somehow be finished.

0      1      2      3      N/A

32. I went on as if nothing had happened.

0      1      2      3      N/A

33. I felt bad that I couldn't avoid the problem.

0      1      2      3      N/A

34. I kept my feelings to myself.

0      1      2      3      N/A

35. I slept more than usual.

0      1      2      3      N/A

36. I got mad at the people or things that caused the problem.

0      1      2      3      N/A

37. I tried to forget the whole thing.

0      1      2      3      N/A

38. I tried to make myself better by eating, drinking, smoking, taking medications.

0      1      2      3      N/A

39. I avoided being with people in general.

0      1      2      3      N/A

40. I kept others from knowing how bad things were.

0      1      2      3      N/A

41. I refused to believe it had happened.

0      1      2      3      N/A

**Part 4:**

Please read each one of these twenty words carefully, then mark or circle the number for each word that best reflects how often you have felt this way during the last month. Please answer all the questions. Use this scale for your answers:

1	2	3	4	5
very slightly or not at all	a little	moderately	quite a bit	extremely

Example: concerned    1    2    3    4    5

- |                 |   |   |   |   |   |
|-----------------|---|---|---|---|---|
| 1. interested   | 1 | 2 | 3 | 4 | 5 |
| 2. distressed   | 1 | 2 | 3 | 4 | 5 |
| 3. excited      | 1 | 2 | 3 | 4 | 5 |
| 4. upset        | 1 | 2 | 3 | 4 | 5 |
| 5. strong       | 1 | 2 | 3 | 4 | 5 |
| 6. guilty       | 1 | 2 | 3 | 4 | 5 |
| 7. scared       | 1 | 2 | 3 | 4 | 5 |
| 8. hostile      | 1 | 2 | 3 | 4 | 5 |
| 9. enthusiastic | 1 | 2 | 3 | 4 | 5 |
| 10. proud       | 1 | 2 | 3 | 4 | 5 |
| 11. irritable   | 1 | 2 | 3 | 4 | 5 |
| 12. alert       | 1 | 2 | 3 | 4 | 5 |
| 13. ashamed     | 1 | 2 | 3 | 4 | 5 |
| 14. inspired    | 1 | 2 | 3 | 4 | 5 |
| 15. nervous     | 1 | 2 | 3 | 4 | 5 |
| 16. determined  | 1 | 2 | 3 | 4 | 5 |
| 17. attentive   | 1 | 2 | 3 | 4 | 5 |
| 18. jittery     | 1 | 2 | 3 | 4 | 5 |
| 19. active      | 1 | 2 | 3 | 4 | 5 |
| 20. afraid      | 1 | 2 | 3 | 4 | 5 |

**Thank You For Completing This Questionnaire. Your Participation Is Appreciated. Please Return It To The Researcher As Soon As Possible.**