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# *"Dementia - The Burden of Care on the Carers"*

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## Abstract

This study is an investigation into the relationship between the objective and subjective burden experienced by adult children caring for their parents with a diagnosis of dementia, and a range of psychological, coping and sociodemographic variables. An adapted Stress, Appraisal and Coping framework (Lazarus & Folkman, 1984) was used to guide the hypotheses and data analyses.

Data was obtained from both caregivers and care recipients. Specifically caregivers were required to complete a battery of questionnaires relating both to their own experiences of caring and to their care recipients' non cognitive abilities. Cognitive features of the care recipient were assessed using the Mini Mental State (Folstein et al., 1975).

Data were statistically analysed using SPSS for Windows (SPSS/PCT, 1988).

Results highlighted the importance of the Stress, Appraisal and Coping framework (Lazarus & Folkman, 1984) in understanding and treating caregiver wellbeing, since mediating variables, and to a much lesser degree demands or objective stressors, were found to buffer the impact of caregiving. In addition different types of variables were linked to positive outcomes (e.g. satisfaction with life) versus negative outcomes (e.g. depression, anxiety). Questions such as which types of interventions would affect caregiver outcomes were therefore raised. The results were discussed in relation to the literature, and implications for future research and clinical practice were discussed.

# 1.0 Introduction.

'Happy families are all alike; every unhappy family is unhappy in its own way' (Tolstoy, 1911, p.1).

This study is an investigation into the subjective and objective burden experienced by adult children caring for their parents who have a diagnosis of dementia. As the opening quotation suggests professional help offered to these family members must never be standardised, as each family is unique (Jones & Miesen, 1992). Professional evaluations based only on caregivers' personal assessment of the situation will inevitably be incomplete; the opinion that family members themselves have of the situation, will also have to contribute to this assessment. Therefore this study aims to explore the relationship between the objective and subjective burden experienced by adult child caregivers of people with dementia, and a range of psychological, coping and sociodemographic variables. The Stress, Appraisal and Coping model (Lazarus & Folkman, 1984) was used to organise a framework within which to operationalise the important constructs under study. It is envisaged that such a theoretical framework will provide a model of caregiving experiences which can guide clinicians in conducting assessments of caregiving families. In addition, an important part of this study will be investigating the validity of an instrument for assessing levels of subjective and objective burden in this specific caregiver group. It is thought that this may provide both researchers and clinicians with more insight into caregivers' needs, facilitating the development of more effective interventions for adult children caring for their parents with a diagnosis of dementia.

A description of how dementia is manifested is offered first. This is then followed by definitions of the constructs to be explored. The Stress, Appraisal and Coping framework (Lazarus & Folkman, 1984) will be used to structure a review of the relevant research literature and, before embarking on the aims of the present study, methodological limitations of previous studies will be highlighted.

## 1.1 The Nature of Dementia

The essential features of dementia, the syndrome produced by chronic and extensive brain disease, are intellectual deterioration, an impaired memory, especially for recent events, disorientation, cognitive losses and changes in speech, behaviour and basic motor skills - all of which can occur cumulatively over a period of time. Most definitions of dementia also emphasise its insidious onset, chronic and progressive course and irreversibility (Burns et al., 1995). Dementia can be a devastating disease, eroding personality as well as intellect and damaging relationships irreparably. Consequently, dementia is an illness that places unrelenting and progressive demands for care on caregivers because the behavioural and cognitive deficits restrict the ability of the impaired individual to perform activities of daily living (Parker 1997).

People with dementia are one of the fastest growing groups in the population. This reflects the increasing number of people over 65 and the much faster growing over 85 age group where the prevalence and incidence of dementia are highest (Alzheimers Disease Society, 1994; Warnes, 1996). Of course, those suffering with dementia are not exclusive to older adults; early onset dementias are now well acknowledged. Studies of the prevalence of dementia in the population as a whole have shown broad agreement, such that the prevalence of individuals aged 40 - 65 is less than 0.1 per cent, those aged 65 - 70 is two per cent, those aged 70 - 80 it is five per cent and for over 80 year olds the prevalence is 20 per cent (Burns et al., 1995). It has been estimated that the number of people with dementia in Britain is expected to increase from 640,000 in 1991 to 900,000 in 2021 (Alzheimers Disease Society, 1994).

## 1.2 Caregivers

In order to provide a contextual framework for understanding the caring process it is necessary to establish who carers are. The past 20 years have seen a burgeoning of research relating to informal carers - those family members and friends who support older adults in the community (Jones & Miesen, 1992). Results of such research have strongly suggested that current perceptions that contemporary families are alienated from older adults is incorrect; rather, the documented evidence reports on the strength of intergenerational ties, the continuity of responsible filial behaviour, the frequency of contacts between generations, and the predominance of family rather than professionals in the provision of health and social services (Duijnstee, 1992).

For the purposes of this project, caregiving is defined as an interaction in which one family member is helping another on a regular (i.e. daily or nearly so) basis with tasks that are essential for independent living.

It has been estimated that approximately 80 per cent of people with dementia are living at home with either their spouse or another family member (Jones & Peters, 1992). Contrary to prevailing stereotypes, informal support systems provide more assistance than formal organizations and, without the care given by family members, many more older adults would probably be forced to leave their homes and enter institutions (Shanas, 1979; Branch & Jette, 1983). Family members, therefore, play a central role in the care rendered to patients with dementia (Huckle, 1994).

Interest in the family carers of older adults has extended to policy, and resulted in support for carers being included as a specific objective of Community Care reforms ushered in by the 1990 NHS and Community Care Act (Department of Health, 1990). Thus the major role played by family members in Community Care is now generally acknowledged and the provision of assistance to those carers is an essential activity for the purchasers and providers of health and social services. In addition, such legislation draws attention to the way in which the policy of Community Care, especially for dementia sufferers, is often achieved at high personal cost to those caring relatives upon whom its success largely depends.

## 1.3 Burden.

When institutionalisation of individuals with dementia occurs, it is usually because of a breakdown in supporters' health because a point of intolerable burden has been reached (Issacs et al., 1972). Historically, Grad & Sainsbury (1963) were the first to acknowledge the burden felt by family members who care for mentally ill relatives, and in 1980 Zarit and colleagues began to study burden in caregivers of demented relatives (Zarit et al., 1980). Subsequently, this pioneering work concerning burden has been examined in various samples and conceptualized in several ways (Poulshock & Deimling, 1984; Stephens & Kinney, 1989; Lawton et al., 1991).

Throughout the caregiving literature the terms "burden " and caregiver "strain", "stress" and "well-being" appear to have been adopted interchangeably, and as such their validity and reliability can be questioned. Irrespective of the terminology applied in the original studies and despite the diverse operational definitions used (Montgomery et al., 1985), in the present project this variable is referred to as burden. Specifically, caregiver burden will be defined as "the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults" (George & Gwyther, 1986, p.253).

Although care by families to functionally dependent individuals is the most effective means of maintaining them in the community (Stoller & Earl, 1983), family caregivers are at risk of becoming overburdened when care demands are high and resources limited. Identifying the specific aspects of care that are burdensome is therefore essential.

## 1.4 Caregiving Stressors

Within the gerontological literature there have been several attempts to catalogue the features of dementia in older adults that are burdensome for carers (Gilleard et al., 1982; Greene et al., 1982). These will be outlined below:

### *1.4.1 Demands arising from decline in cognitive functioning.*

The main approach adopted for the measurement of demands placed on carers as a result of their dependent's cognitive deficits (e.g. memory loss, visuo spatial disturbances, language abnormalities) has been to utilise standard measures. Weak or non significant relationships have generally been observed between these measures and poor carer well being (Zarit et al., 1980; Greene et al., 1982; Farran et al., 1993).

However Eagles et al. (1987), O'Connor et al. (1990) and LoGiudice et al. (1995) reported significant positive correlations between cognitive disability and burden in mixed gender samples of carers, and Harper & Lund (1990) found that carer rated memory loss predicted burden in male caregivers but not in females. Weiler et al. (1994) reported a negative relationship between clinician rated cognitive impairment and burden in their study of adult offspring caregivers. In the only longitudinal study of this relationship, Reis et al. (1994) showed that, although objective measurements of cognitive impairment were significantly related to caregiver burden at the outset of their study, at two years follow up, when cognitive impairment in patients had advanced, this association was not present.

A number of methodological factors may have contributed to these weak associations. Firstly, if the measures used in the various studies were developed as case detection instruments for epidemiological research, they are likely to be biassed in favour of specificity. As such, these measures may be insensitive to mild or moderate levels of impairment and of limited use as dimensional instruments in correlational analyses.

Haley et al. (1987) used correlational procedures to investigate depression in caregivers and measured cognitive ability in patients, but failed to find a significant relationship. Baumgarten et al. (1992), however, used patient scores on the Mini Mental State, measuring cognitive functioning, to categorise carers into groups, and compared depression scores across groups using analysis of variance techniques. These procedures revealed a non linear relationship between cognitive impairment and depression, such that carers of patients with intermediate scores on the Mini Mental State experienced significantly higher levels of depression than the carers of patients with high or low scores.

In support of this finding, Pruncho & Resch (1989) reported that the features of cognitive decline that are most troublesome to carers do not follow a linear trajectory, but peak in the middle stages of dementia when behavioural disturbances are most problematic. They suggested that the burden abates as the caregivers adjust to these demands.

### *1.4.2 Demands arising from the non cognitive features of dementia.*

Although the core feature of dementia is progressive cognitive decline there are additional 'non cognitive' features frequently associated with dementia, including psychotic symptoms (hallucinations, delusions), depressive features (e.g. sadness, apathy) and behavioural disturbances (aggression and wandering) (Burns et al., 1990). Although the definition and names given to each category of non cognitive symptoms have varied widely across the literature, studies have found that these behaviours are strongly related to caregiver burden (Gilleard et al., 1982; Pruncho & Resch, 1989; Drapper et al., 1992; LoGiudice et al., 1995).

Some studies have measured different subcategories of non cognitive features separately and demonstrated differential relationships with burden. Greene et al. (1982) and LoGiudice et al. (1995) suggested that deficits of behaviour such as withdrawal and apathy were more closely related to caregiver burden than were excesses of behaviour such as hoarding and sleep disturbance.

Further studies have examined the relationship between non cognitive disturbances in people with dementia and caregiver depression. Deimling & Bass (1986) and Baumgarten et al. (1992) employed large numbers of participants and used multivariate procedures to analyse this relationship, and both studies found a strong positive relationship between caregiver depression and aspects of non cognitive disturbance in patients. However, Haley et al. (1987) and Brodaty & Hadzi-Pavlovic (1990) used bivariate correlations to examine the data, but failed to find a significant relationship between these variables. These contradictory findings could be explained in terms of the limitations of correlational tests or a lack of statistical power in smaller scale investigations.

The balance of evidence is therefore marginally in favour of an association between non cognitive features of dementia in care recipients and caregiver depression.

### *1.4.3 Demands arising from assistance with activities of daily living.*

Relatively weak or non significant relationships are usually found between measures of limitation in dependents' activities of daily living (self care problems and difficulty carrying out everyday instrumental activities, e.g. managing finances) and carer burden (Gilhooly 1984; Farran et al., 1993; Weiler et al., 1994; LoGiudice et al., 1995). However, Harper & Lund (1990) found that activities of daily living limitations predicted burden in female carers but not in males.

Gilleard et al. (1982) and Brodaty & Hadzi- Pavlovic (1990) measured dependency and disability problems and Weiler et al. (1994) rated everyday activities impairments, but no associations with caregiver depression were noted in any of these studies. Baumgarten et al. (1992) also failed to report a significant independent relationship between measurements of functional impairment and depression in caregivers. However, Deimling & Bass (1986) and Haley et al. (1987) reported significant associations between caregiver depression and activities of daily living limitations.

The conflicting nature of these findings means that little information about the impact of such limitations on caregivers' mood can be derived from these studies. Analysis of the research methodologies used suggests that these contradictory data may be partially attributable to the use of diverse conceptual and operational definitions of activities of daily living limitations (dependency and disability problems, functional impairment, everyday activity impairment, higher level task performance).

With few exceptions (Montgomery et al., 1985; Pruchno & Resch, 1989b), the most common measures of activities of daily living are standard instruments. The critical issue in the present context is whether such instruments can be considered to measure the demands placed on an informal carer. The relationship between care recipient limitations in activities of daily living and caregiver burden is often assumed rather than measured (Morycz, 1985). The appropriateness of activities of daily living measures depends on whether the instrument is completed by the caregiver or some other observer such as day care staff. If the assessments are made by staff members, the validity of scores as a measure of care work may be further questioned.

Although consistent findings across a growing body of research suggest that this aspect of caregiving is not in itself stressful, methodological limitations of previous research justified its inclusion in the present study.

While pinpointing problem behaviours, these studies have not clarified how specific behaviours contribute to the burden of home care. Morris & Morris (1993) point out that the relationship between carer well being and the problems of the person with dementia are not straightforward, and that a number of factors may mitigate or exacerbate stress in the carer.

## 1.5 Background and Contextual Factors.

Research has suggested that demographic factors may increase a carer's vulnerability to burden. Unfortunately, attempts to isolate demographic factors have proved unsuccessful with contradictory or inconclusive findings.

The gender of the carer appears to have an effect, with women finding caring more stressful than their male counterparts (Gilhooly, 1984; Lee et al., 1993; Dwyer & Coward, 1991). However, the substantial body of research appears to focus predominantly on female carers. Horowitz (1985b) expressed concerns that the available literature 'translates into what is known about female caregivers' (p.614). Leff (1993), in a review of carers, suggests that more research on men as carers should be conducted.

Age of carer has also been shown to be strongly predictive of carer well-being. Seltzer & Wailing (1996) found that younger carers, both wives and daughters, felt increased burden compared to older ones. However Ballard et al. (1995) found increasing carer age to be significantly associated with depression in those carers living with the care recipient. By contrast, other work has failed to find any relationship between either the age of the sufferer or their carers, and carer stress (Levin et al., 1983).

It appears from the literature that the closer the blood ties between carer and care recipient the greater the carer distress (Cantor, 1983; Seltzer & Wailing, 1996). According to Cantor (1983), and Harper & Lund (1990), spouses appear to report more burden and have poorer physical and psychological well-being compared to daughters, regardless of their age (George & Gwyther, 1986). However Greenberg et al. (1993) and Jones & Peter (1992) suggested that younger carers, i.e. adult children, experience more burden than their older counterparts.

Furthermore, the patterns of stress over time appear to be different, and the research findings inconsistent. Seltzer & Wailing (1996) found that daughters in the later stages of caring had a more distant relationship to their dependent relative and reported more burden, whereas wives became closer and reported less burden over time.

These differences may have been compounded by living arrangements, as spouse carers are more likely to live with their relatives, compared to adult children. Indeed, when carers live apart from their dependent relatives their burden levels are seen to be much lower (Yeatman et al., 1993).

Past and present intimacy can also be seen to be highly relevant in the experience of distress for carers. Indeed, it has been suggested that a poor premorbid relationship is highly predictive of burden in carers, and for breakdowns in family care (Gilhooly, 1980; Morris et al., 1988). Although the quality of a past relationship does appear to be a vulnerability factor in the experience of burden, the current relationship is also a crucial variable. Those carers with a previously good relationship may find it especially difficult if this breaks down, and the loss of intimacy and reciprocity, as a consequence of the care recipient's dementia, may be particularly stressful (Gilhooly et al., 1994).

## 1.6 Mediators of Stress in Caregivers of People With Dementia.

### *1.6.1 Formal and Informal Support Networks.*

While support to the family has been found to be a crucial factor in maintaining an impaired older adult in the community (Whittick, 1992), it is not entirely clear to what extent social support mediates the impact of caregiving on a caregiver's psychological well-being. Research by Shanas (1979), Cantor (1983) and Johnson (1983), amongst others, indicates that help from informal support networks is the most important source of assistance to carers. Zarit et al. (1980) found that the only factor to contribute to levels of burden among primary caregivers was the frequency of family visits, with more visits associated with lower reported burden.

The role of support and help from professionals in mediating the psychological impact of caregiving is even less clear. Newbiggin (1981) found no association between frequency of day hospital attendance of older adults with dementia and supporters' morale, although more frequent attendance was associated with less depression. Similarly, Gilhooly (1990) noted that there is little evidence that service provision is associated with higher levels of well-being, reduction in burden or a greater willingness to continue providing care. However, Levin et al. (1983) identified home help visits from community nurses, together with day and respite care, as associated with reduced stress levels in carers. Morris et al. (1988) warn that the relationship between formal support and carer burden is a complex one. Once again, part of the problem in the literature, as is the case with other factors examined, maybe that of definition.

Levesque et al. (1995) distinguished between different aspects of service receipt and suggested that it is not how much help and support carers receive that is important, rather, how satisfied or content they are with the help offered. This points to the importance of carers' subjective needs and perceptions. It is how they feel about the frequency of services rather than the actual frequency of services that makes them feel better or worse about their situations.

The level of stress experienced by carers of people with dementia has only been partially accounted for by mediating variables. Coping is another construct that has been identified (Pearlin et al., 1990) as having potential for explaining why caregivers in similar circumstances display variability in exhibited stress.

### *1.6.2 Coping.*

Coping represents the responses people make to stressors, to avoid their harmful consequences (Pearlin & Schooler, 1978). Most research on coping has identified three broad categories of response (Lazarus & Folkman, 1984; Pearlin & Skaff, 1995). Problem focussed coping includes strategies which are focussed on management of the stressors or the situation that gave rise to them. Cognitive coping, in turn, represents efforts to manage the meaning of the stressful situation, for instance relabelling a difficult problem as a learning experience. Finally, emotion focussed coping involves management of the symptoms of stress.

It has generally been reported that cognitive and problem focussed coping is related to lower distress (e.g. higher morale, improved health) and emotion focussed coping to higher distress (anxiety and depression) (Vitaliano et al., 1991).

McKee et al. (1997) investigated the coping strategies used by supporters of community - resident older adults. Care recipients with and without dementia were included in the analysis. Factors derived from the Ways of Coping Checklist (Lazarus & Folkman, 1985) produced a pattern of associations with characteristics of the elder-supporter dyad. The majority of supporters in this study used emotion focussed coping strategies and the use of problem focussed coping strategies were associated with better coping as perceived by the caregivers.

The efficacy of a coping strategy, however, may depend to an extent on the nature of the stressor. When stressors are not easily modifiable, as is the case for caring for someone with dementia, then strategies which manage the meaning or consequences of these events may be more productive (Pearlin & Skaff, 1995).

A fairly consistent finding is that men and women react differently, with men coping rather better than women (Gilleard et al., 1994). Originally it was assumed that this was because men were given more help from other family members, as well as more help from health and social services. However, this initial assumption may have been incorrect; Zarit (1982) found women carers as having more confidantes and a higher quantity of social support than men.

## 1.7 Caregiving Outcomes.

Psychological well-being is seen as a subjective state resulting from both long term personality dispositions, general psychopathology and situation specific stressors, and is therefore viewed as an outcome of caregiving (Donaldson et al., 1997).

There is a great deal of evidence showing that many carers of older adults with dementia experience significant levels of psychological distress. In order to measure this variable most British studies have used the General Health Questionnaire (Goldberg, 1978). Whittick (1992) found a prevalence rate for GHQ caseness of 31 per cent amongst her sample of carers, and in addition 43 per cent were at least mildly depressed. Likewise, McKee et al. (1992) found that those caring for an older adult with dementia had higher GHQ scores compared to a carer of a non dementing relative.

Brodaty & Hadzi- Palvlovic (1990), Draper et al. (1992) and LoGiudice et al. (1995), noted an independent association between aspects of non cognitive disturbance and GHQ morbidity. In Eagle et al's. (1987) community study, scores on a combined measure of disturbed and dependent behaviours (night time wandering, incontinence, immobility) were found to be highly correlated with GHQ scores. Such investigations therefore suggest that GHQ morbidity in carers is closely associated with patient psychopathology.

However, despite the wide use of the GHQ, there have been several criticisms of this measure. Firstly it measures non specific psychological distress, which could easily reflect factors in carers' lives largely independent of their particular role as caregiver. Others point out that the response format makes the measurement of change in distress over time difficult to assess reliably (Gilleard, 1991).

## 1.8 Subjective and Objective Burden

An understanding of the caregiver experience requires consideration, not only of the potential for burden, embedded in a particular context, but also of the way in which that context is perceived or appraised by the carer (Lazarus & Folkman, 1980). Lawton (1983) has argued in favour of distinguishing wherever possible, in both conceptual and operational terms, between objective and subjective phenomena. Conceptually, such distinctions rarely stand up to close scrutiny, but testing their separate effects has distinct value in the early stages of research in a given area. In this light Thompson & Doll (1982) introduced the distinction between objective and subjective burden. Objective burden refers to those factors which would be apparent to an observer, such as changes in the dementia sufferer's behaviour (Gilleard, 1984; O'Connor et al., 1989), in the carers' daily routine (Zarit, 1982; Greene et al., 1982), physical health (Whittick, 1985) status or financial position (Gilhooly, 1990). In comparison, subjective burden is the extent to which carers feel they carry a burden, that is, their emotional reactions to the experiences encountered (Fadden et al., 1987). On this view, objective and subjective burden are distinct and are hypothesised to relate differently to care recipient and caregiver variables.

Levesque et al. (1995) found, that with problems concerning activities of daily living, depression and memory, it was carers feeling more or less disturbed by the problem, rather than the level or severity of these problems, that was related to poorer psychological well being. By contrast, however, the frequency of disruptive behaviour was more closely linked to psychological well-being than the extent to which it disturbed carers.

Hadjistarropoulos et al. (1994) found that, while objective measures of sufferers' functioning did not predict caregiver burden, the caregivers' perceptions of the patients' everyday functioning and dysphoria influenced burden directly. They concluded 'objective patient deficits are not directly predictive of caregiver burden whereas the caregivers assessments of the severity of these deficits are' (Hadjistarropoulos et al., 1994, p.313).

Objective burden has positive but surprisingly small associations with outcome measures such as depression and anxiety. Assisting an older adult with activities of daily living has generally not been found to be related to poor outcomes. Rather, care recipients who have frequent behavioural or emotional problems place more stress on caregivers (Aneshensel et al., 1995; Pruncho & Resch, 1989).

Caregivers also rate behaviour and emotional problems as subjectively more distressing or stressful for them (Teri et al., 1992). Agitated and repetitive behaviours in dementia are generally rated as the most stressful by caregivers. Teri et al. (1992) also noted that depressive behaviours, such as when the care recipient may cry, are very problematic for carers. A much stronger relationship with outcomes such as health and well-being emerges when subjective stressors are added to the objective measures (Aneshensel et al., 1995).

A study by Vitaliano et al. (1991) examined the links between objective and subjective burden, using the Screen for Caregiver Burden (Vitaliano et al., 1991) with anxiety, depression, suppressed anger and life satisfaction in spouses caring for their partners with dementia. Caregiver depression and anxiety were related to both objective and subjective burden. However, they found a much stronger association of caregiver burden with subjective rather than objective burden. Caregiver suppressed anger was also more related to subjective burden than objective burden and caregiver morale was negatively related to both subjective and objective burden.

Another form of anger expression which has important implications regarding vulnerable client groups is 'Anger out'. Individuals are typically classified as 'anger out' if they express their anger towards other persons or objects in the environment. Anger directed outwards may be expressed in physical acts, such as assaulting other individuals, destroying objects, slamming doors or in the form of criticism, insult or verbal threats (Spielberger et al., 1985). It is thought that this form of anger expression may allow identification of those groups of care recipients "at risk" of elder abuse and was therefore included in the present study.

The confounding of objective and subjective sources of burden remains problematic in many measurement approaches. The importance of conceptual clarity was discussed cogently by Stephens & Kinney (1989), who urged the distinction between sources of stress and the appraisal of stressors. This idea of a dual evaluation is the basis for the conceptual framework governing this research.

## 1.9 Critical Evaluation of the Research

A number of methodological factors may have contributed to the lack of consistent relationships between burden and functioning among studies, and made it difficult to discern those consistencies that may exist across studies. Early research into caregiver burden utilized unidimensional burden scales (Zarit et al., 1980), producing total scores representing overall burden (George & Gwyther, 1986). These measures of overall burden support the idea that caregiving affects many parts of caregivers' lives, but because the scales total all items in a single burden score they do not permit distinctions between different dimensions of caregiving. George & Gwyther say that 'reliance upon summary scores masks dimension specific patterns of caregiving impact and precludes identification of the different antecedents or correlates of specific dimensions of caregiver burden' (George & Gwyther, 1986, p.164).

In addition, studies have varied with regards to the definition of burden. As a result of the breadth of issues that have been subsumed under this general term, its use as a unified concept is questionable. Attempts to derive specific measures from a concept so broadly defined have resulted in a lack of precision that leaves the research findings unclear.

Other methodological limitations include non representative samples, the use of diverse definitions and conceptual models of burden and related variables, differences in caregiver samples, the use of varied measurement approaches with, in some cases, limited psychometric justification, and the application of non specific burden measures to different populations of caregivers and care recipients.

In addition, the inconsistencies may stem from researchers tending either to group all care providers into a single category labelled caregivers, or to make the equally erroneous assumption that informal caregivers are primarily women. The homogenization of such crucial variables as the type of relationship, gender, age and work status has resulted in obscuring the differences and the types of burden each may be experiencing. Only by decoupling the various groups of caregivers and examining their respective characteristics can we provide effective intervention modalities.

These methodological difficulties, combined with a failure to conceptualize the investigation of carer well-being within a clear theoretical framework, may have contributed to inconsistent research findings and hindered the development of testable models.

## 1.10 The Stress, Appraisal and Coping Framework

Before progressing further with this study, it is desirable to anchor the construct of burden within a more general theoretical framework, that of Lazarus' stress model (Lazarus & Folkman, 1984). This view suggests that a potentially harmful environmental situation (the stressor) is appraised by the person in terms of whether it is in fact a threat to the person (primary appraisal). The stressor originates outside the behaving individual; Pearlin & Schooler (1978) have identified a stressor as an event or situation that has the potential for arousing threat. The objective stressor has frequently been represented as the degree of disability or impairment of the care recipient (Cantor, 1983; Poulshock & Deimling, 1984).

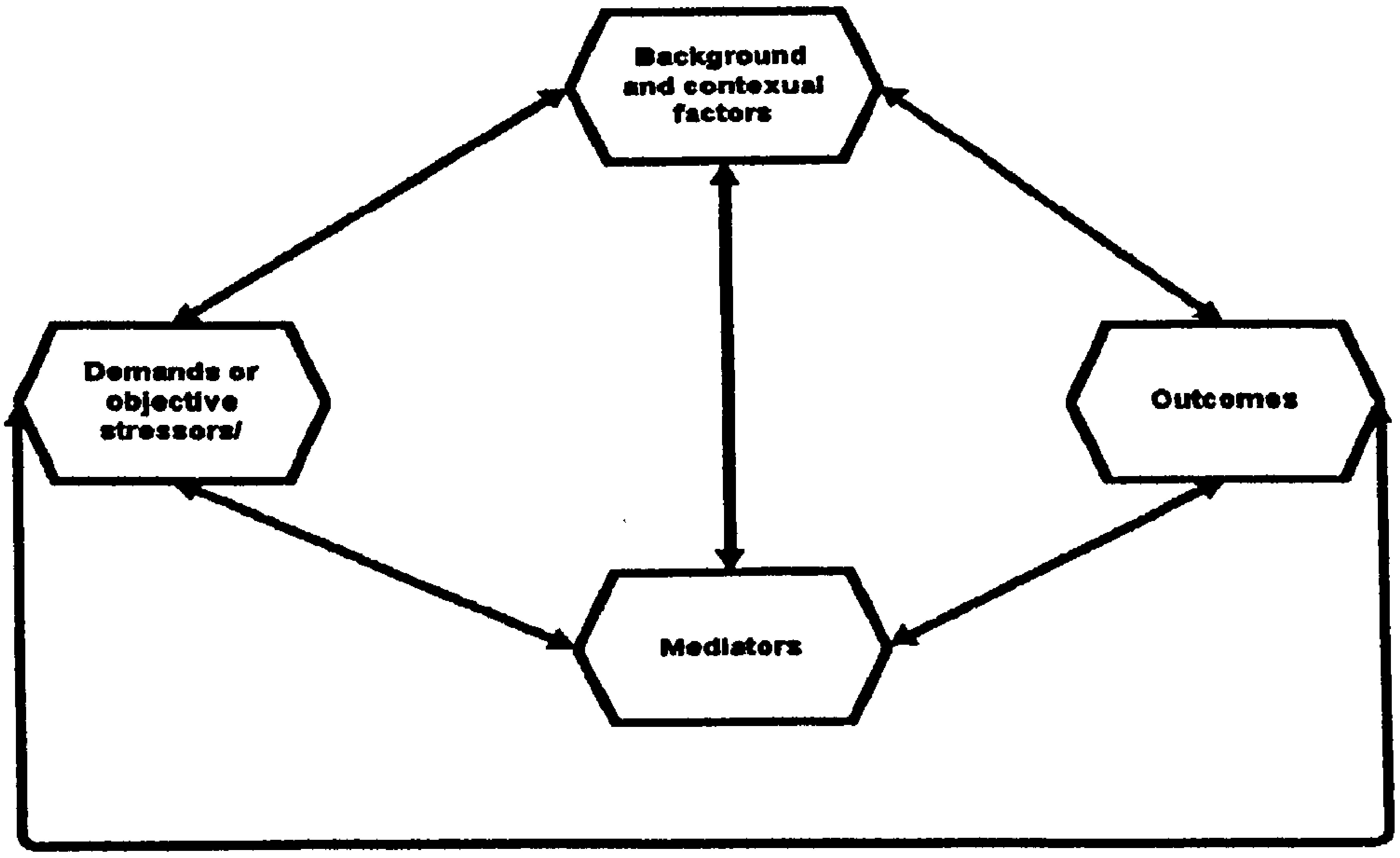
If judged to be threatening, challenging or harmful, a process of secondary appraisal begins whereby the person judges whether the methods available for dealing with the potential stress (coping mechanisms) are adequate. If the objective stressor is appraised as a challenge, then problem focussed coping strategies are usually utilized, resulting in reducing the impact of the stressor which subsequently leads to more positive caregiver outcomes. However, if the objective stressor is perceived as a threat, emotion focussed coping strategies are utilized. Consequently the stressor remains unchanged and negative caregiver outcomes ensue (Lazarus & Folkman, 1984).

Subjective responses to caregiving will be viewed as secondary appraisal - that is the person's evaluation of the ongoing quality of his or her caregiving is seen as the mediator between the demand of caregiving and the outcome of psychological well-being.

Caregiver burden may therefore be viewed as an example of an external demand or potential threat that has been appraised as a stressor. When a shortfall is realised, stress responses will result.

Figure 1 presents a diagrammatic representation of the Stress, Appraisal and Coping Framework (Lazarus & Folkman, 1984).

**Figure 1** Diagrammatic Representation of the Stress, Appraisal and Coping Framework.



## 1.11 The Present Study

It is against this background of previous research that this current study is set. The study rests on the assumption that the level of caregiver burden is partially the outcome of his or her interpretation of the care providing situation, and is based on data gathered from the adult child caregivers assisting their parents who reside in the community. Both carers living with or living nearby the care recipient are included, thus residency is one of the variables under consideration. The findings are therefore more likely to reflect the more common home care situations as opposed to institution based care.

The study includes the investigation of several unresolved issues in caregiving. In particular the study proposes a theoretical framework in which to understand more clearly the experience of caregiving; specifically the effects of caring on psychological outcomes, and aims to examine how background factors, coping and support networks mitigate or mediate the impact of burden.

Rakowski & Clark (1985) observed that most investigations of family caregiving have focussed on the caregiver while paying relatively little attention to the older adult. Including measures of care recipient characteristics and function is exceedingly important and for this reason measures of both cognitive and non cognitive behaviours of the older adult were included in the analysis.

For the purposes of this study the "Screen for Caregiver Burden" (Vitaliano et al., 1991) was chosen to measure objective and subjective burden, since its psychometric properties have been demonstrated in two independent samples (Vitaliano et al., 1989a, 1991). The measure was initially designed to assess both types of burden in spouses caring for their partners with dementia. However, Vitaliano et al. (1991) stated "until the content validity of the Screen for Caregiver Burden is established in other caregivers, its general applicability may be limited" (p.82). In addition the measure was only validated on a U.S. sample.

## **1.12 Aims and Objectives.**

Family caregivers literally perform invaluable services in home health care. With the current emphasis on Community Care, it is essential to identify care recipients effects on caregivers which may be putting home care at risk.

Since a high proportion of adult children take on the role of primary caregiver it has been decided that this study focusses exclusively on the adult child caregivers. Cantor (1983) found that burden varies by the nature of the relationship between caregiver and care recipient. From the perspective of role theory (Hardy & Conway, 1978) one might predict different expectations for giving and receiving care from marital dyads and children. Following this research it is anticipated that interesting comparisons can be made with Vitaliano et al's. (1991)

study examining objective and subjective burden in spouses.

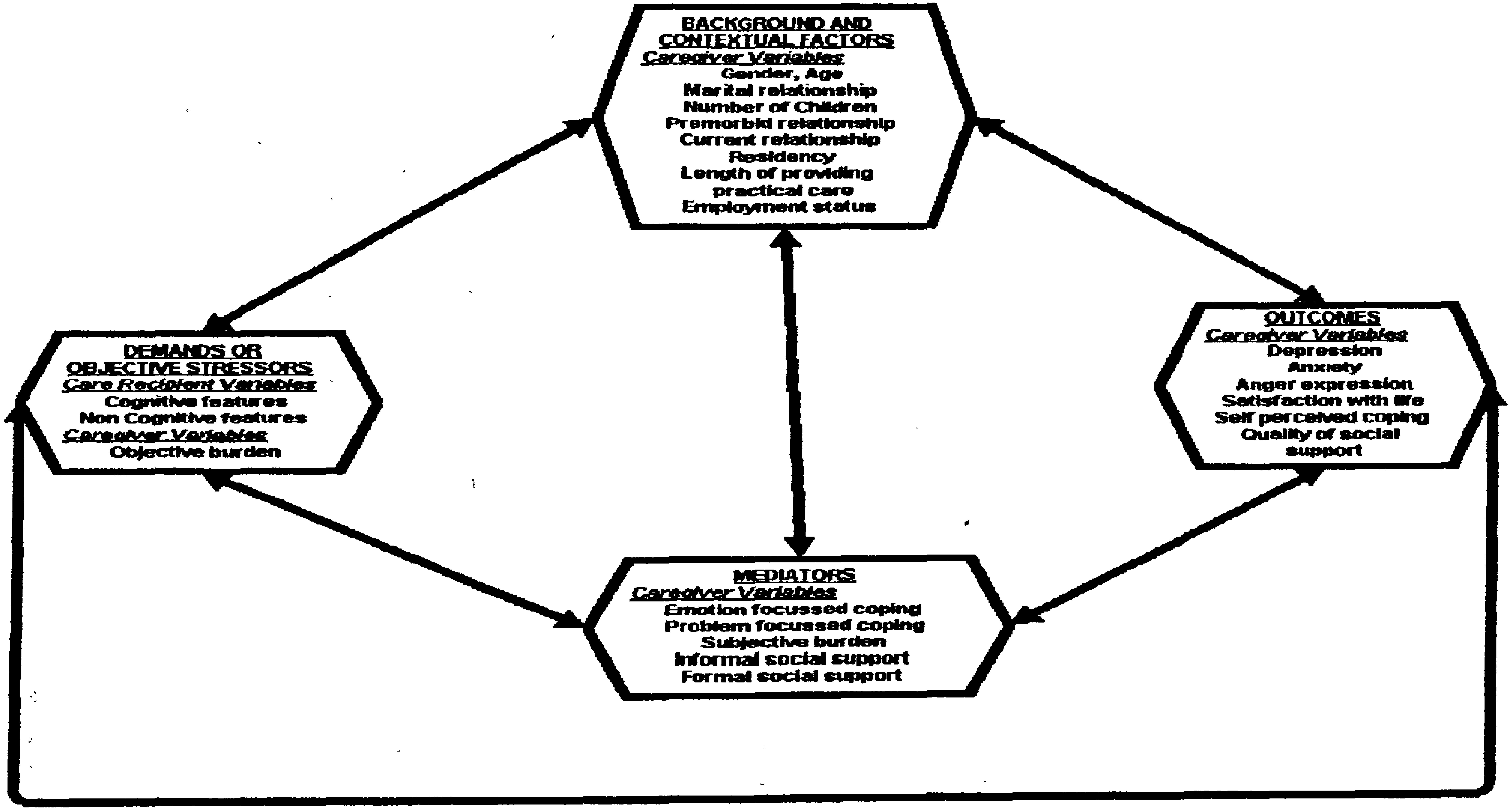
The overall aim of the study is to present findings concerning a variety of variables expected to influence, either directly or indirectly as mediators, the wellbeing of adult offspring caring for their parents with dementia.

The additional aims of this study were three-fold:

1. To incorporate findings from this study within an adapted Stress, Appraisal and Coping theoretical framework (Lazarus & Folkman, 1984), and thus examine the links between demands or objective stressors and mediators of stress, background and contextual factors and caregiver outcomes.
2. To test the face validity and other psychometric properties of the Screen for Caregiver Burden (Vitaliano et al., 1991) on a British sample of adult children caring for their parents with a diagnosis of dementia.
3. To correlate objective burden with measures of mental function and cognitive and behavioural functioning. It is anticipated that this will substantiate the validity of the measure of objective burden.

Figure 2 overleaf presents the Stress, Appraisal and Coping framework of Lazarus & Folkman (1984), and includes all the variables under investigation in the present study. This theoretical model will be used to organise the findings from the study in the remainder of this project.

**Figure 2** Theoretical Model Incorporating the Variables Under Investigation.



# 1.13 Hypotheses.

## 1.13.1 Demands or Objective Stressors With Mediators.

1. Cognitive features of the care recipient will be negatively correlated with subjective burden, informal social support, formal social support and emotion focussed coping strategies and positively correlated with problem focussed coping strategies.
2. The non cognitive features of the care recipient will be positively correlated with subjective burden, informal social support, formal social support and emotion focussed coping factors and negatively correlated with problem focussed coping factors.
3. Objective burden experienced by the caregiver will be positively correlated with emotion focussed coping strategies, subjective burden, informal social support and formal social support and negatively correlated with problem focussed coping strategies.

## 1.13.2 Demands or Objective Stressors With Outcomes.

4. Cognitive features of the care recipient will be negatively correlated with caregiver depression, anxiety, anger expression and self perceived coping and positively correlated with satisfaction with life and quality of social support.
5. Non cognitive features of the care recipient will be positively correlated with caregiver depression, anxiety, anger expression and self perceived coping and negatively correlated with satisfaction with life and quality of social support.
6. Objective burden will be positively correlated with caregiver depression, anxiety, anger expression and self perceived coping and negatively correlated with satisfaction with life and quality of social support.

### 1.13.3. Mediators With Outcomes.

7. Problem focussed coping strategies will be negatively correlated with caregiver depression, anxiety, anger expression and self perceived coping and positively correlated with satisfaction with life and quality of social support.

8. Emotion focussed coping strategies will be positively correlated with caregiver depression, anxiety, anger expression and self perceived coping and negatively correlated with satisfaction with life and quality of social support.

9. Increased informal social support will be negatively correlated with depression, anxiety, anger expression and self perceived coping and positively correlated with satisfaction with life and quality of social support.

10. Increased formal social support will be negatively correlated with depression, anxiety, anger expression and self perceived coping and positively correlated with satisfaction with life and quality of social support.

11. Subjective burden will be positively correlated with caregiver depression, anxiety, anger expression and self perceived coping and negatively correlated with satisfaction with life and quality of social support.

### 1.13.4 Background and Contextual Factors With Demands or Objective Stressors.

12. Females will experience increased objective burden

13. Younger caregivers will experience more objective burden

14. A poor premorbid and current relationship will be negatively correlated with objective burden.

15. Married, employed and those caregivers with children and residing with their care

recipient will experience greater objective burden.

16. Background and contextual factors will not be correlated with care recipient functioning variables.

### 1.13.5 Background and Contextual Factors With Mediators.

17. Those caregivers residing with their care recipients, married caregivers and those pursuing employment will experience greater subjective burden and will be more likely to utilize emotion focussed coping strategies.
18. Non co-resident caregivers, unmarried and those caregivers not pursuing employment will be more likely to utilize problem focussed coping strategies.
19. The premorbid and current caregiver and care recipient relationships will be negatively correlated with subjective burden, formal social support and informal social support.
20. The premorbid and current relationships will be positively correlated with emotion focussed coping strategies and negatively correlated with problem focussed coping strategies.
21. Females will experience greater subjective burden.
22. Age of caregivers will be positively correlated with subjective burden, informal and formal social support.
23. Length of practical care will be positively correlated with subjective burden, informal and formal social support.
24. There will be no additional significant correlations between background and contextual factors with mediators.

### 1.13.6 Background and Contextual Factors With Outcomes.

25. Poor premorbid and current caregiver and care recipient relationships will be negatively correlated with depression, anxiety and anger expression and positively correlated with satisfaction with life, self perceived coping and quality of social support.

26. Those caregivers residing with their care recipient, married and employed caregivers will experience greater depression, anxiety and anger expression and reduced satisfaction with life, self perceived coping and quality of social support.

27. Length of practical care will be positively correlated with depression, anxiety, anger expression and self perceived coping and negatively correlated with satisfaction with life and quality of social support.

28. There will be no additional significant correlations between background and contextual factors with outcomes.

# 2.0. Method

## 2.1. Ethical Approval

An application to the two relevant Local Health Authority Research Ethical Committees regarding this piece of research was submitted and subsequently ratified by both (approval letters in Appendix A).

## 2.2. Design

A cross sectional survey design was used. Relationships between variables were analysed using a correlational approach.

## 2.3. Participants

Data were obtained from both caregivers of people with dementia and their care recipients.

### 2.3.1. Description of Caregivers

Caregivers ranged in age from 28 years to 71 years (*M* = 50.6, SD = 11.01). Table 1 presents descriptive details of male and female caregivers.

**Table 1.** Descriptive Details of Male and Female Caregivers.

| Gender | *N* | % | Age Range | Mean | Standard Deviation |
|---|---|---|---|---|---|
| Male | 15 | 27.8 | 31 - 71 years | 53.3 | 11.20 |
| Female | 39 | 72.2 | 28 - 67 years | 49.6 | 10.90 |

### 2.3.2. Description of Care Recipients

The ages of the care recipients ranged from 54 years to 96 years (*M* = 80.8, SD = 8.96). Table 2 presents the descriptive details of the male and female care recipients.

**Table 2.** Descriptive Details of Male and Female Care Recipients.

| Gender | *N* | % | Age Range | Mean | Standard Deviation |
|---|---|---|---|---|---|
| Male | 8 | 14.8 | 54 - 92 years | 82.6 | 13.08 |
| Female | 46 | 85.2 | 63 - 96 years | 80.6 | 8.21 |

Three (5.6 per cent) of the caregivers who were approached declined to participate in the study. All such participants stated that they were either too distressed or overworked to find time to meet with the researcher.

Criteria for inclusion into the research were as follows:

- Care recipients' meeting the ICD 10 (World Health Organisation, 1992) classification for a dementia of any type.
- The primary caregiver being either the adult son or daughter. The length of time caregivers had cared for their care recipient was not relevant. For the purposes of this study, caregiving was defined as the person who provides half or more of the direct care necessary for the independent living of the care recipient, as reported by the caregiver.
- Care recipient cared for in the community by their adult son or daughter. Caregivers living with the care recipient or those residing within a five mile radius of the care recipient were included.

The exclusion criteria were:

- Those care recipients living in residential care.
- Caregivers and care recipients who had recently or were concurrently taking part in other research projects.

- Caregivers and care recipients who experience difficulties speaking English.
- Caregivers who are unable to read.

Data obtained from a total of 54 families were included in the analysis.

## 2.4. Measures

### *2.4.1 Demographic and social information schedule (Appendix B)*

For the purposes of the study a detailed demographic and social information schedule was designed. Caregivers reported on their age, gender, employment status, household income, marital relationship, number of children and ethnic origin. In addition caregivers were asked to indicate how many months they had been providing care to their care recipient.

The quality of both the premorbid and current parent - child relationship was reported subjectively by the caregiver. Ratings ranging from 1 "Poor relationship" to 10 "Excellent relationship" were made on a linear scale.

In addition caregivers were asked to state the frequency of formal support networks regarding the number of hours per week with which they received assistance in caring. Frequency of contact from informal support networks was indexed as follows; 1 "Main carer no support", 2 "Main carer some support" or 3 "Shared responsibilities".

Caregivers were then required to report on their perception of the quality of both sources of support using a linear scale ranging from 1"I feel overwhelmed and do not know where to turn" up to 4 "I get most of the help I need".

Basic data on care recipients, including age, gender, ethnic origin, duration of dementia, living arrangements and formal diagnosis, were also obtained from caregivers.

Demographic data relating to the sample can be found in the results section.

### 2.4.2. Caregiver Distress and Personality Measures.

#### *2.4.2.1. Ways of Coping Checklist (Lazarus & Folkman, 1985).(Appendix C).*

The Ways of Coping Checklist revised from 68 items to 31 items by Lazarus & Folkman (1985) and Vitaliano et al. (1985), is a self report measure with items representing a broad range of cognitive and behavioural mechanisms that individuals use in an effort to manage specific stressful encounters.

Caregivers were asked to respond to the Checklist with reference to the stressful problems relating to caring for their elderly parent. The four forced choice response categories ranged from "Not used" to "Used a great deal".

The eleven factors derived from the factor analysis conducted by McKee et al. (1997), with carers of people with dementia were applied in this study. Each of the 31 items were scored in terms of degree of use (i.e. 0-3) and scored in the appropriate factor.

The revised scale has been consistently shown to be more reliable and to share substantially less variance than the original scale. It has been demonstrated to be free of demographic biases, and high internal consistencies and construct and concurrent validity have been found (Vitaliano et al., 1985).

In addition caregivers were asked to rate how well they felt they were coping with the stress of supporting their elderly parent, (Appendix D). The forced choice response categories available were either "Well", "So -So or "Poorly".

### 2.4.2.2. *Short Form of the Beck Depression Inventory (Beck & Beck, 1972). (Appendix D)*

The Beck Depression Inventory (BDI) is a self report scale designed to assess the current level of depression and provide some estimate of clinical severity. The 13 item, short form questionnaire consists of a series of ordered statements relating to a particular symptom of depression. Caregivers were advised to indicate which statements describe their current mood state. Items are scored on a 0-3 point basis. Total scores ranged from 0 - 4, 5 -7, 8 - 15, and 16 + reflecting either none or minimal depression, mild, moderate or severe depression respectively (Beck & Beck, 1972).

The reliability and validity of the original BDI have been well demonstrated (Beck & Beck, 1961). Those items that correlated best with the total BDI score and a clinician's rating were selected for the shortened form. The criterion correlation with the total BDI score was reached after only seven items, whereas with the clinician's ratings it was reached after 13 items. Thus the final product was a 13 item questionnaire correlating 0.96 with the total BDI score.

### 2.4.2.3. *Symptom Checklist - 90 R(Anxiety Scale) (Derogatis, 1977) (Appendix E)*

The anxiety dimension of the SCL-90R is composed of a set of 10 symptoms that are clinically associated with high levels of manifest anxiety. Cognitive, physical and somatic correlates of anxiety are included.

Respondents indicate along a 5 point scale ranging from "not at all" at one pole to "extremely" at the other, how distressed they were by each symptom during the previous week.

The psychometric properties of the SCL-90R have been well demonstrated (Derogatis, 1971). The internal consistency coefficients of the anxiety subscale were .85, the test retest reliabilities were .80 and the invariance coefficients were .60. In addition the scale is sensitive to change.

### *2.4.2.4. Anger In and Anger Out Subscales of the State Trait Anger Expression Inventory (Spielberger et al., 1988) (Appendix F)*

'Anger In' is an eight item anger expression scale that measures the frequency with which angry feelings are held in or suppressed. 'Anger Out' is another eight item scale that measures how often an individual expresses anger towards other people or objects in the environment.

Individuals are asked to indicate how often they generally react or behave in the manner described when they feel angry or furious. In responding to each of the items individuals were required to rate the frequency of occurrence of these behaviours on four point scales ranging from "Almost Never" to "Almost Always".

This scale was standardised on a U.S. sample. A factor analysis by Knight et al. (1988) confirmed that the Anger In and Anger Out subscales measure two relatively independent dimensions. In addition the measure was found to have satisfactory levels of reliability and validity.

### *2.4.2.5. Satisfaction With Life Scale (Diener et al., 1985)(Appendix G)*

The Satisfaction with Life Scale is a five item scale designed to assess a person's global judgement of life satisfaction. The global items allow respondents to weight domains in terms of their own values. Individuals are required to indicate their agreement with each item using a 1-7 point scale, ranging from "Strongly Agree" to "Strongly Disagree". The scale was developed for a U.S. sample and has been shown to have favourable psychometric properties, including high internal consistency and high temporal reliability (Diener et al., 1985) Scores on the scale have also been shown to correlate moderately to highly with other measures of subjective wellbeing and correlate predictably with specific personality characteristics.

### *2.4.2.6. The Screen For Caregiver Burden (Vitaliano et al., 1991) (Original Measure in Appendix I; Revised Measure in Appendix J)*

The Screen For Caregiver Burden is a brief measure of upsetting caregiver experiences. As such the measure does not sample the full domain of caregiving experiences, rather those that are potentially related to distress. The 25 item measure, completed by the caregiver, assesses both the prevalence of caregiver experiences and the appraisal of distress associated with experiences encountered when caring for a spouse with dementia.

Two scores are produced; Objective burden and Subjective burden. The former refers to the number of caregiving experiences that have occurred regardless of their distress whereas the latter reflects ratings of overall distress (from 1 - 4) associated with the experiences endorsed. The psychometric properties of this measure have been demonstrated in two independent American samples (Vitaliano et al., 1989a; 1991). Internal consistency coefficients were .85 and .88 for objective and subjective burden respectively. Construct validity (convergent and divergent) was supported by relationships of care recipient behavioural and cognitive functioning with objective burden, and caregiver distress and personality variables with subjective burden. Criterion validity was demonstrated by using age and sex matched controls. Finally sensitivity to change was evident.

Since participants in the present study were adult child carers the wording “spouse” in the original measure was changed to “parent”. In addition the measure was piloted on a sample from the general public for readability. The three items subsequently excluded due to unsuitable application to British participants were “I have had to seek public assistance to pay for my spouse’s medical bills”, “Seeking public assistance is demeaning and degrading” and “My spouse has gotten lost in the grocery store”.

### 2.4.3. Care Recipient Variables

#### *2.4.3.1. The Record of Independent Living (Weiuntraub et al., 1982). (Appendix K)*

This is a broad assessment of the severity of functional and behavioural impairment. The measure is divided into three sections.

The first section includes a total of 17 activities related to self care, household maintenance, recreation, and ability to function outside of the home. The second, communication section consists of four items assessing speaking, understanding, reading and writing. Finally the behaviour section consists of a checklist of 16 statements describing behaviour problems; specifically apathy, depression, hostility, and social inappropriateness. All three sections have showed high test - retest reliabilities (Weintraub et al., 1982).

Each of the items in the activities section is rated on a scale from 0 (no change when compared to prior competence) to 4 (patient no longer performs this activity), with ratings in between representing increased need for assistance in accomplishing the activity. In the communication section ratings range from 0 (no difficulty) to 4 (no longer performs this function). Allowance is made for responding “don’t know” or “not applicable”.

Scoring of the behaviour section acknowledges that certain undesirable behaviour traits may have been lifelong. The caregiver is asked to rate each statement twice, the first time indicating whether or not it describes their parents' behaviour before the onset of dementia and the second indicating whether or not it is currently descriptive.

#### *2.4.3.2. Mini Mental State (Folstein et al., 1975) (Appendix L)*

The Mini Mental State is a 20 item measure designed to quantitatively estimate the severity of cognitive impairment. The test is divided into two sections, the first of which requires vocal responses only and covers orientation, memory and attention; the maximum score is 21. The second part tests ability to name, follow verbal and written commands, write a sentence spontaneously and copy a complex polygon. The maximum score is nine. Lower overall scores indicate greater cognitive impairment.

Psychometric properties have been demonstrated by Folstein et al. (1975). The test-retest reliabilities have not fallen below .89 and inter-rater reliability has not fallen below .82.

## 2.5. Procedure

### *2.5.1. Procedure for recruiting participants*

Meetings were arranged with the appropriate old age Psychiatrists, Clinical Psychologists, Social Workers, Community Psychiatric Nurses, Speech Therapists, Occupational Therapists, Day Hospital Staff and staff from the early onset dementia services and voluntary organisations to inform them of the research and seek their permission and support to recruit participants. As Whittick (1988) has indicated the above mentioned services for older adults suffering with dementia is often only offered when it is thought that the carer is under great stress or can no longer cope without support. While a successful attempt was made to recruit carers from a variety of sources rather than from one specific facility, generalization of these results to other carers has to be treated with caution.

Those caregivers meeting the inclusion criteria were contacted by the health care professional already working with the family, and a verbal explanation of the research was given. This was facilitated by the use of a protocol designed by the researcher (Appendix M). There was no mention in the recruitment process of any service that was to be offered in association with the research.

Those names of carers who gave verbal informed consent to participate were passed to the researcher to make contact to discuss the study and arrange a convenient time and location to meet. All caregivers were met individually by the researcher in their home at a previously negotiated convenient time.

To ensure honesty and confidentiality the need to meet the carer separately from the care recipient was highlighted.

A total of 54 families agreed to participate, representing a response rate of 94.7 per cent.

### 2.5.2. *Procedure for interviews*

At the start of the interview between the researcher and the individual caregivers, carers were given an information sheet (Appendix N) outlining the procedures involved and aims of the research. The opportunity to raise any questions was offered. Providing that all the questions had been answered the carer was asked to sign two consent forms ( Appendices O and P), one for him or herself and one signed on behalf of the care recipient. The ethical issue of who to gain informed consent for the older adult to participate in the study arose. Even if the older adult agreed to participate in the study were they competent to make that decision ? Informed consent, on behalf of the care recipient, was therefore obtained from the offspring acting as caregiver.

Caregivers were initially interviewed using a structured demographic and social information schedule specifically designed for the study (Appendix B).The carer was then asked to complete the series of caregiver distress and personality measures. Before completing each measure the researcher offered verbal instructions and was available to answer any queries. To ensure anonymity and confidentiality no participant was required to write their name on measures and all the information was stored in a locked filing cabinet. The length of the interview sessions ranged from 45 to 190 minutes ($M$ = 107.04, SD = 38.66).

Meetings with the care recipients were arranged in collaboration with the caregivers. With regards to those caregivers residing with the care recipients, a further visit by the researcher was arranged for when the care recipient would be present. If the carer did not live with the parent a convenient time was arranged to visit the care recipient. All caregivers were present when the researcher met with the care recipients and all the interviews were conducted in the home environment. During this meeting an explanation of the research was offered followed by administration of the Mini Mental State. Prior to its administration the researcher stated "Some of the questions I'm going to ask you may seem a bit strange. You may think some of them don't apply to you, but please try to answer them because we have to ask everybody the same questions". The length of the Mini Mental State testing sessions averaged at 12 minutes.

The appropriate GP and Old Age Psychiatrists were informed of the care recipients' involvement in the study by letter (Appendix Q). In addition, with the caregivers' consent, the GP's of those carers that obtained significant scores on the depression and anxiety measures were informed of the results by letter, so that if appropriate they could intervene for the benefit of the carer.

## 2.6. Data Analysis.

The data was analysed using the SPSS for Windows package (SPSS/PCT, 1988). Scatterplots were made to test the linearity of the relationships before carrying out the correlations. Pearson's product moment correlations were computed to investigate the strength of relationships between variables with interval and normally distributed data. Spearmans rho correlations were applied to those variables with ordinal data and data with significant levels of skew and / or kurtosis.

Since there were no missing data each statistical test applied to the data assumes that $N = 54$. Results were taken to be significant at a level of $p < 0.05$ and highly significant at a level of $p < 0.01$. Differences between two non independent correlation coefficients were tested using the procedure designed by Steiger (1980).

Independent sample t - tests were applied to the data to identify any significant differences between categoric variables (i.e. male and female caregivers; those living with and apart from their care recipients). All the t tests were two tailed.

In order to test the extent to which demands or objective stressors and mediators predicted caregiver outcomes a series of stepwise multiple regression analyses were applied to the data. The data were screened for levels of skew and / or kurtosis prior to the regression analysis and only those correlations taken to be significant at a level of $p < 0.01$ were included in the regression equation. Those variables found not to have a normal distribution were transformed (to produce normality) using the procedures described by Tabachnick & Fidell (1996).

# 3.0. Results.

## 3.1. Characteristics of the Sample.

Table 3 presents the demographic data for caregivers. The number and percentages (to the nearest whole number) are included.

**Table 3** Characteristics of Caregivers

| Caregiver Characteristics | Caregivers $N$=54 | |
|---|---|---|
| | $N$ | % |
| **Ethnicity** | | |
| British | 49 | 91 |
| Irish | 1 | 2 |
| Jamaican | 4 | 7 |
| **Employment Status** | | |
| Full time | 17 | 32 |
| Part time | 14 | 26 |
| Unemployed | 5 | 9 |
| Retired | 9 | 17 |
| Disabled | 3 | 6 |
| Left Work | 3 | 6 |
| Housewife | 1 | 2 |
| Maternity Leave | 1 | 2 |
| Education | 1 | 2 |
| **Marital Status** | | |
| Married | 30 | 56 |
| Living As | 1 | 2 |
| Single | 14 | 26 |
| Divorced | 8 | 15 |
| Widowed | 1 | 2 |
| **Household Income (per week)** | | |
| Less than £100 | 9 | 17 |
| £100 -£150 | 14 | 26 |
| £150-£200 | 9 | 17 |
| Over £200 | 22 | 41 |
| **Informal Social Support** | | |
| Main carer no support | 21 | 39 |
| Main carer some support | 25 | 46 |
| Share care equally | 8 | 15 |

Caregiver ages ranged from 28 years to 71 years (*M* =50.6, SD = 11.01).

As outlined in Table 3 the large majority of caregivers (91 per cent) were British. Unfortunately the small representation of caregivers from other ethnic groups restricts an ability to reflect on the ethnic diversities among other caregivers. Over half the caregiver sample (57 per cent) were employed, either full time or part time and 17 per cent were retired. Over half (56 per cent) were married and the majority of the sample (78 per cent) had children. Two fifths of caregivers reported weekly household incomes of over £200.

The largest percentage of caregivers (46 per cent) reported being the main carer and receiving some support, followed by being the main carer with no support. Under a fifth of the sample shared the caring responsibilities equally.

The mean duration of caregiving (in months) was 42.50 (SD = 37.75). Overall caregivers reported a good premorbid relationship (*M* = 8.99, SD= 1.79). With respect to quality of the current relationship, generally caregivers ratings were lower (*M* = 6.45, SD = 3.43).

The average number of hours per week of formal social support received was 16.39 (SD = 10.45). With regards to perceived quality of support networks, the majority (*M* = 2.27, SD = 0.95) reported half way on the scale between 1 'I feel overwhelmed and do not know where to turn' compared with 4 'I get most of the help I need.

At the time of the interviews, 29 (54 per cent) of the caregivers were experiencing minimal depressive features, six (11 per cent) were found to be mildly depressed, 14 (26 per cent) were identified as suffering moderate depression and five (9 per cent) were experiencing severe depression. Seventeen (32 per cent) of the caregivers reported no anxiety symptoms. Just under half the sample (25, 47 per cent) reported feeling dissatisfied (in varying degrees)

with their life, 26 (48 per cent) were reported to be satisfied, again in varying degrees, with their life and the remaining three (5 per cent) were neutral. Twenty-nine (54 per cent) reported that they were coping well with the tasks of caring for their parent, eight (14 per cent) reported to be coping "so-so" and 17 (32 per cent) reported coping poorly. The majority of supporters used problem focussed coping strategies to deal with the burdens of caring.

Table 4 presents the demographic characteristics of the care recipients.

**Table 4** Characteristics of the Care Recipients.

| Demographic Information | Care Recipients $N = 54$ | |
|---|---|---|
| | *N* | % |
| **Ethnicity** | | |
| British | 48 | 89 |
| Irish | 2 | 4 |
| Jamaican | 4 | 7 |
| **Diagnosis** | | |
| Alzheimers Disease | 27 | 50 |
| Multi Infarct Dementia | 9 | 17 |
| Unspecified Dementia | 16 | 30 |
| Dementia Superimposed on Delirium | 2 | 4 |
| **Living Arrangements** | | |
| Living Alone | 32 | 59 |
| With Spouse | 4 | 7 |
| With Carer | 18 | 33 |
| With Other Family | - | - |

Care recipient ages ranged from 54 years to 96 years ($M$ =80.8, SD = 8.96).

Similar to the caregivers the majority of care recipients (89 per cent) were British. The most common diagnosis associated with care recipients' impairments was Alzheimers

Disease (50 per cent) followed by an unspecified dementia (30 per cent), multi infarct dementia (17 per cent) and dementia superimposed on delirium (4 per cent). The mean duration of illness, measured in months, was 43.06 (SD = 32.79). Over half of the sample lived alone, a third lived with their carer and the smallest percent (7.4 per cent) lived with their spouse.

The severity of cognitive impairment was as follows; six (11 per cent) were mildly impaired, 23 (43 per cent) were moderately impaired and 25 (46 per cent) were severely impaired. With regards to activities of daily living, six (11 per cent) were identified as mild to moderately impaired, 27 (51 per cent) were moderately to severely impaired and 20 (37 per cent) were identified as severely impaired. Regarding communicational abilities, 16 (30 per cent) were described as mild to moderately impaired, 14 (26 per cent) were moderate to severely impaired and 24 (44 per cent) were severely impaired.

The data was screened for skewness and kurtosis by dividing the values of skew and kurtosis by the standard error of each respectively. A value between +2 and -2 was considered acceptable (Tabachnick & Fiddell, 1996). Since many of the caregiver and care recipient variables had levels of skew and/or kurtosis unacceptable for parametric analysis they were analysed using non parametric procedures. A table of skewed and kurtosed data can be found in Appendix R.

**Psychometric Properties of the Screen For Caregiver Burden (Vitaliano et al., (1991).**

The internal reliability of the 22 item Screen for Caregiver Burden was measured by calculating coefficient alphas using Cronbach's Alpha.

Table 5 presents the alpha reliabilities of the objective and subjective burden subscales, as compared with those by Vitaliano et al. (1991).

**Table 5** Psychometric Properties of the Screen For Caregiver Burden.

| Subscale | Alpha Reliabilities for the present study | Mean inter item correlation | Alpha Reliabilities Vitaliano et al., (1991) |
|---|---|---|---|
| **Objective Burden** | 0.77 | 0.12 | 0.85 |
| **Subjective Burden** | 0.92 | 0.32 | 0.88 |

Subscales with alpha coefficients above 0.7 were considered acceptable (Breakwell et al., 1995). The mean inter item correlations were considered acceptable, being broadly within the 0.2 to 0.4 range (Briggs & Cheek, 1986).

Objective burden was found to have adequate alpha reliabilities and low, but acceptable, inter item correlations. Subjective burden was found to have high alpha reliabilities and reasonable inter item correlations.

As can be seen in Table 5, the alpha reliabilities on both subscales were broadly comparable to those found in Vitaliano et al's. (1991) study and were therefore judged to have adequate internal reliability.

Correlational results for subjective and objective burden with caregiver outcomes are summarised in Table 6. In order to draw comparisons, results from Vitaliano et al's. (1991)

study are included

**Table 6** Correlations: Subjective and Objective Burden with Caregiver Outcomes.

| **Caregiver Outcomes** | **Present Study** $N = 54$ | | Vitaliano et al., (1991) study $N = 79$ | |
|---|---|---|---|---|
| | **Subjective Burden** $r =$ | **Objective Burden** $r =$ | Subjective Burden $r =$ | Objective Burden $r =$ |
| **Depression** | 0.64** | 0.54** | 0.54*** | 0.41*** |
| **Anxiety** | 0.52** | 0.44** | 0.43*** | 0.26* |
| **Suppressed Anger** | 0.36** | 0.30* | 0.42*** | 0.25 |
| **Anger Out** | 0.02 | -0.02 | Not included | in analysis |
| **Satisfaction With Life** | -0.43** | -0.50** | -0.51*** | -0.48*** |

* $p<0.05$ ** $p<0.01$ *** $p<0.001$

Caregiver depression and anxiety were strongly positively related to both subjective and objective burden ($r = 0.64, p <0.01$ and $r = 0.54, p <0.01$, $r = 0.52, p <0.01$ and $r = 0.44$, $p <0.01$ respectively). In order to test the differences between the two correlations for depression and anxiety with objective and subjective burden respectively, the test devised by Steiger (1980) measuring the difference between two non independent correlations was applied to the data (Appendix S). For depression with objective and subjective burden a value of t = 1.46 for 50 d.f. was found to be non significant. For anxiety a value of t = 1.05 for 50 d.f. was again found to be non significant. This suggests that stronger correlations were not displayed for depression or anxiety and subjective burden compared to objective burden.

Caregiver suppressed anger was found to be more strongly related to subjective burden than objective burden ($r = 0.36, p < 0.01$ and $r = 0.30, p < 0.05$). Caregiver morale measured on the Life Satisfaction Scale was strongly negatively related to both subjective ($r = -0.43$, $p < 0.01$) and objective burden ($r = -0.50, p < 0.01$). Anger Out, included in the present study, was not shown to be significantly correlated to either subjective or objective burden.

Findings from the present sample of adult child caregivers is therefore broadly comparable with results obtained by Vitaliano et al. (1991).

The remainder of the section uses Figure 2 found in the introduction to organise findings of the results.

## Correlations Within Model Elements.

Before presenting results of correlational analyses between demands or objective stressors with mediators, Tables 7 and 8 display the correlational results of all the variables within the demands or objective stressor category and the variables within the mediator category respectively.

As can be seen in Table 7, scores obtained on the Mini Mental State, for care recipients, were found to be strongly negatively correlated with non cognitive care recipient features of activities and communication ( $r = -0.49, p < 0.01$ and $r = -0.45, p < 0.01$). In addition a significant negative correlation with objective burden was found ($r = -0.33, p < 0.05$).

Care recipient activities of daily living were found to be strongly positively correlated with communication abilities of the care recipient ($r = 0.35, p < 0.01$), and positively correlated with apathy ($r = 0.29, p < 0.05$) and objective burden ($r = 0.31, p < 0.05$). Communication was found to be positively correlated with both hostility ( $r = 0.32, p < 0.05$) and objective burden ($r = 0.37, p < 0.05$). Behavioural manifestations of the care recipient were found to be strongly positively correlated with apathy ($r = 0.38, p < 0.01$), depression ($r = 0.72, p < 0.01$), hostility ($r = 0.81, p$

$<0.01$) and social inappropriateness, ($r = 0.56, p < 0.01$) and significantly positively correlated with objective burden ($r = 0.34, p < 0.05$).

Care recipient depression was found to be strongly positively correlated with care recipient hostility ($r = 0.54, p < 0.01$). Care recipient hostility was found to be strongly positively correlated with care recipient social inappropriateness ( $r = 0.38, p < 0.01$) and objective burden ( $r = 0.50, p < 0.01$). Finally, care recipient social inappropriateness was found to be strongly positively correlated with objective burden ( $r = 0.38, p < 0.01$).

Regarding correlations between mediator variables, as can be seen in Table 8, 'Optimism in the future' was found to be strongly positively correlated with 'Informal help seeking' ( $r = 0.52, p < 0.01$), 'Optimism in the present' ($r = 0.41, p < 0.01$), 'Mental preparation' ($r = 0.61, p < 0.01$), and 'Previous experience' ($r = 0.52, p < 0.01$) and strongly positively correlated with the emotion focussed coping factors of 'Fantasy' ($r = 0.39, p < 0.01$), 'Externalize' ($r = 0.47, p < 0.01$) and 'Isolation and resignation' ( $r = 0.58, p < 0.01$). 'Informal help seeking' was found to be strongly positively correlated with the problem focussed coping factors 'Optimism in the present' ($r = 0.50, p < 0.01$), 'Mental preparation' ($r = 0.72, p < 0.01$), 'Formal help seeking' ( $r = 0.55, p = < 0.01$) and 'Previous experience' ($r = 0.56$, p $< 0.01$). In addition, a positive correlation was found with the emotion focussed factor 'Externalize' ($r = 0.31, p < 0.05$). 'Optimism in the present' was found to be strongly correlated positively with the problem focussed coping factors 'Mental preparation' ($r = 0.41, p < 0.01$) and 'Previous experience' ($r = 0.57, p < 0.01$). In addition, significant positive correlations were found with the emotion focussed coping factors 'Internalize' ($r = 0.33, p < 0.05$) and 'Isolation and resignation' ( $r = 0.35, p < 0.05$) and strongly positively correlated with 'Externalize' ( $r = 0.44, p < 0.01$).

The problem focussed coping factor 'Mental preparation' was found to be positively correlated with 'Previous experience' ($r = 0.50, p < 0.01$) and 'Formal help seeking' ($r = 0.31, p < 0.05$), and strongly positively correlated with the emotion focussed coping factor 'Fantasy' ($r = 0.57, p < 0.01$). The factor 'Formal help seeking' was strongly positively correlated with the corresponding problem focussed coping factor of 'Previous experience' ($r = 0.46, p < 0.01$) and significantly positively correlated with the emotion focussed factors 'Externalize' ($r = 0.30, p < 0.05$) and 'Isolation and resignation' ( $r= 0.80, p < 0.01$). The factor 'Previous experience' was found to be negatively correlated with the emotion focussed factor 'Angry fixed response' ($r = -0.28, p < 0.05$) and strongly positively correlated with the factor 'Externalize' ($r = 0.52, p < 0.01$).

The emotion focussed coping factor 'Internalize' was found to be significantly positively correlated with 'Externalize' ($r = 0.29, p < 0.05$), 'Isolation and resignation' ($r = 0.33, p < 0.05$), and subjective burden ($r = 0.35, p < 0.05$), and there was a highly significant negative correlation with informal social support ($r = -0.44, p < 0.01$). 'Angry fixed response' was positively correlated with 'Isolation and resignation' ($r = 0.33, p < 0.05$), negatively correlated with informal social support ($r = -0.30, p < 0.05$) and strongly positively correlated with subjective burden ($r = 0.57, p < 0.01$). Finally, the emotion focussed coping strategy 'Isolation and resignation' was strongly positively correlated with subjective burden ($r = 0.45, p < 0.01$). No other significant correlations were identified.

**Table 7** Correlational Results for Demands or Objective Stressor Variables.

| | Mini Mental State | Activities | Communication | Behaviour | Apathy | Depression | Hostility | Social Inappropriateness | Objective Burden |
|---|---|---|---|---|---|---|---|---|---|
| **Mini Mental State** | - | -0.49** | -0.45** | -0.03 | -0.15 | 0.23 | -0.16 | -0.08 | -0.33* |
| **Activities** | - | - | 0.35** | 0.15 | 0.29* | -0.12 | -0.01 | 0.25 | 0.31* |
| **Communication** | - | - | - | 0.26 | 0.31 | -0.04 | 0.32* | 0.12 | 0.37* |
| **Behaviour** | - | - | - | - | 0.38** | 0.72** | 0.81** | 0.56** | 0.34* |
| **Apathy** | - | | - | - | - | 0.12 | 0.13 | 0.25 | 0.12 |
| **Depression** | - | - | - | - | - | - | 0.54** | 0.11 | 0.03 |
| **Hostility** | - | - | - | - | - | - | - | 0.38** | 0.50** |
| **Social Inappropriateness** | - | - | - | - | - | - | - | - | 0.38** |
| **Objective Burden** | - | - | - | - | - | - | - | - | - |

$^{*}p < 0.05$ $^{**}p < 0.01$

### Table 8 Correlational Results For Mediator Variables.

| | Optimism in the future | Informal help seeking | Optimism in the present | Mental preparation | Formal help seeking | Previous experience | Fantasy | Internalize | Angry Fixed Response | Externalize | Isolation & Resignation | Subjective burden | Informal Social Support | Formal Social Support |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Optimism in the future** | - | 0.52** | 0.41** | 0.61** | 0.16 | 0.52** | 0.39** | 0.04 | -0.02 | 0.47** | 0.58** | 0.07 | 0.03 | 0.08 |
| **Informal help seeking** | - | - | 0.50** | 0.72** | 0.55** | 0.56** | 0.22 | -0.21 | -0.18 | 0.31* | 0.16 | -0.20 | 0.20 | -0.10 |
| **Optimism in the present** | - | - | - | 0.41** | 0.25 | 0.57** | 0.08 | 0.33* | -0.05 | 0.44** | 0.35* | 0.15 | -0.25 | -0.05 |
| **Mental preparation** | - | - | - | - | 0.31* | 0.50** | 0.57** | -0.06 | -0.23 | 0.22 | 0.06 | -0.06 | 0.17 | -0.19 |
| **Formal help seeking** | - | - | - | - | - | 0.46** | 0.07 | -0.12 | -0.18 | 0.30* | 0.80** | -0.19 | 0.10 | -0.06 |
| **Previous experience** | - | - | - | - | - | - | 0.17 | 0.06 | -0.28* | 0.52** | 0.05 | -0.23 | 0.09 | -0.05 |
| **Fantasy** | - | - | - | - | - | - | - | 0.16 | 0.06 | 0.20 | 0.09 | 0.24 | 0.02 | -0.10 |
| **Internalize** | - | - | - | - | - | - | - | - | 0.26 | 0.29* | 0.33* | 0.35* | -0.44** | 0.11 |
| **Angry fixed response** | - | - | - | - | - | - | - | - | - | 0.11 | 0.33* | 0.57** | -0.30* | 0.18 |
| **Externalize** | - | - | - | - | - | - | - | - | - | - | -0.02 | 0.08 | -0.11 | 0.16 |
| **Isolation &resignation** | - | - | - | - | - | - | - | - | - | - | - | 0.45** | -0.23 | 0.13 |
| **Subjective burden** | - | - | - | - | - | - | - | - | - | - | - | - | -0.25 | 0.22 |
| **Informal social support** | - | - | - | - | - | - | - | - | - | - | - | - | - | -0.13 |
| **Formal social support** | - | - | - | - | - | - | - | - | - | - | - | - | - | - |

$^{*}p < 0.05$ $^{**}p < 0.01$

**Table 9** Correlational Results for Caregiver Outcome Variables.

| | Depression | Anxiety | Anger in | Anger out | Satisfaction with life | Self perceived coping | Quality of social support |
|---|---|---|---|---|---|---|---|
| **Depression** | - | 0.78** | 0.38** | -0.15 | -0.53** | 0.49** | -0.32* |
| **Anxiety** | - | - | 0.31* | -0.02 | -0.46** | 0.41** | -0.22 |
| **Anger in** | - | - | - | -0.34* | -0.21 | 0.19 | -0.26 |
| **Anger out** | - | - | - | - | -0.01 | -0.04 | -0.14 |
| **Satisfaction with life** | - | - | - | - | - | -0.41** | 0.16 |
| **Self perceived coping** | - | - | - | - | - | - | -0.40** |
| **Quality of social support** | - | - | - | - | - | - | - |

* $p<0.05$ ** $p<0.01$

Caregiver depression was strongly positively correlated with anxiety (*r* = 0.78, *p* <0.01), anger in (*r* = 0.38, *p* <0.01), self perceived coping (*r* = 0.49, *p* <0.01), and strongly negatively correlated with satisfaction with life (*r* = -0.53, *p* <0.01) and quality of social support (*r* = -0.32, *p* <0.05). Caregiver anxiety was significantly positively correlated with anger in (*r* = 0.31, *p* <0.05), strongly negatively correlated with satisfaction with life (*r* = -0.46, *p* <0.01) and strongly positively correlated with self perceived coping (*r* = 0.41, *p* <0.01). The only significant correlation with anger in was anger out, displaying a negative correlation of *r* = -0.34, *p* <0.05. Satisfaction with life was strongly negatively correlated with self perceived coping (*r* = -0.41, *p* <0.01) and self perceived coping was strongly negatively correlated with quality of social support (*r* = -0.40, *p* <0.01).

**Table 10** Correlational Results for Background and Contextual Factor Variables.

| | **Carer age** | **Premorbid relationship** | **Current relationship** | **Length of practical care** | **Number of children** |
|---|---|---|---|---|---|
| **Carer age** | - | 0.02 | 0.15 | 0.03 | 0.20 |
| **Premorbid relationship** | - | - | 0.14 | -0.06 | -0.05 |
| **Current relationship** | - | - | - | 0.18 | -0.19 |
| **Length of practical care** | - | - | - | - | -0.15 |
| **Number of children** | - | - | - | - | - |

* *p*<0.05 ** *p*<0.01

As can be seen from Table 10 above, no significant correlations were identified between any of the background and contextual factor variables included in the present study.

## Demands or Objective Stressors with Mediators.

**Table 11** Correlational Results For Care Recipient Functioning Variables and Objective Burden and Emotion Focussed Coping Strategies.

| **DEMANDS** | **MEDIATORS** | | | | |
|---|---|---|---|---|---|
| | **Fantasy** | **Internalize** | **Angry Fixed Response** | **Isolation & Resignation** | **Externalize** |
| | *r* = | *r* = | *r* = | *r* = | *r* = |
| **Care Recipient Functioning Variables** | | | | | |
| **Mini Mental State** | 0.08 | -0.14 | -0.20 | -0.09 | 0.03 |
| **Record of Independent Living** | | | | | |
| Activities | -0.02 | 0.13 | -0.01 | 0.13 | 0.003 |
| Communication | 0.02 | 0.14 | 0.11 | 0.17 | -0.05 |
| Behaviour | -0.03 | 0.22 | 0.04 | 0.33* | 0.02 |
| (apathy) | -0.29* | -0.08 | 0.11 | 0.06 | -0.05 |
| (depression) | -0.05 | 0.23 | -0.13 | 0.06 | 0.03 |
| (hostility) | 0.08 | 0.35** | 0.28* | 0.34* | 0.08 |
| (social inappropriateness) | -0.02 | 0.16 | 0.15 | 0.34* | -0.10 |
| **Objective Burden** | 0.16 | 0.38** | 0.54** | 0.55** | 0.06 |

* $p<0.05$ ** $p<0.01$

Contrary to a component of hypothesis 1, the cognitive functioning of the care recipient, as measured on the Mini Mental State, was not found to be significantly correlated with any of the emotion focussed coping strategies. Regarding the non cognitive features of the care recipient, as measured on the Record of Independent Living, a significant positive correlation was found between behaviour of the care recipient and the factor 'Isolation and resignation' ($r = 0.33$, $p < 0.05$), supporting a component of hypothesis 2, and a significant negative correlation was found between apathy and 'Fantasy' ($r = -0.29$, $p < 0.05$). In addition, hostility in the care recipient was found to be positively correlated with the strategies 'Angry fixed response' ($r = 0.28$, $p < 0.05$) and 'Isolation and resignation' ($r = 0.34$, $p < 0.05$), and a highly positive correlation was found with the strategy 'Internalize' ($r = 0.35$, $p < 0.01$). Social inappropriateness manifested in the care recipient was found to be positively correlated with the strategy 'Isolation and resignation' ($r = 0.34$, $p < 0.05$), again supporting a component of hypothesis 2.

Regarding objective burden, highly positive correlations were found with 'Internalize' ($r = 0.38$, $p < 0.01$), 'Angry fixed response' ($r = 0.54$, $p < 0.01$) and 'Isolation and resignation' ($r = 0.55$, $p < 0.01$), supporting a component of hypothesis 3.

**Table 12** Correlational Results For Care Recipient Functioning Variables and Objective Burden and Problem Focussed Coping.

| **DEMANDS** | **MEDIATORS** | | | | | |
|---|---|---|---|---|---|---|
| | **Optimism in the Future** | **Informal Help Seeking** | **Optimism in the Present** | **Mental Preparation** | **Formal Help Seeking** | **Previous Experience** |
| | $r =$ | $r =$ | $r =$ | $r =$ | $r =$ | $r =$ |
| **Care Recipient Functioning Variables** | | | | | | |
| **Mini Mental State** | -0.13 | 0.11 | 0.04 | 0.08 | 0.14 | -0.03 |
| **Record of Independent Living** | | | | | | |
| Activities | 0.24 | -0.04 | 0.09 | 0.01 | -0.26 | 0.11 |
| Communication | 0.10 | -0.06 | -0.04 | -0.05 | 0.02 | -0.02 |
| Behaviour | -0.03 | -0.12 | 0.10 | -0.17 | 0.06 | 0.06 |
| (apathy) | -0.15 | -0.13 | -0.12 | -0.31* | -0.11 | -0.03 |
| (depression) | -0.12 | -0.16 | 0.13 | -0.14 | -0.04 | -0.08 |
| (hostility) | -0.02 | -0.16 | 0.10 | -0.15 | 0.15 | -0.01 |
| (social inappropriateness) | -0.14 | -0.20 | -0.12 | -0.18 | 0.02 | -0.08 |
| **Objective Burden** | 0.01 | -0.23 | -0.07 | -0.17 | 0.02 | -0.18 |

* $p<0.05$ ** $p<0.01$

No significant correlations were found between cognitive features of the care recipient, as measured on the Mini Mental State, with any of the problem focussed coping strategies, contrary to a component of hypothesis 1. However, apathy manifested by the care recipient was found to be negatively correlated with the factor 'Mental preparation' ($r = -0.31, p < 0.05$), supporting a component of hypothesis 2. No significant correlations were identified between objective burden and problem focussed coping strategies, failing to support a component of hypothesis 3.

**Table 13** Correlational Results for Care Recipient Functioning Variables and Objective Burden and Subjective Burden and Support Networks.

| **DEMANDS** | **MEDIATORS** | | |
|---|---|---|---|
| | **Subjective Burden** | **Informal Social Support** | **Formal Social Support** |
| | $r =$ | $r =$ | $r =$ |
| **Care Recipient Functioning Variables** | | | |
| **Mini Mental State** | -0.27* | 0.16 | -0.12 |
| **Record of Independent Living** | | | |
| Activities | 0.22 | -0.03 | 0.20 |
| Communication | 0.27 | 0.09 | 0.22 |
| Behaviour | 0.26 | -0.11 | 0.11 |
| (apathy) | 0.21 | -0.01 | 0.13 |
| (depression) | 0.07 | -0.06 | -0.11 |
| (hostility) | 0.35** | -0.12 | 0.11 |
| (social inappropriateness) | 0.25 | -0.22 | 0.15 |
| **Objective Burden** | 0.80** | -0.27* | 0.22 |

* $p < 0.05$ ** $p < 0.01$

As anticipated, (hypothesis1) cognitive limitations of the care recipient, as measured on the Mini Mental State, were significantly negatively correlated to subjective burden ($r = -0.27$, $p < 0.05$). No significant relationships between care recipient cognitive functioning variables and informal or formal social support networks were found, contrary to a component of hypothesis 1.

With regards to care recipient non cognitive functioning variables, as measured on the Record of Independent Living, hostility was found to be highly positively correlated with subjective burden ($r = 0.35$, $p < 0.01$), supporting a component of hypothesis 2.

Furthermore, objective burden showed a highly positive correlation with subjective burden ($r = 0.80, p < 0.01$), supporting a component of hypothesis 3, and a negative correlation with informal social support ($r = -0.27, p < 0.01$) was found, but in a direction opposite to that anticipated in hypothesis 3.

## Demands or Objective Stressors With Caregiver Outcomes.

**Table 14** Correlational Results for Care Recipient Functioning Variables and Objective Burden and Caregiver Outcomes.

| **DEMANDS** | **OUTCOMES** | | | | |
|---|---|---|---|---|---|
| | Depression | Anxiety | Anger In | Anger Out | Satisfaction With Life |
| | $r =$ | $r =$ | $r =$ | $r =$ | $r =$ |
| **Care Recipient Functioning Variables** | | | | | |
| **Mini Mental State** | -0.31* | -0.09 | -0.17 | -0.03 | 0.31* |
| **Record of Independent Living** | | | | | |
| Activities | 0.22 | 0.15 | 0.04 | -0.06 | -0.29* |
| Communication | 0.30* | 0.15 | -0.01 | 0.07 | -0.13 |
| Behaviour | 0.05 | -0.01 | 0.18 | 0.02 | 0.04 |
| (apathy) | 0.20 | 0.02 | 0.08 | 0.17 | -0.01 |
| (depression) | -0.17 | -0.21 | 0.17 | -0.12 | 0.13 |
| (hostility) | 0.08 | 0.01 | 0.17 | 0.11 | -0.10 |
| (social inappropriateness) | 0.17 | 0.22 | 0.23 | 0.07 | - 0.03 |
| **Objective Burden** | 0.54** | 0.44** | 0.30* | -0.02 | -0.50** |

* $p < 0.05$ ** $p < 0.01$

As anticipated, (hypothesis 4) cognitive features of the care recipient, as measured on the Mini Mental State, were negatively related to caregiver depression ($r = -0.31, p < 0.05$) and significantly positively related to satisfaction with life ($r = 0.31, p < 0.05$). No significant relationships with caregiver anxiety or forms of anger expression were found, failing to support a component of hypothesis 4.

Regarding the non cognitive features of the care recipient, limitations of activities of daily living were found to be negatively related to caregiver satisfaction with life ($r = -0.29$,

$p < 0.05$). In addition, a restricted ability to communicate was also found to be positively correlated with caregiver depression ($r = 0.30$, $p < 0.05$), supporting an aspect of hypothesis 5. With regards to care recipient behavioural problems and their subdivisions, no significant relationships were found with caregiver outcome variables.

However, in support of hypothesis 6, objective burden was found to be strongly positively correlated with caregiver depression ($r = 0.54$, $p < 0.01$) and anxiety ($r = 0.44$, $p < 0.01$), positively correlated with suppressed anger ($r = 0.30$, $p < 0.05$) and strongly negatively related to caregiver satisfaction with life ($r = -0.50$, $p < 0.01$). No significant associations with Anger Out were found.

**Table 15** Correlational Results for Care Recipient Functioning Variables and Objective Burden and Self Perceived Coping and Quality of Social Support.

| **DEMANDS** | **OUTCOMES** | |
|---|---|---|
| | **Self Perceived Coping** | **Quality of Social Support** |
| | $r$ – | $r$ – |
| **Care Recipient Functioning Variables** | | |
| **Mini Mental State** | -0.19 | 0.26 |
| **Record of Independent Living** | | |
| Activities | 0.21 | -0.02 |
| Communication | 0.30* | -0.32* |
| Behaviour | 0.09 | -0.20 |
| (apathy) | 0.09 | -0.37** |
| (depression) | 0.04 | -0.07 |
| (hostility) | 0.18 | -0.22 |
| (social inappropriateness) | 0.04 | -0.08 |
| **Objective Burden** | 0.56** | -0.52** |

* $p < 0.05$ ** $p < 0.01$

No significant correlations were found between care recipient cognitive impairment and caregiver self perceived coping and quality of social support, contrary to a component of hypothesis 4.

With respect to the non cognitive care recipient functioning variables, as measured on the Record of Independent Living, communication was found to be positively correlated with self perceived coping ($r = 0.30, p < 0.05$) and negatively correlated with quality of social support ($r = -0.32, p < 0.05$). In addition, apathy was found to be highly negatively related to quality of social support ($r = -0.37, p < 0.01$), supporting a component of hypothesis 5. Finally, objective burden was strongly positively correlated with caregivers' perception of coping ($r = 0.56, p < 0.01$) and highly negatively correlated to quality of social support ($r = -0.52, p < 0.01$), supporting a component of hypothesis 6.

## Mediators With Outcomes.

**Table 16** Correlational Results between Coping and Subjective Burden and Caregiver Outcomes.

| **MEDIATORS** | **OUTCOMES** | | | | |
|---|---|---|---|---|---|
| **Coping Factors** | **Depression** | **Anxiety** | **Anger In** | **Anger Out** | **Satisfaction With Life** |
| | *r* = | *r* = | *r* = | *r* = | *r* = |
| **Problem Focussed Coping** | | | | | |
| **Optimism in the future** | 0.02 | -0.08 | -0.15 | 0.07 | -0.06 |
| **Informal help seeking** | -0.30* | -0.14 | -0.31* | 0.19 | 0.21 |
| **Optimism in the present** | -0.37** | -0.38** | -0.19 | 0.24 | 0.06 |
| **Mental preparation** | -0.14 | -0.07 | -0.19 | 0.18 | 0.05 |
| **Formal help seeking** | -0.29* | -0.05 | -0.20 | 0.10 | 0.14 |
| **Previous experience** | -0.25 | -0.33* | -0.27* | 0.31* | 0.12 |
| **Emotion Focussed Coping** | | | | | |
| **Fantasy** | 0.26 | 0.25 | 0.09 | 0.22 | -0.13 |
| **Internalize** | 0.36** | 0.16 | 0.33* | 0.05 | -0.41* |
| **Angry fixed response** | 0.31* | 0.28* | 0.21 | 0.12 | -0.33* |
| **Isolation and resignation** | 0.43** | 0.35* | 0.36** | -0.35** | -0.37* |
| **Externalize** | 0.10 | -0.04 | 0.001 | 0.18 | -0.08 |
| **Subjective Burden** | 0.64** | 0.52** | 0.36** | 0.03 | -0.43** |

$^{*}p < 0.05$ $^{**}p < 0.01$

Certain problem focussed coping factors showed significant negative correlations with depression in caregivers; specifically 'Optimism in the present' ($r = -0.37, p < 0.01$), 'Informal help seeking' and 'Formal help seeking' ($r = -0.30, p < 0.05$) and ($r = -0.29, p < 0.05$ respectively), supporting a component of hypothesis 7.

As anticipated, (supporting a component of hypothesis 8) the emotion focussed coping strategies were strongly positively correlated to caregiver depression; specifically 'Internalize' ($r = 0.36, p < 0.01$) and 'Isolation and resignation' ($r = 0.43, p =< 0.01$). The remaining emotion focussed factor showing a significant positive correlation with caregiver depression was 'Angry fixed response' ($r = 0.31, p < 0.05$).

The problem focussed factor 'Optimism in the present' was found to be strongly negatively correlated to caregiver anxiety ($r = -0.38, p < 0.01$) and 'Previous experience' was negatively correlated to caregiver anxiety ($r = -0.33, p < 0.05$) again supporting a component of hypothesis 7. The emotion focussed factors 'Isolation and resignation'($r = 0.35, p < 0.05$) and 'Angry fixed response' ($r = 0.28, p < 0.05$) were found to be positively correlated with caregiver anxiety, supporting a component of hypothesis 8.

As anticipated the problem focussed factors 'Informal help seeking' and 'Previous experience' were found to be negatively associated with caregiver suppressed anger ($r = -0.31, p < 0.05$ and $r = -0.27$, $p = < 0.05$ respectively), whilst the emotion focussed factors 'Internalize' and 'Isolation and resignation' were found to be positively correlated with suppressed anger ($r = 0.33, p < 0.05$ and $r = 0.36, p < 0.01$ respectively), supporting components of hypotheses 7 and 8. The only two coping factors found to be significantly associated with Anger Out were the emotion focussed coping factors 'Isolation and resignation' showing a highly significant negative correlation ($r = -0.35, p < 0.01$) and the problem focussed coping factor 'Previous experience' showing a positive correlation ($r = 0.31, p < 0.05$), but in a direction opposite to that anticipated in hypotheses 7 and 8.

With regards to coping factors and satisfaction with life the emotion focussed coping factors 'Internalize', 'Angry fixed response' and 'Isolation and resignation' were all found to show negative correlations ($r = -0.41, p < 0.05$, $r = -0.33, p < 0.05$ and $r = -0.37, p < 0.05$ respectively), supporting a component of hypothesis 8.

In addition subjective burden was found to be highly positively correlated with depression ($r = 0.64, p < 0.01$), anxiety ($r = 0.52, p < 0.01$) and suppressed anger ($r = 0.36$, $p < 0.01$), and strongly negatively correlated with satisfaction with life ($r = -0.43$, $p < 0.01$), supporting a component of hypothesis 11.

**Table 17** Correlational Results between Coping and Subjective Burden and Self Perceived Coping and Quality of Social Support.

| **MEDIATORS** | **OUTCOMES** | |
|---|---|---|
| **Coping Factors** | **Self Perceived Coping** | **Quality of Social Support** |
| | *r* – | *r* – |
| **Problem Focussed Coping** | | |
| **Optimism in the future** | 0.08 | 0.34* |
| **Informal help seeking** | -0.25 | 0.32* |
| **Optimism in the present** | -0.24 | 0.19 |
| **Mental preparation** | -0.17 | 0.26 |
| **Formal help seeking** | -0.34* | 0.13 |
| **Previous experience** | -0.31* | 0.30* |
| **Emotion Focussed Coping** | | |
| **Fantasy** | 0.14 | -0.01 |
| **Internalize** | 0.25 | -0.16 |
| **Angry fixed response** | 0.34* | -0.33* |
| **Isolation and resignation** | 0.31* | -0.28* |
| **Externalize** | 0.02 | 0.24 |
| **Subjective Burden** | 0.65** | -0.53** |

$^*p<0.05$ $\quad$ $^{**}p<0.01$

The problem focussed coping factors of 'Formal help seeking' and 'Previous experience' were found to be significantly negatively correlated to self perceived coping ($r$ =-0.34, $p$ <0.05 and $r$ =-0.31, $p$<0.05 respectively), (self perceived coping is scored 1 'well', 2 'so-so', 3 'poor'). In contrast, the emotion focussed coping factors were found to be significantly positively correlated with self perceived coping and included 'Angry fixed response' ($r$ = 0.34, $p$ <0.05) and 'Isolation and resignation' ($r$ = 0.31, $p$ <0.05), supporting components of hypotheses 7 and 8. In addition, subjective burden was found to be strongly positively correlated with self perceived coping ($r$ = 0.65, $p$ <0.01), supporting a component of hypothesis 11.

As anticipated, (hypothesis 7) certain problem focussed coping factors were found to be positively correlated with quality of social support; specifically 'Optimism in the future' ($r$ = 0.34, $p$ <0.05), 'Informal help seeking' ($r$ = 0.32, $p$ <0.05) and 'Previous experience'

($r = 0.30, p < 0.05$).

In contrast and supporting a component of hypothesis 8, certain emotion focussed coping strategies were found to be negatively correlated with quality of social support; specifically 'Angry fixed response' ($r = -0.33, p < 0.05$) and 'Isolation and resignation' ($r = -0.28$, $p < 0.05$). In addition a highly negative correlation was found between subjective burden and quality of social support ($r = -0.53, p < 0.01$), supporting a component of hypothesis 11.

**Table 18** Correlational Results For Informal and Formal Social Support and Caregiver Outcome Variables.

| **MEDIATORS** | **OUTCOMES** | | | | |
|---|---|---|---|---|---|
| | **Depression** | **Anxiety** | **Anger In** | **Anger Out** | **Satisfaction With Life** |
| | *r* – | *r* – | *r* – | *r* – | *r* – |
| **Informal Social Support** | -0.25 | -0.12 | -0.23 | -0.01 | 0.34* |
| **Formal Social Support** | 0.18 | 0.09 | 0.11 | 0.02 | -0.21 |

* $p < 0.05$ ** $p < 0.01$

The only significant correlation identified was informal social support, which was positively correlated with caregiver satisfaction with life ($r = 0.34, p < 0.05$), supporting a component of hypothesis 9. The absence of any significant correlations with formal social support fails to support a component of hypothesis 10.

**Table 19** Correlational Results between Informal and Formal Social Support and Caregiver Self Perceived Coping and Quality of Social Support.

| **MEDIATORS** | **OUTCOMES** | |
|---|---|---|
| | **Self Perceived Coping** | **Quality of Social Support** |
| | *r* – | *r* – |
| **Informal Social Support** | -0.13 | 0.15 |
| **Formal Social Support** | 0.24 | -0.05 |

* $p<0.05$ ** $p<0.01$

No significant correlations were identified between informal and formal social support and self perceived coping and quality of social support, contrary to components of hypotheses 9 and 10.

## Background and Contextual factors With Demands or Objective Stressors.

**Table 20** Correlational Results between Background and Contextual Factors and Care Recipient Functioning Variables and Objective Burden.

| **DEMANDS** | **BACKGROUND FACTORS** | | | | |
|---|---|---|---|---|---|
| | **Carer age** | **Premorbid Relationship** | **Current Relationship** | **Length of Practical Care** | **Number of Children** |
| | *r* = | *r* = | *r* = | *r* = | *r* = |
| **Care Recipient Functioning Variables** | | | | | |
| **Mini Mental State** | 0.14 | -0.30* | 0.33* | -0.08 | 0.04 |
| **Record of Independent Living** | | | | | |
| Activities | -0.04 | 0.04 | -0.18 | 0.35** | 0.07 |
| Communication | -0.26 | 0.08 | -0.33* | -0.04 | 0.09 |
| Behaviour | -0.21 | 0.17 | -0.12 | -0.09 | 0.11 |
| (apathy) | -0.19 | -0.01 | -0.21 | -0.18 | 0.45** |
| (depression) | 0.09 | 0.21 | 0.20 | -0.04 | -0.10 |
| (hostility) | -0.21 | 0.19 | -0.19 | -0.12 | -0.02 |
| (social inappropriateness) | -0.30* | -0.18 | -0.24 | 0.02 | 0.16 |
| **Objective Burden** | -0.29 | 0.04 | -0.37** | -0.12 | 0.09 |

* $p < 0.05$ **$p < 0.01$

Cognitive functioning of the care recipient, as measured on the Mini Mental State, was found to be negatively correlated with the quality of the premorbid caregiver and care recipient relationship ($r = -0.30, p < 0.05$) and positively correlated with their current relationship ($r = 0.33, p < 0.05$).

Regarding the non cognitive features of the care recipient, as measured on the Record of Independent Living, activities were strongly positively correlated with the length of practical care ($r = 0.35, p < 0.01$). Communication was found to be significantly negatively correlated with the quality of the current relationship ($r = -0.33, p < 0.05$). Apathy manifested in the care recipient was found to be highly positively correlated with the caregivers' number of children ( $r = 0.45, p = <0.01$) and social inappropriateness was negatively correlated with caregiver age ($r = -0.30, p < 0.05$), contrary to hypothesis 16.

In addition objective burden was found to be strongly negatively correlated with quality of the current caregiver and care recipient relationship ($r = -0.37, p < 0.01$), supporting a component of hypothesis 14.

**Table 21** Independent Samples T Tests for Gender, Residency, Marital and Employment Status of Caregivers and Objective Burden.

| | Objective Burden | |
|---|---|---|
| | $t =$ | d.f. |
| **Gender** | 1.04 | 52 |
| **Residency** | 1.97* | 52 |
| **Marital status** | -2.11* | 52 |
| **Employment status** | -0.31 | 52 |

*$p < 0.05$ **$p < 0.01$

No significant differences were identified between gender or the employment status of the caregiver with regards to the degree of objective burden experienced, rejecting hypothesis 12 and an aspect of hypothesis 15. However significant differences were found between those caregivers residing with their care recipient ($t = 1.97, p < 0.05$) and the marital status of the caregiver ($t = -2.11, p < 0.05$) with objective burden. Co-resident caregivers experienced more objective burden, supporting a component of hypothesis 15 and unmarried caregivers experienced more objective burden, contrary to hypothesis 15.

## Background and Contextual Factors With Mediators.

**Table 22** Correlational Results between Background and Contextual Factors and Emotion Focussed Coping Factors.

| BACKGROUND FACTORS | MEDIATORS | | | | |
|---|---|---|---|---|---|
| | Fantasy | Internalize | Angry Fixed Response | Isolation & Resignation | Externalize |
| | $r =$ | $r =$ | $r =$ | $r =$ | $r =$ |
| **Caregiver Age** | 0.24 | 0.09 | -0.15 | -0.20 | 0.07 |
| **Premorbid Relationship** | 0.06 | 0.45** | 0.02 | 0.05 | 0.13 |
| **Current Relationship** | -0.10 | -0.07 | -0.37** | -0.13 | -0.02 |
| **Length of Practical Care** | 0.18 | -0.05 | -0.15 | -0.07 | -0.02 |
| **Number of Children** | 0.07 | -0.11 | 0.22 | 0.01 | -0.02 |

$*p < 0.05$ $**p < 0.01$

Age of the caregiver, length of providing practical care and number of children were not found to be associated with any of the emotion focussed coping factors, supporting a component of hypothesis 24. However quality of the caregiver and care recipient premorbid relationship was found to be highly positively correlated with the factor 'Internalize' ($r = 0.45, p < 0.01$), supporting a component of hypothesis 20, and quality of the current relationship was found to be highly negatively correlated with the factor 'Angry Fixed Response' ($r = -0.37, p < 0.01$), in a direction opposite to that anticipated in hypothesis 20.

**Table 23** Independent T Tests for Background and Contextual Factors and Emotion Focussed Coping.

| Caregiver Variables | Fantasy | | Internalize | | Angry fixed response | | Isolation & resignation | | Externalize | |
|---|---|---|---|---|---|---|---|---|---|---|
| | *t* = | d.f. = | *t* = | d.f. = | *t* = | d.f. = | *t* = | d.f. = | *t* = | d.f. = |
| **Gender** | 0.19 | 52 | 0.65 | 52 | -0.19 | 52 | -2.35* | 43 | 0.34 | 52 |
| **Residency** | -0.06 | 52 | 2.95** | 52 | 0.37 | 52 | -0.86 | 52 | -0.20 | 52 |
| **Marital status** | 1.26 | 52 | -0.57 | 52 | -1.57 | 52 | 0.004 | 52 | 0.01 | 52 |
| **Employment status** | -1.03 | 52 | -0.42 | 52 | -0.08 | 52 | 0.24 | 52 | 0.53 | 52 |

* $p < 0.05$ ** $p < 0.01$

No significant differences were found between marital and employment status with the emotion focussed factors. However, and in support of a component of hypothesis 17 there were significant gender differences identified for the factor 'Isolation and resignation' ($t = -2.35, p < 0.05$), suggesting more women utilize this way of coping and between residency and the factor 'Internalize' ($t = 2.95, p < 0.01$), suggesting that co-resident caregivers are more likely to Internalize, supporting a component of hypothesis 17.

**Table 24** Correlational Results between Background and Contextual Factors and Problem Focussed Coping Factors.

| **BACKGROUND FACTORS** | **MEDIATORS** | | | | | |
|---|---|---|---|---|---|---|
| | **Optimism in the Future** | **Informal Help Seeking** | **Optimism in the Present** | **Mental Preparation** | **Formal Help Seeking** | **Previous Experience** |
| | *r* = | *r* = | *r* = | *r* = | *r* = | *r* = |
| **Caregiver Age** | -0.02 | 0.03 | 0.26 | 0.19 | -0.19 | -0.08 |
| **Premorbid Relationship** | 0.06 | -0.11 | 0.001 | -0.02 | -0.23 | 0.02 |
| **Current Relationship** | 0.01 | 0.21 | 0.14 | 0.08 | 0.17 | 0.15 |
| **Length of Practical Care** | 0.19 | 0.11 | 0.13 | 0.23 | 0.05 | 0.18 |
| **Number of Children** | -0.06 | -0.25 | -0.25 | -0.18 | -0.15 | -0.20 |

* $p < 0.05$ ** $p < 0.01$

None of the background and contextual factors outlined in Table 24 above were found to be significantly correlated with any of the problem focussed coping factors, contrary to a component of hypothesis 20 but supporting a component of hypothesis 24.

**Table 25** Independent T Tests for Background and Contextual Factors and Problem Focussed Coping.

| | Optimism in the future | | Informal help seeking | | Optimism in the present | | Mental preparation | | Formal help seeking | | Previous experience | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | $t =$ | d.f. = | $t =$ | d.f. = | $t =$ | d.f. = | $t =$ | d.f. = | $t =$ | d.f. = | $t =$ | d.f. = |
| **Gender** | -0.35 | 52 | 0.09 | 52 | 1.52 | 52 | 0.59 | 52 | 0.80 | 52 | 0.32 | 52 |
| **Residency** | 0.24 | 52 | -2.75** | 52 | 0.59 | 52 | -1.68 | 52 | -1.54 | 52 | -1.13 | 52 |
| **Marital status** | 0.51 | 52 | 2.86** | 52 | -0.52 | 52 | 1.98* | 52 | 0.80 | 52 | 1.13 | 52 |
| **Employment status** | -0.58 | 52 | -0.02 | 52 | -1.68 | 52 | -0.87 | 52 | -0.05 | 52 | -0.14 | 38 |

* $p < 0.05$ ** $p < 0.01$

No significant differences were identified between gender and employment status with any of the problem focussed coping strategies. However, and in support of hypothesis 18, highly significant differences were found between residency and the factor 'Informal help seeking' ($t = -2.75, p < 0.01$) and between marital status and 'Informal help seeking' ($t = 2.86, p < 0.01$), suggesting that non co-resident and married caregivers (contrary to a component of hypothesis 18) were more likely to utilize this way of coping. In addition a significant difference was found between marital status and 'Mental preparation' ($t = 1.98, p < 0.05$) such that unmarried caregivers were more likely to use 'Mental preparation' as a way of coping, again in support of hypothesis 18.

**Table 26** Correlational Results for Background and Contextual Factors and Social Support Networks and Subjective Burden.

| **BACKGROUND FACTORS** | **MEDIATORS** | | |
|---|---|---|---|
| | **Subjective Burden** | **Informal Social Support** | **Formal Social Support** |
| | *r* = | *r* = | r = |
| **Caregiver Age** | -0.19 | -0.05 | -0.18 |
| **Premorbid Relationship** | 0.17 | 0.02 | -0.03 |
| **Current Relationship** | -0.49** | -0.04 | -0.13 |
| **Length of Practical Care** | -0.07 | 0.22 | 0.17 |
| **Number of Children** | 0.17 | 0.04 | 0.17 |

* $p < 0.05$ ** $p < 0.01$

Quality of the current caregiver and care recipient relationship was found to be significantly negatively correlated with subjective burden ($r = -0.49$, $p < 0.01$), supporting a component of hypothesis 19. No other significant correlations outlined in Table 26 were identified, failing to support hypotheses 22 and 23.

**Table 27** Independent T Tests For Background and Contextual Factors With Subjective Burden and Support Networks.

| | **Subjective burden** | | **Informal social support** | | **Formal social support** | |
|---|---|---|---|---|---|---|
| | *t* = | d.f. = | *t* = | d.f. = | *t* = | d.f. = |
| **Gender** | 0.23 | 52 | -0.60 | 52 | -0.34 | 52 |
| **Residency** | 1.29 | 52 | -0.99 | 52 | 0.23 | 52 |
| **Marital status** | -0.77 | 52 | 3.18** | 52 | 0.31 | 52 |
| **Employment status** | 0.40 | 52 | -0.23 | 38 | 1.79 | 52 |

* $p < 0.05$ ** $p < 0.01$

No significant differences were found between gender, employment status and residency with either subjective burden or support networks, rejecting hypothesis 21 and a component of hypothesis 17. However, a highly significant difference was found between marital status and informal social support ($t = 3.18, p < 0.01$), suggesting that married caregivers were more likely to seek informal social support.

## Background and Contextual Factors With Outcomes.

**Table 28** Correlational Results between Background and Contextual Factors and Caregiver Outcomes.

| **BACKGROUND FACTORS** | **OUTCOMES** | | | | |
|---|---|---|---|---|---|
| | **Depression** | **Anxiety** | **Anger In** | **Anger Out** | **Satisfaction With Life** |
| | $r =$ | $r =$ | $r =$ | $r =$ | $r =$ |
| **Caregiver Age** | -0.17 | -0.17 | -0.10 | 0.04 | -0.06 |
| **Premorbid Relationship** | 0.20 | 0.04 | 0.28* | -0.15 | -0.22 |
| **Current Relationship** | -0.42** | -0.33* | -0.08 | -0.33* | 0.21 |
| **Length of Practical Care** | -0.17 | -0.09 | -0.18 | 0.02 | -0.07 |
| **Number of Children** | 0.08 | 0.01 | 0.07 | 0.09 | -0.01 |

* $p < 0.05$ ** $p < 0.01$

Caregiver age, length of practical care and number of children were not found to be significantly associated with any of the caregiver outcomes outlined in Table 28 above, rejecting hypothesis 27.

However, quality of the premorbid caregiver and care recipient relationship was found to be positively correlated with suppressed anger ($r = 0.28, p < 0.05$), but in a direction opposite to that anticipated in hypothesis 25. In addition, quality of the current relationship was found to be highly negatively correlated with caregiver depression ($r$ =-0.42, $p$ <0.01) and significantly negatively correlated with anxiety and anger out (both $r$ =-0.33 $p$ <0.05), supporting a component of hypothesis 25.

**Table 29** Independent T Tests For Background and Contextual Factors and Caregiver Outcome Variables.

| | Depression | | Anxiety | | Anger In | | Anger Out | | Satisfaction with life | |
|---|---|---|---|---|---|---|---|---|---|---|
| | $t$ = | d.f. = | $t$ = | d.f. = | $t$ = | d.f. = | $t$ = | d.f. = | $t$ = | d.f. = |
| **Gender** | -1.44 | 52 | -0.37 | 52 | -0.07 | 52 | 1.56 | 52 | 0.90 | 52 |
| **Residency** | 1.32 | 24 | -0.54 | 52 | 1.28 | 52 | 0.73 | 25 | -2.44* | 52 |
| **Marital status** | -0.74 | 52 | 0.51 | 52 | -0.90 | 52 | 0.09 | 52 | 2.23* | 52 |
| **Employment status** | 1.13 | 52 | -0.16 | 52 | 0.87 | 52 | -0.02 | 52 | 2.67** | 52 |

* $p$ <0.05 ** p <0.01

No significant differences were found between caregiver gender with the outcome variables listed in Table 29 above. However there were significant differences between residency and marital status of the caregiver with satisfaction with life ($t$ = -2.44, $p$ <0.05; $t$ = 2.23, $p$ <0.05), suggesting that non co-resident and married caregivers experienced increased satisfaction with life. In addition a highly significant difference was found between the employment status of the caregiver and satisfaction with life ($t$ = 2.67, $p$ <0.01) such that employed caregivers had increased satisfaction with life, rejecting a component of hypothesis 26.

**Table 30** Correlational Results for Background and Contextual Factors and Self Perceived Coping and Quality of Social Support.

| **BACKGROUND FACTORS** | **OUTCOMES** | |
|---|---|---|
| | **Self Perceived Coping** | **Quality of Social Support** |
| | $r =$ | $r =$ |
| **Caregiver Age** | -0.12 | 0.19 |
| **Premorbid Relationship** | 0.16 | -0.18 |
| **Current Relationship** | -0.22 | 0.36** |
| **Length of Practical Care** | -0.13 | 0.10 |
| **Number of Children** | 0.03 | -0.07 |

* $p$ <0.05 ** $p$ <0.01

The only significant correlation found in Table 30 above was between quality of the current caregiver and care recipient relationship and quality of social support ($r = 0.36, p < 0.01$), supporting a component of hypothesis 25.

**Table 31** Independent T Tests for Background and Contextual Factors and Self Perceived Coping and Quality of Social Support.

| **Caregiver Variables** | **Self Perceived Coping** | | **Quality of Social Support** | |
|---|---|---|---|---|
| | $t =$ | d.f. = | $t =$ | d.f. = |
| **Gender** | -0.22 | 52 | -0.32 | 52 |
| **Residency** | 2.02* | 52 | -2.19* | 52 |
| **Marital status** | -0.03 | 52 | 1.66 | 52 |
| **Employment status** | -0.95 | 52 | -0.24 | 52 |

* $p$ <0.05 ** $p$ <0.01

No significant differences were found between gender, marital and employment status with self perceived coping and quality of social support. However significant differences were found between residency and self perceived coping and quality of social support ($t = 2.02$, $p < 0.05$, $t = -2.19$, $p < 0.05$)., such that caregivers residing with their care recipient were more likely to perceive their ways of coping and their quality of social support more negatively, supporting a component of hypothesis 26.

Before beginning a discussion on the multiple stepwise regression, Table 32 overleaf summarizes all the variables, in the appropriate model elements, found to be significantly correlated with the outcome measures

**Table 32** Summary of the Variables Correlated With Outcome Measures (continued overleaf)

| **Outcomes** | **Demands or Objective Stressors** | *p*= | **Mediators** | *p*= | **Background & Contextual Factors** | *p*= |
|---|---|---|---|---|---|---|
| **High Depression** | Care recipient features | | Problem focussed coping | | Worse Current relationship | 0.0002 (0.01) |
| | Poor Mini Mental State | 0.02 (<0.05) | Less Informal help seeking | 0.03 (<0.05) | | |
| | Poor Communication | 0.04 (<0.05) | Less Optimism in the present | 0.01 (<0.01) | | |
| | Caregiver Variable | | Less Formal help seeking | 0.04 (<0.05) | | |
| | High Objective burden | 0.0001 (<0.01) | Emotion focussed coping | | | |
| | | | More Internalize | 0.01 (<0.01) | | |
| | | | More Angry fixed response | 0.02 (<0.05) | | |
| | | | More Isolation & resignation | 0.01(<0.01) | | |
| | | | More Subjective burden | 0.0001 (<0.01) | | |
| **High Anxiety** | Caregiver variable | | Problem focussed coping | | Worse Current relationship | 0.0003 (<0.05) |
| | High Objective burden | 0.0002 (<0.01) | Less Optimism in the present | 0.01 (<0.01) | | |
| | | | Less Previous experience | 0.02 (<0.05) | | |
| | | | Emotion focussed coping | | | |
| | | | More Angry fixed response | 0.08 (<0.05) | | |
| | | | More Isolation & resignation | 0.01 (<0.05) | | |
| | | | More Subjective burden | 0.0001 (<0.01) | | |
| **High Anger In** | Caregiver variable | | Problem focussed coping | | Better Premorbid relationship | 0.02 (<0.05) |
| | High Objective burden | 0.03 (<0.05) | Less Informal help seeking | 0.02 (<0.05) | | |
| | | | Less Previous experience | 0.04 (<0.05) | | |
| | | | Emotion focussed coping | | | |
| | | | More Internalize | 0.02 (<0.01) | | |
| | | | More Isolation & resignation | 0.01 (<0.01) | | |
| | | | More Subjective burden | 0.01 (<0.01) | | |

| Outcomes | Demands or Objective Stressors | $p=$ | Mediators | $p=$ | Background & Contextual Factors | $p=$ |
|---|---|---|---|---|---|---|
| **High Anger Out** | - | | Problem focussed coping | | Worse Current relationship | 0.01 (<0.01) |
| | | | More Previous experience | 0.04 (<0.05) | | |
| | | | Emotion focussed coping | | | |
| | | | Less Isolation & resignation | 0.01 (<0.01) | | |
| **Reduced Satisfaction With Life** | Care recipient variables | | Emotion focussed coping | | - | |
| | Poor Mini Mental State | 0.02 (<0.05) | More Internalize | 0.04 (<0.05) | | |
| | Poor Activities | 0.03 (<0.05) | More Angry fixed response | 0.02 (<0.05) | | |
| | Caregiver variables | | More Isolation & resignation | 0.02 (<0.05) | | |
| | High Objective burden | 0.0004 (<0.01) | | | | |
| | | | More Subjective burden | 0.0001 (<0.01) | | |
| **Poor Self Perceived Coping** | Care recipient variables | | Problem focussed coping | | - | |
| | More Communication | 0.03 (<0.05) | Less Formal help seeking | 0.01 (<0.05) | | |
| | Caregiver variables | | Less Previous experience | 0.03 (<0.05) | | |
| | More Objective burden | 0.0002 (<0.01) | Emotion focussed coping | | | |
| | | | More Angry fixed response | 0.02 (<0.05) | | |
| | | | More Isolation & resignation | 0.02 (<0.05) | | |
| | | | More Subjective burden | 0.0002 (<0.01) | | |
| **Poor Quality of Social Support** | Care recipient variables | | Problem focussed coping | | Worse Current relationship | 0.0007 (<0.01) |
| | More Communication | 0.02 (<0.05) | Less Optimism in the future | 0.03 (<0.05) | | |
| | More Apathy | 0.0003 (<0.01) | Less Informal help seeking | 0.02 (<0.05) | | |
| | Caregiver variables | | Less Previous experience | 0.03 (<0.05) | | |
| | More Objective burden | 0.0001 (<0.01) | Emotion focussed coping | | | |
| | | | More Angry fixed response | 0.02 (<0.05) | | |
| | | | More Isolation & resignation | 0.03 (<0.05) | | |
| | | | More Subjective burden | 0.0001 (<0.01) | | |

Table 33 overleaf shows the results of the multiple stepwise regression analyses which were performed to identify the particular demands, objective stressors or mediators which were most closely associated with caregiver outcomes. Only those variables found to be correlated with the outcome measures at a significance level of $p < 0.01$ were entered into the regression equation.

Table 33 Multiple Stepwise Linear Regression Analyses of Demands or Objective Stressors and Mediators on Caregiver Outcome Variables.

| Dependent Variable | Adjusted R Square | Independent Variable in Equation | B | S.E. | Beta | *t* | *p* |
|---|---|---|---|---|---|---|---|
| **Depression** | 0.55 | **Subjective burden** | 0.22 | 0.05 | 0.48 | 4.61 | 0.000 |
| | | **Optimism in the present** | -0.61 | 0.15 | -0.41 | -3.96 | 0.000 |
| | | **Internalize** | 0.82 | 0.27 | 0.32 | 2.99 | 0.004 |
| **Anxiety** | 0.36 | **Subjective burden** | 2.1E-02 | 0.01 | 0.50 | 4.53 | 0.000 |
| | | **Optimism in the present** | -4.1E-02 | 0.02 | -0.30 | -2.68 | 0.01 |
| **Anger in** | 0.11 | **Isolation and resignation** | 1.94 | 0.69 | 0.36 | 2.79 | 0.007 |
| **Anger Out** | 0.14 | **Isolation and resignation** | -0.23 | 0.07 | -0.39 | -3.08 | 0.003 |
| **Satisfaction with life** | 0.20 | **Objective burden** | -0.97 | 0.26 | -0.46 | -3.73 | 0.000 |
| **Quality of social support** | 0.32 | **Subjective burden** | -3.2E-02 | 0.01 | -0.44 | -3.80 | 0.000 |
| | | **Apathy** | -0.25 | 0.10 | -0.30 | -2.61 | 0.011 |
| **Self perceived coping** | 0.42 | **Subjective burden** | - 4.4E-02 | 0.01 | -0.65 | -6.21 | 0.000 |

Variables not included in the final equation for each outcome is as follows: For depression, current relationship and objective burden. For anxiety, objective burden. For anger in, subjective burden. For satisfaction with life, subjective burden. For quality of social support, current relationship and for self perceived coping, objective burden. No variables were excluded for anger out.

Those variables identified within the mediator component of the model were the only variables in the final regression equation for caregiver depression. Specifically subjective burden, the problem focussed coping factor 'Optimism in the present' and the emotion focussed coping factor 'Internalize' were strongly associated with depression. The adjusted R square was high (0.55) with 55 per cent of the variance in caregiver depression being accounted for by these three variables. Higher levels of depression were therefore associated with higher subjective burden and higher 'Internalizing' and lower 'Optimism in the present'.

Caregiver anxiety was associated with mediating variables, specifically subjective burden and the problem focussed coping factor 'Optimism in the present'. The adjusted R square was reasonable (0.36), indicating that 36 per cent of the variance in caregiver anxiety was accounted for by these two variables. Higher levels of anxiety was associated with higher subjective burden and lower 'Optimism in the present'.

The only variable entered into the regression equation for caregiver suppressed anger was 'Isolation and resignation'. The multiple R square was 0.11, suggesting that 11 per cent of the variance in caregiver suppressed anger was accounted for by this emotion focussed coping factor. Higher levels of suppressed anger were associated with greater 'Isolation and resignation'. Similarly anger directed outwards was predicted only by 'Isolation and resignation'. The adjusted R square was 0.14, suggesting that 14 per cent of the variance in anger out was accounted for by this factor. Higher anger directed outwards was therefore associated with lower levels of 'Isolation and resignation'.

Caregiver satisfaction with life was predicted by a demand or objective stressor variable; specifically objective burden. The adjusted R square was 0.20 suggesting that 20 per cent of the variance in satisfaction with life is accounted for by this demand variable. Greater satisfaction with life was associated with lower objective burden.

The mediator variable subjective burden and the demand or objective stressor variable apathy (non cognitive care recipient variable) were the only variables entered into the regression equation for quality of social support. The adjusted R square was 0.32 indicating that 32 per cent of the variance in perceived quality of social support was accounted for by these two variables. A greater perceived quality of social support was associated with increased subjective burden and higher levels of apathy manifested in the care recipient.

Caregiver self perceived coping was associated with the mediating variable subjective burden. The adjusted R square was high (0.42) accounting for 42 per cent of the variance in self perceived coping. Greater self perceived coping was associated with increased subjective burden.

# 5.0. Discussion

This study was designed to investigate the impact of a particular 'life event' namely, caring for a parent with dementia. The conceptual basis for the research is anchored within Lazarus & Folkmans' (1984), Stress, Appraisal and Coping framework, which guided the hypotheses and data analyses. Therefore, the aim of the study was concerned with investigating the correlates or mediators of caregivers' wellbeing.

Before this is considered the psychometric properties and limitations of the measure for objective and subjective burden will be discussed. This will be followed by a discussion of the main research findings within the context of previous literature. Limitations of the present study will then be addressed, followed by the clinical implications and recommendations for future research.

## 5.1. Psychometric Properties of the Screen For Caregiver Burden

The internal reliabilities of the Screen for Caregiver Burden on a British sample of adult offspring caring for their parents with dementia was considered acceptable for use in this study. The alpha reliabilities for both the objective and subjective subscales of the measure were broadly comparable to those reported by Vitaliano et al. (1991) on an American general population of spouse caregivers. The construct validity, criterion validity and sensitivity to change have all been demonstrated elsewhere (Vitaliano et al., 1989a, 1991).

The limitations of the Screen for Caregiver Burden include the lack of subscales for various burden dimensions and the inclusion of subjective statements in the objective burden score. For example, although the Screen for Caregiver Burden provides separate measures of objective and subjective burden, several of the actual items involve appraisals ("I am upset that .....", "It is exhausting ....."), so even objective scores involve subjectivity. This problem exists because both caregiver and care recipient centred items are represented and the caregiver centred experiences tend to be more subjective than the care recipient experiences. This observation is consistent with the slightly depressed mean inter item correlation coefficient for objective burden and the particularly high correlation coefficient between objective and subjective burden.

The fact that the self reported objective burden scale involves subjectivity suggests that the use of the label objective burden may not be appropriate. To be consistent with the burden literature thus far the labels objective and subjective burden were applied. However a more accurate set of labels would be 'prevalence of experiences' for objective burden and for subjective burden 'appraisal of distress from experiences'. Such labels more closely parallel components of the Stress, Coping and Appraisal framework of Lazarus & Folkman, (1984).

However, the objective and subjective scales do appear to reflect objective and subjective burden by virtue of their respective associations with care recipient and caregiver variables. This study has therefore found that it is possible to use the Screen for Caregiver Burden on a British sample of adult children caring for their parent with dementia.

## 5.2. The Sample

### 5.2.1. *Caregivers*

The majority of caregivers were British, white and female, which is consistent with much past research (Donaldson et al., 1997).

The fact that more daughters than sons act as primary caregivers has to do in part with the socioeconomic position of women and a socialisation process that has lasted for centuries. The fact that traditional caring roles are changing may indicate that when women of the current younger generation, who are more used to independence, are faced with the possibility of caring for a parent with dementia things may be different from past generations.

Over half of the caregivers were employed and half were married. Jones & Peter (1992) report that offspring carers seem to suffer hardship in caring because they experience the demands of caregiving as an imposition on their lifestyle. With regards to juggling the competing demands of female caregivers, Brody (1981) coined the phrase "Women in the middle".

Interestingly, the use of problem focussed coping strategies as a main coping strategy was associated, in the present study, with better coping as perceived by the caregiver. This finding is consistent with previous research (Seltzer et al., 1995). Although the research literature might emphasise the negative aspects of caring in relation to caregivers' health and wellbeing, the majority of caregivers in the present sample felt that they were coping well with the stress of caring. Supporters who cannot cope with their parent with dementia may seek ways in which to disengage from the caregiving role, by allowing formal services to take over the main burden of caring, or by seeking a residential placement for their parent. This latter group of 'poorer' copers would not have been selected for the study if their parent was no longer living in the community.

There has been little research to determine what individuals believe to be 'good' coping. It may be that both lay and professional persons are biassed towards equating problem focussed coping with 'good' coping and emotion focussed coping as 'bad' coping. However, Lazarus (1993) points out that coping should be judged on its adaptiveness and success rather than its overt functional characteristics.

### *5.2.2.Care Recipients*

The most common diagnosis associated with the care recipients' impairments was Alzheimers disease, which implies that the sample used in this study was reflective of the general population (Burns et al., 1995). The extent of cognitive and behavioural impairment manifested in the care recipient sample indicates that there was a fairly extensive degree of impairment. In a few cases the duration of the disorders was as long as 15 years.

Therefore the problems resulting from dementia faced by the caregivers covered a wide range of severity and duration.

## 5.3. Comparisons With Vitaliano et al. (1992) Study.

Age differences are one of a number of potentially important differences between adult child and spouse caregivers (Noelker & Wallace, 1985). According to Cantor (1983) burden varies with the nature of the relationship between the caregiver and care recipient. It was therefore envisaged that by drawing comparisons with Vitaliano et al.'s (1992) study, and examining the links between both subjective and objective burden and caregiver outcomes, interesting comparisons could be made between marital dyads and children acting as caregivers for their parents.

Although results of the present study were broadly comparable with those found in Vitaliano et al.'s study, the correlations for both objective and subjective burden with the caregiver outcomes, depression and satisfaction with life, were stronger for spouse caregivers. Generally speaking, spouses of people with dementia are from an older adult population. These results could therefore be explained in that old age is a time when many roles are lost due to retirement, restrictions imposed by health problems and the like (Mace & Rabins, 1981). Therefore, the addition of the caregiving role during a period of loss may account, at least in part, for the stronger patterns of poor psychological wellbeing observed in spouse caregivers. An additional explanation could stem from differences in pattern of co-residence. Therefore, it is possible that the distinct patterns observed are due, in part, to differences in their residential arrangements.

Unlike the study by Vitaliano et al. (1991), the present study did not find stronger relationships between caregiver anxiety or depression with subjective burden suggesting that both the prevalence of caregiver experiences (objective burden) and their subsequent appraisal (subjective burden) exert direct and powerful influences on caregiver outcomes.

However, correlations between objective burden and anxiety and suppressed anger were stronger in the present study (adult offspring caregivers). This finding is of particular interest since offspring caregivers are more likely to engage in a greater number of roles compared with spouse caregivers (such as employment, caring for their own family) and so may experience greater anxiety and suppressed anger because of the competing role demands.

A peripheral aim of the study was to correlate objective burden with both care recipient cognitive and non cognitive features. With the exception of behaviour and depression, objective burden was strongly associated with the remaining care recipient features thereby substantiating the validity of the measure of objective burden.

Before embarking on a discussion of the hypothesised paths relating to the main model elements there is a need to highlight the cross sectional nature of this data set which means that the direction and causality of the relationships cannot be presumed. While causal priority may sometimes be assigned from a temporal perspective, the present model is an intrapersonal model and makes no firm assertions about causality.

## 5.4. Demands and Objective Stressors and Mediators.

Before discussing the main findings it seems important to note that the absence of significant correlations between certain variables is almost as important as those variables which are associated. Such findings will therefore be discussed in relation to previous research studies.

Surprisingly, there were no significant associations between care recipient cognitive functioning and either emotion or problem focussed coping (contrary to hypothesis 1). This finding, however, appears to be supported by previous studies which, generally, have failed to find significant relationships between care recipient cognitive abilities and caregiver variables (Farran et al., 1993; Zarit et al., 1980). This finding could imply that the relationship between care recipient cognitive functioning and coping styles may not actually be linear. Caring for care recipients with very mild cognitive impairment may require less supervision and those with severe cognitive impairment may reach an almost vegetative state requiring only basic nursing care. It is those patients with a moderate degree of dementia that are most likely to exhibit more problematic behaviour and therefore require constant supervision. This suggestion may therefore explain why the correlational design used in this study, using a single measure for severity of cognitive impairment, failed to find a significant relationship with coping.

However, in support of a component of hypothesis 1, care recipient cognitive functioning was found to be significantly associated with subjective burden. One would not expect cognitive functioning to have much of an impact on the physical care tasks (objective burden). The finding that such care recipient features are linked to caregiver appraisals (subjective burden) appears plausible. Such appraisals would be linked to carer expectations or the emotional strain of caring for someone who is seen as becoming less fully human.

Regarding care recipient non cognitive impairment, significant correlations were found mainly with the emotion focussed coping factors, supporting a component of hypothesis 2. In light of this finding this suggests that caregivers view the non cognitive care recipient features as more taxing of their resources (Lazarus & Folkman, 1984). This finding is consistent with previous research studies (O'Connor et al., 1990, Donaldson et al., 1998) that found care recipient non cognitive features to be the most burdensome for carers. The significant non cognitive associations, behaviour problems, apathy, hostility and social inappropriateness, are particularly informative as each of these features of dementia are less likely to be perceived by family caregivers and society at large as products of the care recipients illness. In turn such symptoms may therefore be seen as unexplainable and uncontrollable and thus appraised as a threat.

In support of an aspect of hypothesis 3, objective burden was found to be strongly associated with certain emotion focussed coping strategies, such that the more objective burden experienced, the more likely caregivers were to 'Internalize', have an 'Angry fixed response' and 'Isolate and resign' themselves. As dementia may be appraised by the caregiver as an unmodifiable problem, employing emotion focussed coping strategies might be thought to be adaptive (Coyne et al., 1981).

The hypotheses (1&2) that care recipient functioning variables (both cognitive and non cognitive) would be correlated with both formal and informal social support was not supported by the analyses. This would seem to confirm previous studies finding little evidence for any associations (Levesque et al., 1995) (see discussion of findings in Mediators and Outcomes section).

The finding that objective burden was associated with informal social support is consistent with a component of hypothesis 3, but in a direction opposite to that anticipated. This suggests that the more objective burden experienced by caregivers, the more likely carers were to share their caring responsibilities with others. This finding is surprising since previous research, which has looked at both offspring and spouse caregivers, has found that, on the whole, only one caregiver takes responsibility (Parker, 1997). This finding could be explained in that such carers may have experienced such high levels of burden that their families and or friends responded by giving them additional support.

## 5.5 Demands and Outcomes.

Of all the caregiver outcomes, care recipient cognitive functioning was only found to be associated with caregiver depression and satisfaction with life (supporting a component of hypothesis 4). The more cognitively impaired the care recipient, the more likely caregivers were to experience symptoms of depression and reduced satisfaction with life. This finding seems to confirm findings of previous studies (Farran et al., 1993, Donaldson et al., 1997). However, the absence of more correlations (rejecting components of hypothesis 4) again supports the view of a possible inverted U shaped function of cognitive impairment with caregiver variables.

Regarding associations between the non cognitive care recipient features and caregiver outcomes, limitations in activities of daily living was only found to be associated with satisfaction with life (supporting a component of hypothesis 5), such that the more impairment within this domain of function the more likely caregivers were to experience reduced satisfaction with life. This finding could be explained in that limitations of activities of daily living are more likely to prevent caregivers from participating in enjoyable activities rather than increasing anxiety and depression levels. Although the evidence in this study did not support a relationship between activities of daily living limitations and other caregiver outcomes, previous studies have found many carers to experience extreme difficulties and subsequently poorer wellbeing with tasks, relating to activities of daily living, such as feeding (Argyle et al., 1985). The absence of more correlations argues in favour of a more differentiated approach to the measurement of activities of daily living. The lack of associations in the present study may be because all the symptoms were grouped together and their collective rather than individual impacts were assessed.

The remaining non cognitive features found to be associated with caregiver outcomes included communication (supporting a component of hypothesis 5) which was positively correlated with depression. Loss of communication implies a loss of intimacy and reciprocity within the caregiver and care recipient relationship which could make the caregiver more prone to depression. In a similar vein, a reduced ability to communicate was also found to be associated with the caregiver perceiving their way of coping poorly. Perhaps this association was found because caregivers were not receiving any recognition for their efforts and therefore evaluated their coping pessimistically.

In a similar vein a reduced ability to communicate and apathy manifested in the care recipient were found to be related to caregivers perceiving their quality of social support (both informal and formal) negatively, supporting a component of hypothesis 5. These findings could be explained in that deficits of behaviour, such as apathy and reduced ability to communicate, are rarely, if at all addressed by service providers or informal networks and therefore caregivers are more likely to perceive their quality of social support negatively.

Overall, the relationships between non cognitive features and caregiver outcomes was not as compelling as that found in previous research studies (Deimling & Bass, 1986, Donaldson et al., 1997, 1998). Such contradictory findings could be explained in terms of the limitations of correlational tests or the lack of statistical power in the present project's smaller scale investigation. Further research is required to enable the nature of this relationship to be determined conclusively.

In contrast, however the data provided considerable support for hypothesis 6. With the exception of anger directed outwards, objective burden was found to be significantly associated with all the caregiver outcomes. The frequency of high correlations seems to be inconsistent with the few correlations found with the other demand or objective stressor model elements of cognitive and non cognitive features. Perhaps this finding could be explained because of already mentioned subjective statements within the objective domain.

## 5.6. Mediators and Outcomes.

Previous research has generally accepted that problem focussed coping strategies are associated with better caregiver outcomes (Seltzer et al., 1995). The findings from this study clearly support this view and hypothesis 7. Problem focussed coping strategies were associated with reduced depression, anxiety, suppressed anger, and allowed caregivers to perceive their coping and quality of social support more positively. This finding could be explained in that problem focussed coping usually involves proactive attempts by the caregiver to deal with their burden by acting on their environment or the self and therefore positive outcomes are more likely to ensue.

On the other hand, it has been well documented that emotion focussed coping strategies are associated with more negative caregiver outcomes (Vitaliano et al., 1991). This was supported in the present study (hypothesis 8), depression, anxiety, suppressed anger, satisfaction with life, self perceived coping and quality of social support were all found to be negatively affected. It could be speculated that this is because emotion focussed coping factors do little to offer the caregiver a sense of release or control within the caring context. As Lazarus & Folkman's (1984) model suggests; emotion focussed coping does not deal with the source of stress and therefore levels of stress remain high.

Regarding anger out and coping factors, significant associations were found but in a direction opposite to that anticipated in hypotheses 7 and 8. The use of problem focussed coping was associated with a greater likelihood of increased anger out and vice versa for emotion focussed coping. Looking more closely at the significant associations, the reasons for this disparity become clearer. Use of the emotion focussed coping strategy 'Isolation and resignation' indicated a decreased likelihood of anger out which would seem to make sense. However, those caregivers with a 'Previous experience' of caregiving were more likely to direct their anger outwards. This finding could be explained in that if you assume a certain level of caregiver anger, emotion focussed coping strategies are likely to lead to anger suppression; whereas problem focussed coping strategies allow the outward expression of that anger.

In support of hypothesis 11, with the exception of anger directed outwards, subjective burden was found to be associated with all the caregiver outcomes. The fact that both objective and subjective burden were directly associated with caregiver outcomes lends no support to the suggestion by Hadjistarropoulous et al. (1994) that subjective burden would be more directly related to caregiver outcomes than objective burden. Results of the study suggest that both objective and subjective burden exert direct and powerful influences on caregiver outcomes.

Regarding informal and formal social support (hypotheses 9 and 10), less encouraging findings emerged. With the exception of satisfaction with life which was significantly related to informal social support, no significant associations between informal support networks were found with any of the caregiver outcomes. This finding is contrary to research by Shanas (1979) and Johnson (1983), both of whom suggested that informal social support was the most important source of assistance to carers.

An explanation for this finding could be the way in which both formal and informal support networks were measured in the present study. The forced choice response format for informal social support could be criticised as not adequately measuring informal social support either in terms of frequency or quality.

However, the lack of any association with formal social support is a finding in agreement with past studies (Gilhooly, 1990). A possible explanation for such findings could lie in the design of the study. Since this study (and most other studies) used a correlational procedure, the lack of association could be explained in that the independent variable (formal social support) did not vary significantly to produce a significant relationship. Service provision tends to be relatively uniform. If service provision does not vary then a significant result will not be produced. In addition to the possibility of a statistical artefact the apparent ineffectiveness of formal services in addressing the needs of carers may lie in the way in which such services are operationalised and the problems targeted. It may be that services are targeted towards those caregivers in the worst situations. Services that appropriately aid adaptation for carers need to address the factors that compound the experience of stress. Perhaps future research could examine the role of both informal and formal support services more closely by examining the quality and usefulness of each individual support network.

## 5.7 Background and Contextual Factors and Demands or Objective Stressors.

Although it was hypothesised (hypothesis 16) that there would be no significant correlations between these two model elements, some interesting findings emerged. Care recipient cognitive functioning was found to be significantly correlated with quality of the caregiver and care recipient premorbid and current relationships, such that reduced cognitive abilities were associated with a better premorbid relationship. This finding should be treated with caution since caregivers will undoubtedly experience problems in assessing the quality of a previous relationship in the light of current difficulties. The finding that reduced cognitive abilities were associated with a poorer current relationship appears plausible due to the disruption of bonds of affection and reciprocity that are vital in maintaining interpersonal relationships. In addition, impairment in cognitive functioning could erode the care recipients' personality, which in turn could damage interpersonal relationships irreparably. As Cummings & Benson (1983) stated 'it seems as if the true self dies long before the bodies death and in the intervening years, a smudged caricature disintegrates noisily and without dignity into chaos'.

Regarding care recipient non cognitive features, an informative finding emerged in that a improved ability to communicate was associated with a reduced perception of the current caregiver care recipient relationship. This finding should be treated with caution since an ability to communicate does not necessarily imply an ability to communicate articulately . Since dementia is characterised by disorientation in time, person and place, this finding could be explained in that the loss of an ability to communicate, as one used to, is bound to affect interpersonal relationships, resulting in caregivers perceiving their current relationship more negatively.

An aspect of hypothesis 14 was supported; specifically quality of the current relationship was found to be negatively correlated with objective burden, such that the more objective burden experienced the poorer the current relationship. Again this finding appears plausible since caregivers are less likely to perceive their current relationship positively when they are immersed in their caregiving duties.

Apathy was found to be strongly associated with the caregiver's number of children. This finding is a little unclear but could be explained in that ratings of non cognitive features including apathy relied on the caregiver's assessment. Perhaps therefore those caregivers with a greater number of children rated their care recipient as being more apathetic and less responsive in order to justify the caregivers increased involvement with their own family.

Danis & Silverstone (1981) draw attention to the stresses involved in living with a care recipient, pointing out that there is no one else to buffer the impact of caring between caregiver and care recipient. This suggestion is supported by the present project's finding that co-resident caregivers experience more objective burden compared with non co-resident supporters. The hypothesis that married caregivers would experience increased objective burden was not supported by the analyses, rather single caregivers were found to experience increased objective burden, possibly because they have no one else to share the burden with.

There were no gender differences for objective burden, therefore failing to support hypothesis 13 and other research findings (Seltzer &Wailing, 1996). Perhaps this finding could be explained by the fact that younger caregivers are more likely to be healthier and therefore more able to cope with the objective burdens of caring.

### 5.8 Background and Contextual Factors and Mediators.

A number of interesting findings emerged from these model elements. A poor premorbid relationship was found to be significantly associated with the emotion focussed coping strategy 'Internalize', supporting a component of hypothesis 20. One explanation for this finding is that caring in such circumstances may exacerbate old resentments and hostility which are then internalized and subsequently pose a threat on the caregivers' own wellbeing.

In support of hypothesis 20, but in a direction opposite to that anticipated, a poor current relationship suggested an increased use of the emotion focussed strategy 'Angry fixed response'. This finding could be explained in that such individuals would be more likely to experience frustration and anger as a result of the caregiver and care recipient relationship becoming increasingly non equal and unrewarding.

Female caregivers scored higher than male supporters on the emotion focussed factor 'Isolation and resignation'. It is a fairly consistent finding that female caregivers report themselves as coping less well compared with male caregivers (Gilhooly et al., 1994) and may 'resign' themselves to the caregiving role due to the pressures of social norms (Orbell, 1996).

The emotion focussed coping factor 'Internalize' was found to be more common in co-resident supporters, supporting a component of hypothesis 17. Since living with a care recipient restricts the kind of coping strategies that can be adopted, this finding appears plausible. Living with problems on a 24 hour basis might lead to the adoption of the strategy 'Internalising' as there is little opportunity to pass the responsibility for supporting the care recipient on to others. The carer may therefore be 'stuck' in the caregiving role and, as such, internalizing may be one of the few coping strategies available.

The finding that non co-resident supporters were more likely to utilize the problem focussed coping strategy 'Informal help seeking' (supporting a component of hypothesis 18) suggests that such caregivers perceive their situation as more of a challenge (cf. threat). This appears logical since non co-resident supporters are less likely to feel entrenched by the tasks of caregiving, allowing them to utilize external sources of assistance. Also, given the findings discussed earlier, caregivers may have shared responsibilities which would also be highlighted in 'Informal help seeking'.

Unmarried caregivers were found to be more likely to utilize the problem focussed coping strategy of 'Mental preparation'. This suggests that such a cohort of caregivers are able to mentally prepare for the fate of their parent because they do not have to divide their loyalties between spouses or partners.

In addition, married caregivers were more likely to utilize the problem focussed coping factor 'Informal help seeking' and make use of informal social support networks, contrary to a component of hypothesis 17. This may indicate that married caregivers, because of the presence of a confidante, are able to utilize this coping strategy and resource provision more readily.

The finding that non co-resident caregivers utilized 'Informal help seeking' more than co-resident caregivers supports a component of hypothesis 18 and could be explained in that non co-resident caregivers are more able to 'escape' from the caregiving situation and seek informal help.

The importance of the current relationship was highlighted further when a highly significant association was found with subjective burden, supporting a component of hypothesis 19, such that a poor current relationship suggested an increased likelihood of more subjective burden. This finding appears plausible since such caregivers are more likely to appraise their caregiving duties negatively and therefore a negative caregiver and care recipient relationship is more likely to result possibly because of resentments. This supports findings by Gilhooly et al. (1994) stating that the quality of the current relationship is a crucial variable when investigating burden in caregiver samples.

However the quality of the premorbid relationship was not found to be associated with subjective burden, contrary to a component of hypothesis 19 and failing to support previous findings by Gilhooly (1986) and Morris et al. (1988). This finding suggests that the quality of the current relationship is a more important variable than the premorbid relationship.

Interestingly, neither the premobid nor the current relationship were found to be associated with informal or formal social support, contrary to hypothesis 19.

The hypothesis (hypothesis 17) that co-resident caregivers, married and employed caregivers would experience greater subjective burden was not supported. Perhaps the married and employed caregivers use either their employment or partners to buffer the play of emotions between caregiver and care recipient, and are thus able to reduce the amount of subjective burden experienced. As for the co-resident caregivers not experiencing increased subjective burden, reasons for this are unclear.

Results failed to support hypotheses 21-23; female caregivers, the length of practical care and caregiver age were not found to be associated with increased subjective burden.

### 5.9. Background and Contextual Factors and Outcomes.

In partial support of hypothesis 25, a reduced perceived quality of the current relationship was associated with higher caregiver depression, anxiety and anger directed outwards. Again this supports findings by Gilhooly et al. (1994). Caregivers may become angry and resentful toward their care recipient because they are not fulfilling their obligations as care recipient due to the increasingly nonequal relationship.

However, it was also noted that a poor current relationship results in caregivers perceiving their quality of social support more negatively. This seems logical since formal services and informal support networks would be unlikely to be able to address specific concerns of caregivers such as a poor relationship.

The present data provided little support for the remaining components within hypothesis 25. The only caregiver outcome found to be related to the premorbid relationship was suppressed anger such that a positive premorbid relationship implied a greater likelihood of caregivers suppressing their anger. This finding appears to make sense; such caregivers are more likely to feel guilty for their angry feelings, and in an attempt not to manifest them, will suppress them.

There was negligible support for hypothesis 26. Co-resident caregivers were found to experience reduced satisfaction with life and were more likely to evaluate their coping and quality of social support negatively. This supports previous findings by Yeatman et al. (1993). This is a plausible finding since caregivers when residing with their care recipient are less able to avoid the stresses associated with caring resulting in a reduced satisfaction with life. The finding that caregivers perceived their coping negatively could be explained by the probable lack of recognition for their efforts by their care recipient and others sharing the care. As Hirsfield (1981) stated, the critical component of caregiver distress lies within the 'loss of mutuality'; that is, a breakdown in the existing relationship with the care recipient. Furthermore, those caregivers living with their care recipient were more likely to experience a reduced quality of social support. This finding could be explained in that services usually give priority to older adults living alone, which may partially account for this finding.

Married caregivers were found to experience increased satisfaction with life, failing to support a component of hypothesis 26. This finding could be explained in that married caregivers are possibly more able to 'switch off' from the demands of caregiving because of the presence of a confidante and are therefore more able to enjoy life.

In contrast to previous studies, Seltzer & Wailing (1996), there were sparse correlations with length of practical care, failing to support hypothesis 27. Again this finding may reflect the unsuitability of a correlational design to a data set that did not vary sufficiently to allow significant correlations to be identified.

It has been well acknowledged that co-resident supporters have slightly lower morale and poorer mental health when compared with non co-resident supporters (Yeatman et al., 1993). The finding that those caregivers not residing with their care recipient were more likely to experience increased satisfaction with life is plausible since such caregivers may be able to 'avoid' the problems associated with caregiving when they return to their own homes.

Hong & Seltzer (1995) suggested that those caregivers holding multiple roles tended to experience more favourable wellbeing. The finding in the present study of employed caregivers experiencing an improved satisfaction with life, does not support hypothesis 26, but supports this previous finding and suggests that such caregivers can 'escape' from the burdens of caring through employment.

## 5.10. The Adapted Stress, Appraisal and Coping Framework.

It seems important to begin this section by noting the limitations of multiple regressions. In particular, it is quite impossible to attribute variance in the dependent variables (outcomes) unequivocally to any one independent variable. Nonetheless multiple stepwise regressions were applied to the data. In particular the focus was on caregiver outcomes, since these are potentially treatable entities and are therefore subject to therapeutic change.

Those variables identified within the mediator model element were the only variables in the final regression equation for caregiver depression; specifically subjective burden, the problem focussed coping factor 'Optimism in the present' and the emotion focussed coping factor 'Internalize'. Findings suggest that those caregivers experiencing increased subjective burden and using internalizing as a way of coping were at risk of experiencing increased levels of depression. However, those caregivers using 'Optimism in the present' as a way of coping were at a reduced risk of experiencing depression.

Caregiver anxiety was again associated with mediating variables, namely subjective burden and the problem focussed coping factor 'Optimism in the present'. Again those caregivers experiencing increased subjective burden were at risk of experiencing anxiety and those caregivers practising 'Optimism in the present' were more likely to be at a reduced risk of experiencing anxiety.

The emotion focussed coping factor 'Isolation and resignation' was associated with both types of anger expression in caregivers. Regarding suppressed anger, the more a caregiver used this factor as a way of coping the more likely they were to suppress their anger. With respect to anger directed outwards, those caregivers not using this factor as a way of coping would be more likely to direct their anger outwards.

Caregiver satisfaction with life was associated with the demand or objective stressor variable objective burden. Findings suggested that increased objective burden would result in a reduced satisfaction with life.

In summary the results of the regression analyses highlight the importance of mediating variables, and to a much lesser degree demands or objective stressors, in buffering the impact of caregiving.

Figure 3 will be used to summarize the main themes of the study.

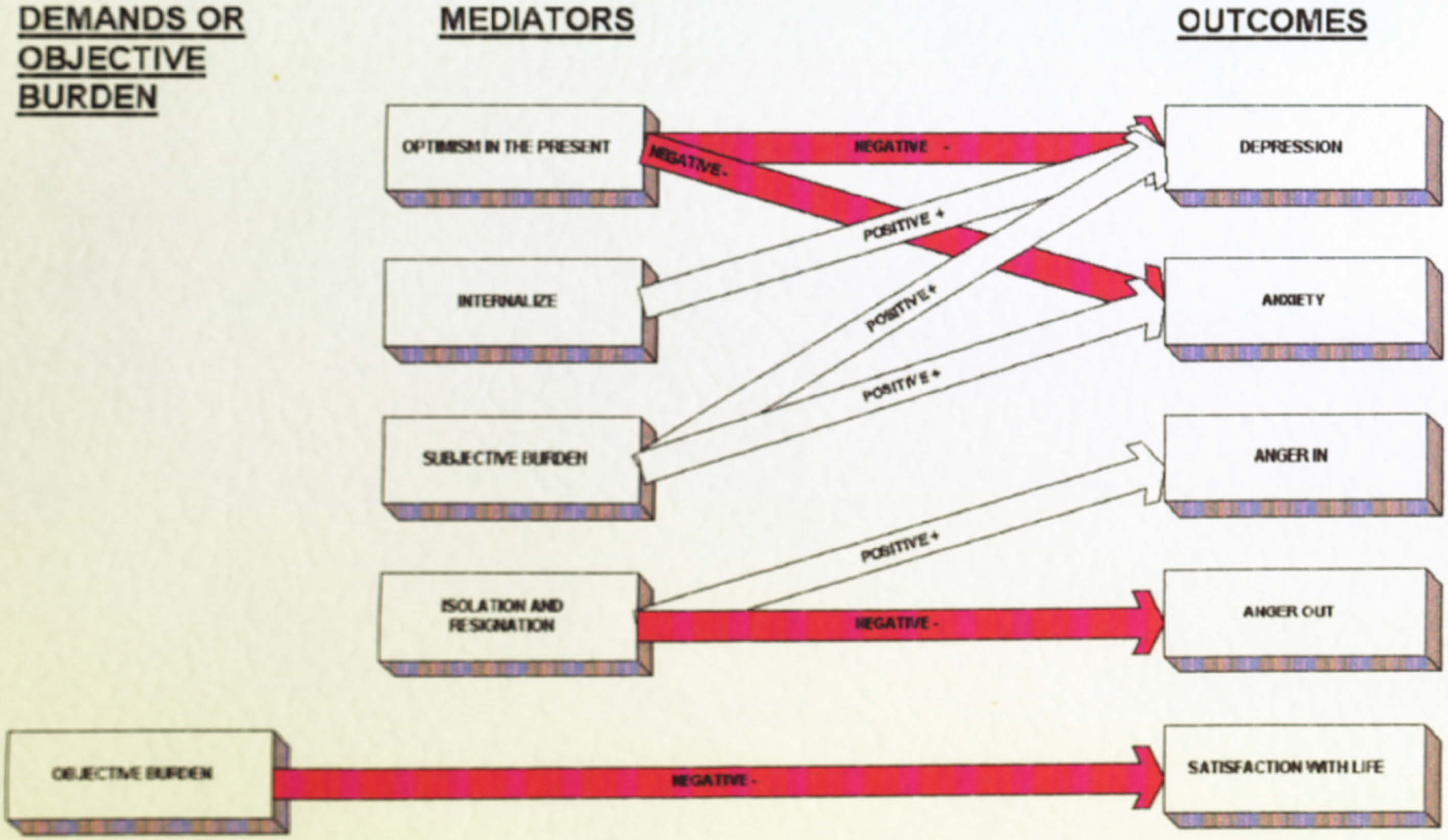
- Mediators generally seem to be more strongly linked to outcomes than objective stressors. This highlights the importance of the Stress, Appraisal and Coping model (Lazarus & Folkman, 1984) in understanding and treating caregiver wellbeing.

- Different types of variables are linked to positive outcomes (e.g. satisfaction with life) versus negative outcomes (e.g. depression and anxiety). Questions therefore arise as to which types of interventions will affect which caregiver outcomes. For example, it would appear that reducing objective burden will not have much of an impact on reducing depression.

- More attention needs to be paid to anger. Clearly 'Isolation and resignation' is the coping strategy by which anger is suppressed, or given an outlet. Current research views anger (either in or out) as always negative. Perhaps some degree of anger is inevitable; maybe interventions should attempt to address harnessing that anger to positive and problem solving ends rather than trying to eliminate it.

- There were close links in mediators linked to depression and anxiety (subjective burden and 'Optimism in the present'). Clearly, subjective burden is central and interventions may need to start focussing on caregiver appraisals and emotions rather than just providing practical support. The role of 'Optimism in the present' is interesting, while seeming to be protective, services should address this given that optimism may be misplaced in this group. Although 'Optimism in the present' is positive in orientation it is in fact emotion focussed. In addition 'Internalizing' seems to distinguish anxiety from depression.

**Figure 3** Diagrammatic Representation of Results of the Multiple Stepwise Linear Regressions



## 5.11. Methodological Limitations.

Some study limitations have been addressed earlier, and more are considered below:-

☐ Generalization of these results must be treated with caution, as they are limited by the representativeness of the sample and the measures used. The carers had all been selected for the research by a variety of professionals and had agreed to participate, and were therefore not a random sample. The findings cannot therefore be generalized to rural older adults and caregivers who are members of non traditional family groups.

☐ The cross sectional design of this study does not answer the directional nature of relationships between the main model elements. Time ordered data are necessary to disentangle the directionality of the relationships.

☐ The conceptual framework shows the objective and subjective burden of a primary caregiver at a particular moment in time; specifically when the interviews were being held. What this framework does not show is the change in burden experienced by the primary caregiver over time. Stress and burden are likely to change over time as the requirements of caregiving change. In this sense this is a static and not a process model.

☐ Caregivers were not asked to report what could be considered high levels of burden. All of the caregivers had decided, at least for the present, not to institutionalize their parent with dementia. They may therefore not be representative of all families caring for individuals with dementia.

☐ Despite marginal evidence of associations between non cognitive features and coping strategies, it should not be forgotten that such non cognitive impairments were rated by caregivers. Attempts must therefore be made to determine whether more objective ratings of non cognitive features would be as closely related to mediators as caregiver appraisals of these behaviours. Subjective ratings of patient behaviour are unlikely to be independent of caregivers' feelings of strain and thus may be conceptually closer and show stronger correlations with caregiving variables, than more objective measurements of these symptoms (Eagles et al., 1987). In order to limit this opportunity for confounding, future research must look at alternative methods of assessing non cognitive features. Scales that are rated with the assistance of an interviewer and contain objectively stated items relevant to specific areas of impairment may minimize reporting bias and provide more reliable estimates of functioning.

☐ It must be noted that a rich source for understanding the complexities and ambiguities of caring fully emerged only from conversations during the interview sessions rather than responses to the questionnaires. It could therefore be argued that the quantitative nature of this study did not allow for more detailed analysis of qualitative information.

☐ Comments provided by suitable participants indicated that some carers felt unable to take part in the study because they were too distressed or overworked. This suggests that the relationships found in the present project might not apply to caregivers in extreme circumstances or in real crisis. However the inclusion of such caregivers may have ensued greater variation in scores.

Given these limitations it is important that these findings are viewed as a beginning step in understanding the experience of carers, and that they be replicated and extended in longitudinal investigations using more representative samples.

## 5.12. Clinical Implications.

It is hoped that with the help of information gathered in this study the effectiveness of professional care rendered to primary caregivers of parents with dementia can be improved. Specifically, it is necessary that professional caregivers can make a correct estimate of the degree of the subjective burden of the primary caregivers. Hopefully professionals will recognise that the primary caregiver possesses valuable information which is not only supplementary to the information gathered by professionals, but necessary and indispensable. Only with such information can a true estimate of the burden of primary caregivers be estimated.

Findings suggest that both the cognitive and non cognitive features of the older adult should be included in any study of caregiver burden. Although non cognitive care recipient features are the best targets for pharmacological therapies, such treatments have only modest efficacy (Schneider & Subin, 1994). Thus, the significant potential for intervention may lie with supporters. Carers are vital to the success of Community Care. Therefore if older adults with dementia are to continue to be cared for at home, it seems likely that some priority will have to be allocated to the alleviation of burden in their carers and the problems producing it. Interventions designed to prevent or reduce burden in carers are a critical element in continued dementia care in the community (Lieberman & Kramer, 1991).

The rhetoric of Community Care, at least in Britain, is about delaying and preventing institutionalization. It is believed to be beneficial for older adults to stay at home surrounded by caring friends and relatives (Alzheimers Disease Society, 1994). The outcomes examined in the present study reveal potentially treatable problems and therefore some priority should be given to this, enabling the older adult to remain at home.

Of relevance to clinical work there seems to be a research pattern emerging in terms of emotion focussed coping strategies being positively associated with levels of burden and other caregiver outcomes. Thus interventions that aim to minimize the avoidance aspects of coping, whilst utilizing their relief and recuperation value and which advise, facilitate and encourage tactile coping responses, may be more influential in minimizing carer stress and be worthy of evaluation.

Family interventions of any kind incur significant costs and clinicians need to know far more about which kinds of people are helped by which kind of approach. There is a need to highlight the individual, complex, multiple and changing needs of service users and their carers and the importance of comprehensive, sensitive, flexible and reliable support from health and social welfare agencies. This calls for more flexible domiciliary care, both to meet the needs of isolated and confused older adults (Alzheimers Disease Society, 1994), and to fit in with the needs and working hours of carers (Philp et al., 1995). In addition, the help needed is great and cannot be fully met by one professional or branch of services, indicating the importance of a multidisciplinary focus on all the clients' needs.

## 5.13. Recommendations For Future Research

The often commented upon increase in the number of older adults (Burns et al., 1995), those at most risk of getting dementia, makes it imperative that research focuses on the impact of providing care to relatives. Certainly when researching specific aspects of the caregiving situation, such as the framing and coping styles of caregivers, a richer source of information could be yielded by applying a qualitative methodology.

Continued research is needed into the overlap between key variables identified in this study and in other similar studies in order to optimize the quality of support offered to care recipients with dementia and their relatives while they continue to live together in the community. There may have been other events besides caregiving in the caregivers' lives which may well have influenced wellbeing and it is hoped that these can be examined in other projects.

Future research might focus on the value of advising carers against emotion focussed coping strategies alone, as they may constitute an unhelpful avoidance response to the caring situation, that needs to be addressed

In addition, there should be a more comprehensive examination of the costs of caring based upon geographically and socially representative samples of carers across all the various stages in their caregiving careers. Such information informs health care policy makers, purchasers and providers about the economic and human resource implications of dementia as a significant public health issue that every region and district must address. It requires a multidisciplinary approach to determining costs and a multicentre framework which can target whole populations rather than particular service using subsets of the older adult population with dementia.

Although this study is concerned only with those caregivers who have come into contact with services, it is hoped that the results will add to the growing body of knowledge about

Community Care of impaired older adults and will go some way to promoting a better quality of life for both caregivers and care recipients.

# References

Alzheimers Disease Society. (1994). Home Alone: Living Alone With Dementia. London: Alzheimers Disease Society.

Aneshensel, C., Pearlin, I., Mullan, J.T., Zarit, S.H. & Whitlach, C.J. (1995). Profiles of Caregiving. The Unexpected Career. New York: Academic Press.

Argyle, N., Jestice, S. & Brook, C.B.P. (1985). Psychogeriatric patients. Their supporters problems. Age and Ageing, 14, 355 - 360.

Ballard, C.G., Saad, K., Coupe, B., Graham, C., Gabir, M., Wilcock, G.K. & Oyebode, F. (1995). The aetiology of depression in the carers of dementia sufferers. Journal of Affective Disorders, 35, 59 - 63.

Baumgarten, M., Infante-Rivard, C., Hanley, J.A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia. Journal of Clinical Epidemiology, 45(1), 61 - 70.

Beck, A.T. & Beck, R.W. (1972). Screening for depressed patients in family practice. A rapid technique. Postgraduate Medicine, 52, 81 - 85.

Beck, A.T., Ward, C.H., Henderson, M., Lock, J.G. & Erbaugh, J.K. (1961). An inventory for measuring depression. Archives of General Psychiatry, 4, 561 - 571.

Branch, L.G. & Jette, A.M. (1983). Elders' use of long tern care assistance. The Gerontologist, 23, 51 - 56.

Brodaty, H. & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. Australian and New Zealand Journal of Psychiatry, 24, 351 - 361.

Breakwell, G.M., Hammond, S. & Fife-Schaw, C. (1995). Research Methods in Psychology. London: Sage.

Briggs, S.R. & Cheek, J.M. (1986). The role of factor analysis in the development and evaluation of personality scales. Journal of Personality, 54(1), 106 - 148.

Burns, A., Howard, R. & Pettit, W. (1995). Alzheimers Disease. A Medical Companion. London: Blackwell.

Cantor, M.H. (1983). Strain among caregivers. A study of experience in the United States. The Gerontologist, 23, 597 - 604.

Connell, C.M. & Gibson, G.D. (1997). Racial, ethnic and cultural differences in dementia caregiving. Review and analysis. The Gerontologist, 37(3), 355 - 364.

Coyne, J.C., Aldwin, C. & Lazarus, R.S. (1981). Depression and coping in stressful episodes. Journal of Abnormal Psychology, 90, 439 - 447.

Cummings, J.L. & Benson, F.D. (1983). Dementia. A Clinical Approach. Stoneham: Butterworth.

Deimling, G.T. & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41, 778 - 784.

Deiner, E., Emmons, R.A., Lausen, R.S. & Griffin, S. (1985). The Satisfaction with Life Scale. Journal of Personality Assessment, 49, 71 - 75.

Department of Health. (1989). Caring For People. Community Care in the Next Decade and Beyond. London: HMSO.

Derogatis, L.R. (1977). SCL-90 Administration, Scoring and Procedures Manual. 1. For the Revised Version and Other Instruments of the Psychopathology Rating Scale Series. Baltimore: John Hopkins University.

Donaldson, C., Tarrier, N. & Burns, A. (1997). The impact of the symptoms of dementia on caregivers. British Journal of Psychiatry, 170, 62 - 68.

Donaldson, C, Tarrier, N. & Burns, A. (1998). Carer stress in Alzheimers Disease. Journal of Geriatric Psychiatry, 13, 248 - 256.

Danis, B.J. & Silverstone, B. (1981). The impact of caregiving. A difference between wives and daughters. Paper presented at the 34th annual meeting of the Gerontological Society.

Drapper, B.M., Poulos, C.J., Cole, A.M.D., Poulos, R.G. & Enrich, F. (1992). A comparison of caregivers for elderly stroke and dementia victims. Journal of the American Geriatrics Society, 40, 896 - 901.

Duijnstee, M. (1992). Caring for a demented family member at home. Objective observation and subjective evaluation of burden. In G. Jones & B.M.L. Miesen (Eds), Caregiving in Dementia. Research & Applications, pp. 359 - 380 London: Routledge.

Dwyer, J.W. & Coward, R.T. (1991). The longitudinal study of residential differences in the composition of the helping network of impaired elders. Journal of Ageing Studies, 5, 391 - 407.

Eagles, J.M., Beattie, J.A.G., Blackwood, G.W., Restall, D.B. & Ashcroft, G.W. (1987). The mental health of elderly couples. The effects of the cognitively impaired spouse. British Journal of Psychiatry, 150, 299 - 308.

Eastman, M. (1984). Old Age Abuse, Age Concern England: Mitcham.

Fadden, G., Bebbington, P. & Kuipers, L. (1987). The burden of care. The impact of functional psychiatric illness on the patients family. British Journal of Psychiatry, 150, 285 - 292.

Farran, C.J., Keane-Hagerty, E. & Tatarowiez, L. (1993). Dementia care. Receiver needs and their impact on caregivers. Clinical Nursing Research, 2, 86 - 97.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini Mental State: a practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research,12, 189 - 198.

George, L.K. & Gwyther, L.P. (1986). Caregiver wellbeing. A multidimensional examination of family caregivers of demented adults. The Gerontologist, 3, 253 - 259.

Gilhooly, M.L.M. (1980). The impact of caregiving on caregivers. British Journal of Medical Psychology,57, 33 - 44.

Gilhooly, M.L.M. (1984). The impact of caregiving on caregivers. Factors associated with the psychological wellbeing of people supporting a dementing relative in the community. British Journal of Medical Psychology, 57, 35 - 44.

Gilhooly, M.L.M. (1986). Senile dementia. Factors associated with caregivers preference for institutionalised care. British Journal of Medical Psychology, 59, 165 - 171.

Gilhooly, M.L.M. (1990). Do services prevent or delay institutionalisation of people with dementia. Research Report, Dementia Services Development Centre, University of Stirling, Stirling.

Gilhooly, M.L.M., Sweeting, H.N. & Whittick, J.E. (1994). Family care of the dementing elderly. International Review of Psychiatry, 6, 29 - 40.

Gilleard, C.J. (1984). Living With Dementia: Community Care of the Elderly Mentally Infirm.

London: Croom Helm.

Gilleard, C.J. (1991). Research methods in the study of carers of dementing elderly people: A workshop report. Health Bulletin, 49 (6), 349 - 351.

Gilleard, C.J. Boyd, W.D. & Watt, G. (1982). Problems in caring for the elderly mentally infirm at home. Archives of Gerontology and Geriatrics, 1, 151 - 158.

Goldberg, D.P. (1978). Manual For The General Health Questionnaire. Windsor: NFER Nelson.

Grad, J. & Sainsbury, P. (1963). Mental illness and the family. The Lancet,1, 544 - 547.

Greene, J.G., Smith, R, & Gardiner, M. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives. A factor analytic study. Age and Ageing, 11, 121 - 126.

Greenberg, J., Seltzer, M. & Greenley, J. (1993). Ageing parents of adults with disabilities. The gratifications and frustrations of later life caregiving. The Gerontologist, 33, 542 - 550.

Hadjistarropoulos, T., Taylor, S., Mokko, H. & Beattie, B.C. (1994). Neurological deficits. Caregivers' perceptual deficits and caregivers burden. Journal of the American Geriatrics Society, 42, 308 - 314.

Haley, W.E., Brown, S.L. & Levine, E.G. (1987). Caregiver appraisals of patient behavioural disturbance in senile dementia. Clinical Gerontologist, 6, 25 - 34.

Haley, W.E., Levine, E.G. & Brown, S.L. (1987). Stress, appraisal, coping and social support as predictors of adaptional outcome among dementia caregivers. Psychology and Ageing, 2, 323 - 330.

Hardy, M.E. & Conway, M.E. (1978). Role Theory: Perspectives for Health Professionals. Norwalk: Appleton Century Crofts.

Harper, S. & Lund, D.A. (1990). Wives, husbands and daughters caring for institutionalised and noninstitutionalized dementia patients. Toward a model of caregiver burden. International Journal of Ageing and Human Development, 30, 241 - 262.

Hirsfield, M.J. (1981). Families living with senile brain disease. Unpublished PhD thesis, University of California.

Homer, A.C. & Gilleard, C. (1990). Abuse of elderly people by their carers. British Medical Journal, 301, 1359 - 1362.

Hong, J. & Seltzer, M.M. (1995). The psychological consequences of multiple roles. The normative case. Journal of Health and Social Behaviour, 36, 386 - 398.

Horowitz, A. (1985b). Family caregiving to the frail elderly. Annual Review of Gerontology and Geriatrics, 25, 194 - 246.

Howell. D.C. (1987). Statistical Methods for Psychology, 2nd ed. Boston: Pluskent.

Huckle, P.L. (1994). Review: Families and dementia. International Journal of Geriatric Psychiatry, 9, 735 - 741.

Jenike, M.A. (1985). Monoamine oxidase inhibitors for treatment of depressed patients with primary dementia. American Journal of Psychiatry, 142, 763 - 764.

Johnson, C.L. (1983). Dyadic family relations and social support. The Gerontologist, 23, 377 - 383.

Jones, D.A. & Peter, T.J. (1992). Coping for elderly dependants. Effects on the supporters quality of life. Age and Ageing, 21, 471 - 480.

Jones, G. & Miesen, B.M.L. (1992). Caregiving in Dementia, Research and Applications. London: Routledge.

Kinnear, P.R. & Gray, D.C. (1997). SPSS For Windows, 2nd ed. Psychological Press.

Knight, R.G., Chisholm, B.J., Pavlin, J.M. & Hendrika, J. (1988). The Spielberger Anger Expression Scale: some psychometric data. British Journal of Clinical Psychology, 27, 279 - 281.

Lawton, M.P. (1983). Environment and other determinants of wellbeing in older people. The

Gerontologist, 23, 349 - 357.

Lazarus, R.S. (1993). Coping theory and research. Past, Present and Future. Psychosomatic Medicine, 55, 234 - 247.

Lazarus, R.S. & Folkman, S. (1985). Stress, Appraisal and Coping. New York: Springer.

Lee, G.R., Dwyer, J.W. & Coward, R.T. (1993). Gender differences in parent care. Demographic factors and some gender preferences. Journal of Gerontology, Social Sciences, 48, S9 - S16.

Leff, J. (1993). Carers. A paper presented at the workshop on Economic and Social Appraisal of Hospital and Community Care. London.

Levesque, L., Cossette, S. & Laumm, L. (1995). Multidimensional examination of the psychological and social wellbeing of caregivers of a demented relative. Research on Ageing, 17(3), 332 - 360.

Levin, E., Sinclair, I. & Gorbach, P. (1983). The supporters of confused elderly people at home. Extract from the Main Service , London. National Institute: London.

Lieberman, M. & Kramer, J. (1997). Factors affecting decisions to institutionalise dementing elderly. The Gerontologist, 31, 371 - 374.

LoGiudice, D., Waltrowicz, W. & McKenzie, S. (1995). Prevalence of dementia among patients referred to an aged care assessment team and association. Stress in their carers. Australian Journal of Public Health, 19, 275 - 279.

Lund, D.A.., Pett, M.A. & Caserta, M.S. (1988). Institutionalising dementia victims: Some caregiver considerations. Journal of Gerontological Social Work, 11, 25 - 37.

McKee, K.J., Whittick, J.E., Ballinger, B.B. & Gilhooly, M.M.L. (1992). Coping in family supporters of elderly people with dementia. British Journal of Clinical Psychology, 36, 323 - 340.

MacMilian, D. (1969). Features of service breakdown. Geriatrics, 24, 109 - 118.

Mace, N.L. & Rabins, P. (1981). The 36 Hour Day. A Family Guide to Caring for Persons With Alzheimers Disease Related Dementing Illnesses and Memory Loss in Later Life. Baltimore: John Hopkins Press.

Montogomery, R.J.V., Gonyea, J.K. & Houyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. Family Relations, 34, 19 - 26.

Morris, R. & Morris, L. (1993). Psychosocial aspects of caring for people with dementia. In A. Burns (Ed.), Ageing and Dementia: A Methodological Approach., pp. 45-76 London: Edward Arnold.

Morris, R.G., Morris, L.W. & Britton, P.G. (1988). Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. British Journal of Psychiatry, 153, 147 - 156.

Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimers Disease. Research in Ageing, 7, 329 - 361.

Newbiggin, K. (1981). 'A ripe old age'. An investigation of relatives of elderly dependants with dementia. Inquiry Report. British Psychological Society. Diploma in Clinical Psychology.

Noelker, L.S. & Wallace, R.W. (1985). The organisation of family care for impaired elderly. Journal of Family Issues, 6, 23 - 44.

O'Connor, D.W., Pollitt, P.A., Roth, M., Brook, D.P.B. & Reiss, B.B. (1989). Problems Reported by Relatives in a Community Study of Dementia. Cambridge: Hughes Hall.

O'Connor, D.W., Pottitt, D.A., Roth, M., Brook, C.P.B. & Reiss, B.B. (1990). Problems reported by relatives in a community study of dementia. British Journal of Psychiatry, 156, 835 - 841.

Orbell, S. (1996). Informal carers in social context. A social psychological analysis of participation impact and intervention in care of the elderly. Psychology and Health, 11, 155 - 178.

Orbell, S. & Gillies, B. (1993). What's stressful about caring? Journal of Applied Social Psychology, 23, 272 - 290.

Parker, G. (1997). Coping with caring for a person with dementia. In S. Hunter (Ed.), Dementia. Challenges and New Directions, pp.121 - 139 London: Jessica Kingsley Publishers.

Pearlin, L. & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behaviour, 19, 2 - 21.

Pealin, L. & Skaff, M.M. (1995). Caregiving and the stress process. The gerontologist, 30, 583 - 594.

Pearlin, L., Mullan, J., Semples, S. & Skaff, M. (1990). Caregiving and the stress process. An overview of concepts and their measures. The Gerontologist, 30, 583 - 594.

Philp, I., McKee, K.J., Meldrum, P., Gilhooly, M.L.M., Gordon, D.S., Mutch, W.J. & Whittick, J.E. (1995). Community care for demented and nondemented elderly people. Comparison study for financial burden, service use and unmet needs in family supporters. British Medical Journal, 310, 1503 - 1506.

Poulshock, S.W. & Deimling, G.T. (1984). Families caring for elders in residence. Issues in the measurement of burden. Journal of Gerontology, 39, 230 - 239.

Pruncho, R.A. & Resch, N.L. (1989) Aberrant behaviours and Alzheimers Disease. Mental health effects on spouse caregivers. Journal of Gerontology, 44, 5177 - 5182.

Rakowski, W. & Clarke, N.M. (1985). Future outlook, caregiving and care receiving in the family context. The Gerontologist, 25, 618 - 623.

Reiss, M.F, Gold, D.P. & Gauthier, S. (1994). Personality traits as determinants of burden and health complaints in caregiving. International Journal of Ageing and Human Development, 39, 257 - 271.

Schneider, L.S. & Subin, P. (1994). Treatment for psychiatric symptoms and behavioural disturbances in dementia. In A. Burns & R. Levy (Eds) Dementia, pp. 519 - 540. London: Chapman and Hall.

Seltzer, M. & Wailing, L. (1996). The transitions of caregiving, subjective and objective definitions. The Gerontologist, 36, 514 - 626.

Seltzer, M.M.., Greenberg, J.S. & Krauss, M.W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. Psychology and Aging, 10, 64 - 75.

Shanas, E. (1979). The family as a social support system in old age. The Gerontologist, 19, 169 - 174.

Spielberger, C.D. Krasner, S.S. & Soloman, E.P. (1988). The experience, expression and control of anger. In M.P. Janisse (Ed), Health Psychology: Individual Differences and Stress, pp. 89 - 108 New York: Springer.

Spielberger, C.D., Jacobs, G.A., Johnson, E.G., Russell, S.S., Crane, R.J. & Worden, T.J. (1985). The experience and expression of anger: Construction and validation of an anger expression scale. In M.A. Chesney & R.H. Rosenman (Eds), Anger and Hostility in Cardiovascular and Behavioural Disorders. pp. 5 - 30 New York: Hemisphere.

Steiger, J.H. (1980). Tests for comparing elements of a correlational matrix. Psychological Bulletin, 87, 245 - 251.

Stephens, J.M. & Kinney, M.A.P. (1989). Caregiving hassles scale. Assessing the daily hassles of caring for a family member with dementia. The Gerontologist, 29, 328 - 332.

Stoller, E.P. & Earl, L.L. (1983). Help with activities of everyday life. Sources of support for the noninstitutionalized elderly. The Gerontologist, 23, 64 - 70.

SPSS/PCT (1988). Statistical Package for the Social Sciences. SPSS, Chicago.

Tabachnik, B.G. & Fidell, L.S. (1996). Using Multivariate Statistics, 3rd ed. California State University.

Teri, L., Truax, P., Logson, R., Zarit, S., Vomoto, J. & Vitaliano, P.P (1992). Assessment of behavioural problems in dementia: The revised memory and behaviour problems checklist. Psychology and Ageing, 7, 622 - 631.

Thompson, E.H. & Doll, W. (1982). The burden of families coping with the mentally ill. An invisible crisis. Family Relations, 31, 379 - 388.

Tolstoy, L. (1911). Anna Karenin. London: Heineman.

Vitaliano, P.P., Russo, J., Carr, J.E., Maiuro, R.S. & Becker, J. (1985). The Ways of Coping Checklist. Revision and psychometric properties. Multivariate Behavioural Research, 20, 3 - 26.

Vitaliano, P.P, Becker, J., Russo, J., Magana- Amato, A. & Maiuro, R.D. (1989a). Expressed emotion in spouse caregivers of patients with Alzheimers Disease. Journal of Applied Social Sciences, 13, 215 - 250.

Vitaliano, P.P., Russo, J., Young, H.M., Becker, J. & Maiuro, R.D. (1991). The Screen for Caregiver Burden. The Gerontologist, 30, 583 - 594.

Warnes, A.M. (1996). The demography of old age. In R. Bland (Ed.), Developing Services For Older People and Their Families, pp. 287 - 304 London: Jessica Kingsley Publishers.

Weiler, P.G. Chiriboga, D.A. & Black, S.A. (1994). Comparison of mental status tests. Implications for Alzheimer patients and their caregivers. Journal of Gerontology, 49, 544 - 551.

Weiuntraub, S., Barataz, R. & Metulam, M. (1982). Daily living activities in the assessment of dementia. In S. Corkin., K. Davis., J. Crauden., E, Usdin. & J. Wurtman (Eds). A Report of Progress in Research, pp. 189 - 192 New York: Raven.

Whittick, J.E. (1985). The impact of psychogeriatric day care on the supporters of the elderly mentally infirm. Paper presented at the Age Concern Scotland conference, Dementia, Research, Innovation and Management.

Whittick, J.E. (1988). Dementia and mental handicap. Emotional distress in supporters. British Journal of Clinical Psychology, 27, 167 - 172.

Whittick, J.E. (1992). Carers of the dementing elderly: Coping techniques and expressed emotion. Dissertation submitted for the Degree of Dr of Philosophy, Faculty of Medicine, University of Glasgow.

Wolf, R.S. & Pillemer, K.A. (1989). Helping Elderly Victims. The Reality of Elder Abuse. New York: Columbia University Press.

World Health Organisation (1992) The ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines. Geneva.

Yeatman, E., Bennetts, K., Allen, A., Ames, D., Flicker, L. & Waltrowicz, W. (1993). Is caring for elderly relatives with dementia as stressful as caring for those without dementia? A pilot study in Melbourne. International Journal of Geriatric Psychiatry, 8, 339 - 342.

Zarit, S.H. (1982). Families under stress. Interventions for caregivers of senile dementia patients. Psychotherapy: Theory, Research and Practice, 19, 461 - 471.

Zarit, S.H. (1982). Families under stress: Interventions for caregivers of senile dementia patients. Psychotherapy Theory, Research and Practice, 19, 461 - 471.

Zarit, S.H., Reever, K.E. & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist, 20, 649 - 655.

Zarit, S.H., Todd, P.A. & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers. A longitudinal study. The Gerontologist, 26(3), 260 - 267.

Appendix B

# Basic Data - Carers.

Age ..................................

Sex MALE FEMALE

Employment Fulltime Part time Retired Unemployed Education

In employment before taking on care giving role ? YES NO.

If YES, please state ......................................................................

Marital relationship Married Living as Single Divorced Widowed

Number of children ................................

Number of children living in household ..........................

Household income Less than £100 £100-£150 £150-£200 over £200
(per week)

Ethnic origin ................................

How long since first had to provide practical care? (months) ..................

Quality of the prior (premorbid) parent child relationship

1 ——————————————— 10
POOR EXCELLENT

Quality of the current parent child relationship

1 ——————————————— 10
POOR EXCELLENT

**Please estimate the frequency of SOCIAL SUPPORT from**

**Informal sources (family / friends) *No of hours* ..........................................**

**Formal sources (services provided by agencies or other paid helpers)**

**..........................................**

**Combined total of formal / informal help ..........................................**

**Please rate the quality of the support**

| | |
|---|---|
| **1** | **4** |
| **"I feel overwhelmed & do not know where to turn"** | **"I get most of the help I need".** |

## Basic Data - Care Recipient.

**Age** ..........................................

**Sex** MALE FEMALE

**Ethnic Origin** ..................................

**Duration of dementia** (time since first noticed symptoms) ......................................

**Living arrangements** ALONE WITH SPOUSE WITH OTHER FAMILY

**Living with carer** YES NO

**Formal diagnosis** ......................................

**Name of Consultant** ......................................

**Name of GP** ......................................

Appendix C

## Coping Questionnaire.

I have a list here of different ways that people can have of coping. As I go through the list can you tell me how much you use each one. Remember I'm thinking particularly of the ways you use to cope with the stress of your parent's illness.

| | NOT USED | A LITTLE | QUITE A BIT | A GREAT DEAL |
|---|---|---|---|---|
| ..Turn to other activity eg (house)work, gardening, to take your mind off things. | | | | |
| Just concentrate on one step at a time. | | | | |
| Try to get the person responsible to change his/her mind. | | | | |
| Talk to someone to find out more about the situation. | | | | |
| Criticise or lecture yourself. | | | | |
| Try not to burn your bridges but leave things a bit open. | | | | |
| Hope a miracle will happen. | | | | |
| Carry on as if nothing has happened. | | | | |
| Try to keep your feelings to yourself. | | | | |
| Try to look on the bright side of things. | | | | |
| Wish that the situation would go away or somehow be over with. | | | | |

| | NOT USED | A LITTLE | QUITE A BIT | A GREAT DEAL |
|---|---|---|---|---|
| Get angry with the person who caused the problem. | | | | |
| Get professional help. | | | | |
| Change as a person in a good way. | | | | |
| Make a plan of action and follow it. | | | | |
| Realise you brought the problem on yourself. | | | | |
| Come out of each experience better than when you went in. | | | | |
| Prepare yourself for the worst. | | | | |
| Talk to someone who can do something concrete about the problem. | | | | |
| Rediscover what is important in life. | | | | |
| Don't let it get to you; you refuse to think too much about it. | | | | |
| Ask a relative or friend you respect for advice. | | | | |
| Have fantasies or wishes about how things might turn out. | | | | |
| Keep others from knowing how bad things are. | | | | |
| Make light of the situation and refuse to get too serious about it. | | | | |

| | NOT USED | A LITTLE | QUITE A BIT | A GREAT DEAL |
|---|---|---|---|---|
| Stand your ground and fight for what you want. | | | | |
| Draw on your past experience; you've been in a similar situation before. | | | | |
| Know what has to be done so you double your efforts to make things work. | | | | |
| You make a promise to yourself that things will be different next time. | | | | |
| Turn to your faith and prayer. | | | | |
| Talk to someone about how you are feeling and get sympathy and understanding from them. | | | | |

Appendix D

# Self Perceived Coping

How well do you feel you are coping with the stress of supporting your parent with dementia? (Please tick).

WELL________

SO SO________

POOR________

# Appendix E

## Beck Depression Inventory (Short form)

**INSTRUCTIONS: This is a questionnaire. On the questionnaire are groups of statements. Please read each statement in each category. Then pick out the one statement in that group which best describes the way you feel today, that is, RIGHT NOW. Circle the number beside the statement you have chosen. If several statements in the group seem to apply equally well, circle each one.**

---

**Be sure to read all the statements in each group before making your choice.**

---

**A. (Sadness)**
**3 I am so sad or unhappy that I can't stand it**
**2 I am sad or blue all the time and I can't snap out of it**
**1 I feel sad or blue**
**0 I do not feel sad**

**B. (Pessimism)**
**3 I feel that the future is hopeless and that things cannot improve**
**2 I feel I have nothing to look forward to**
**1 I feel discouraged about the future**
**0 I am not particularly pessimistic or discouraged about the future**

**C. (Sense of failure)**
**3 I feel I am a complete failure (parent, husband, wife)**
**2 As I look back on my life, all I can see is a lot of failures**
**1 I feel I have failed more than the average person**
**0 I do not feel like a failure**

**D. (Dissatisfaction)**
**3 I am dissatisfied with everything**
**2 I don't get satisfaction out of anything anymore**
**1 I don't enjoy things the way I used to**
**0 I am not particularly dissatisfied**

**E. (Guilt)**
**3 I feel as though I am very bad or worthless**
**2 I feel quite guilty**
**1 I feel bad or unworthy a good part of the time**
**0 I don't feel particularly guilty**

F. (Self dislike)
3 I hate myself
2 I am disgusted with myself
1 I am disappointed in myself
0 I don't feel disappointed in myself

G. (Self harm)
3 I would kill myself if I had the chance
2 I have definite plans about committing suicide
1 I feel I would be better off dead
0 I don't have any thoughts about harming myself

H. (Social withdrawal)
3 I have lost all my interest in other people and don't care about them at all
2 I have lost all my interest in other people and have little feeling for them
1 I am less interested in other people than I used to be
0 I have not lost interest in other people

I. (Indecisiveness)
3 I can't make any decisions at all any more
2 I have great difficulty in making decisions
1 I try to put off making decisions
0 I make decisions about as well as ever

J. (Self image)
3 I feel that I am ugly or repulsive looking
2 I feel that there are permanent changes in my appearance and they make me look unattractive
1 I am worried that I'm looking old or unattractive
0 I don't feel that I look any worse than I used to

K. (Work difficulty)
3 I can't do any work at all
2 I have to push myself very hard to do anything
1 It takes extra effort to get started at doing something
0 I can work about as well as before

L. (Fatigability)
3 I get too tired to do anything
2 I get tired from doing anything
1 I get tired more easily than I used to
0 I don't get any more tired than usual

M. (Anorexia)
3 I have no appetite at all any more
2 My appetite is much worse now
1 My appetite is not as good as it used to be
0 My appetite is no worse than usual

TRUCTIONS:

w is a list of problems people sometimes have. se read each one carefully, and blacken the circle best describes HOW MUCH THAT PROBLEM HAS RESSED OR BOTHERED YOU DURING THE PAST 7 S INCLUDING TODAY. Blacken the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask about them.

**EXAMPLE**

| | NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY | HOW MUCH WERE YOU DISTRESSED BY: |
|---|---|---|---|---|---|---|
| 1 | 0 | 1 | 2 | ● | 4 | Bodyaches |

| NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY | HOW MUCH WERE YOU DISTRESSED BY: |
|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | Headaches |
| 0 | 1 | 2 | 3 | 4 | Nervousness or shakiness inside |
| 0 | 1 | 2 | 3 | 4 | Repeated unpleasant thoughts that won't leave your mind |
| 0 | 1 | 2 | 3 | 4 | Faintness or dizziness |
| 0 | 1 | 2 | 3 | 4 | Loss of sexual interest or pleasure |
| 0 | 1 | 2 | 3 | 4 | Feeling critical of others |
| 0 | 1 | 2 | 3 | 4 | The idea that someone else can control your thoughts |
| 0 | 1 | 2 | 3 | 4 | Feeling others are to blame for most of your troubles |
| 0 | 1 | 2 | 3 | 4 | Trouble remembering things |
| 0 | 1 | 2 | 3 | 4 | Worried about sloppiness or carelessness |
| 0 | 1 | 2 | 3 | 4 | Feeling easily annoyed or irritated |
| | 1 | 2 | 3 | 4 | Pains in heart or chest |
| | 1 | 2 | 3 | 4 | Feeling afraid in open spaces or on the streets |
| | 1 | 2 | 3 | 4 | Feeling low in energy or slowed down |
| | 1 | 2 | 3 | 4 | Thoughts of ending your life |
| | 1 | 2 | 3 | 4 | Hearing voices that other people do not hear |
| | 1 | 2 | 3 | 4 | Trembling |
| | 1 | 2 | 3 | 4 | Feeling that most people cannot be trusted |
| | 1 | 2 | 3 | 4 | Poor appetite |
| | 1 | 2 | 3 | 4 | Crying easily |
| | 1 | 2 | 3 | 4 | Feeling shy or uneasy with the opposite sex |
| | 1 | 2 | 3 | 4 | Feelings of being trapped or caught |
| | 1 | 2 | 3 | 4 | Suddenly scared for no reason |
| | 1 | 2 | 3 | 4 | Temper outbursts that you could not control |
| | 1 | 2 | 3 | 4 | Feeling afraid to go out of your house alone |
| | 1 | 2 | 3 | 4 | Blaming yourself for things |
| | 1 | 2 | 3 | 4 | Pains in lower back |
| | 1 | 2 | 3 | 4 | Feeling blocked in getting things done |
| | 1 | 2 | 3 | 4 | Feeling lonely |
| | 1 | 2 | 3 | 4 | Feeling blue |
| | 1 | 2 | 3 | 4 | Worrying too much about things |
| | 1 | 2 | 3 | 4 | Feeling no interest in things |
| | 1 | 2 | 3 | 4 | Feeling fearful |
| | 1 | 2 | 3 | 4 | Your feelings being easily hurt |
| | 1 | 2 | 3 | 4 | Other people being aware of your private thoughts |
| | 1 | 2 | 3 | 4 | Feeling others do not understand you or are unsympathetic |
| | 1 | 2 | 3 | 4 | Feeling that people are unfriendly or dislike you |

HOW MUCH WERE YOU DISTRESSED BY:

| NOT AT ALL | A LITTLE BIT | MODERATELY | QUITE A BIT | EXTREMELY | |
|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | Having to do things very slowly to insure correctness |
| 0 | 1 | 2 | 3 | 4 | Heart pounding or racing |
| 0 | 1 | 2 | 3 | 4 | Nausea or upset stomach |
| 0 | 1 | 2 | 3 | 4 | Feeling inferior to others |
| 0 | 1 | 2 | 3 | 4 | Soreness of your muscles |
| 0 | 1 | 2 | 3 | 4 | Feeling that you are watched or talked about by others |
| 0 | 1 | 2 | 3 | 4 | Trouble falling asleep |
| 0 | 1 | 2 | 3 | 4 | Having to check and double-check what you do |
| 0 | 1 | 2 | 3 | 4 | Difficulty making decisions |
| 0 | 1 | 2 | 3 | 4 | Feeling afraid to travel on buses, subways, or trains |
| 0 | 1 | 2 | 3 | 4 | Trouble getting your breath |
| 0 | 1 | 2 | 3 | 4 | Hot or cold spells |
| 0 | 1 | 2 | 3 | 4 | Having to avoid certain things, places, or activities because they frighten you |
| 0 | 1 | 2 | 3 | 4 | Your mind going blank |
| 0 | 1 | 2 | 3 | 4 | Numbness or tingling in parts of your body |
| 0 | 1 | 2 | 3 | 4 | A lump in your throat |
| 0 | 1 | 2 | 3 | 4 | Feeling hopeless about the future |
| 0 | 1 | 2 | 3 | 4 | Trouble concentrating |
| 0 | 1 | 2 | 3 | 4 | Feeling weak in parts of your body |
| 0 | 1 | 2 | 3 | 4 | Feeling tense or keyed up |
| 0 | 1 | 2 | 3 | 4 | Heavy feelings in your arms or legs |
| 0 | 1 | 2 | 3 | 4 | Thoughts of death or dying |
| 0 | 1 | 2 | 3 | 4 | Overeating |
| 0 | 1 | 2 | 3 | 4 | Feeling uneasy when people are watching or talking about you |
| 0 | 1 | 2 | 3 | 4 | Having thoughts that are not your own |
| 0 | 1 | 2 | 3 | 4 | Having urges to beat, injure, or harm someone |
| 0 | 1 | 2 | 3 | 4 | Awakening in the early morning |
| 0 | 1 | 2 | 3 | 4 | Having to repeat the same actions such as touching, counting, or washing |
| 0 | 1 | 2 | 3 | 4 | Sleep that is restless or disturbed |
| 0 | 1 | 2 | 3 | 4 | Having urges to break or smash things |
| 0 | 1 | 2 | 3 | 4 | Having ideas or beliefs that others do not share |
| 0 | 1 | 2 | 3 | 4 | Feeling very self-conscious with others |
| 0 | 1 | 2 | 3 | 4 | Feeling uneasy in crowds, such as shopping or at a movie |
| 0 | 1 | 2 | 3 | 4 | Feeling everything is an effort |
| 0 | 1 | 2 | 3 | 4 | Spells of terror or panic |
| 0 | 1 | 2 | 3 | 4 | Feeling uncomfortable about eating or drinking in public |
| 0 | 1 | 2 | 3 | 4 | Getting into frequent arguments |
| 0 | 1 | 2 | 3 | 4 | Feeling nervous when you are left alone |
| 0 | 1 | 2 | 3 | 4 | Others not giving you proper credit for your achievements |
| 0 | 1 | 2 | 3 | 4 | Feeling lonely even when you are with people |
| 0 | 1 | 2 | 3 | 4 | Feeling so restless you couldn't sit still |
| 0 | 1 | 2 | 3 | 4 | Feelings of worthlessness |
| 0 | 1 | 2 | 3 | 4 | The feeling that something bad is going to happen to you |
| 0 | 1 | 2 | 3 | 4 | Shouting or throwing things |
| 0 | 1 | 2 | 3 | 4 | Feeling afraid you will faint in public |
| 0 | 1 | 2 | 3 | 4 | Feeling that people will take advantage of you if you let them |
| 0 | 1 | 2 | 3 | 4 | Having thoughts about sex that bother you a lot |
| 0 | 1 | 2 | 3 | 4 | The idea that you should be punished for your sins |
| 0 | 1 | 2 | 3 | 4 | Thoughts and images of a frightening nature |
| 0 | 1 | 2 | 3 | 4 | The idea that something serious is wrong with your body |
| 0 | 1 | 2 | 3 | 4 | Never feeling close to another person |
| 0 | 1 | 2 | 3 | 4 | Feelings of guilt |
| 0 | 1 | 2 | 3 | 4 | The idea that something is wrong with your mind |

Appendix G

## Anger Expression Scale.

**Everyone feels angry or furious from time to time, but people differ in the ways they react when they are angry. A number of statements are listed below which people use to describe their reactions when they feel angry or furious.**
**Read each statement and then tick the column which indicates how often you generally react or behave in the manner described when you are feeling angry or furious.**
**Remember that there are no right or wrong answers. Do not spend too much time on any one statement.**

| | ALMOST NEVER | SOMETIMES | OFTEN | ALMOST ALWAYS |
|---|---|---|---|---|
| I control my temper | | | | |
| I express my anger | | | | |
| I keep things in | | | | |
| I am patient with others | | | | |
| I pout or sulk | | | | |
| I withdraw from people | | | | |
| I make sarcastic remarks to others | | | | |
| I keep my cool | | | | |
| I do things like slam doors | | | | |
| I boil inside, but I don't show it | | | | |
| I control my behaviour | | | | |
| I argue with others | | | | |
| I tend to harbour grudges that I don't tell anyone about | | | | |
| I strike out at whatever infuriates me | | | | |
| I can stop myself from losing my temper | | | | |
| I am secretly quite critical of others | | | | |
| I am angrier than I am willing to admit | | | | |
| I calm down faster than most other people | | | | |
| I say nasty things | | | | |

| | ALMOST NEVER | SOMETIMES | OFTEN | ALMOST ALWAYS |
|---|---|---|---|---|
| **I try to be tolerant and understanding** | | | | |
| **I'm irritated a great deal more than people are aware of** | | | | |
| **I lose my temper** | | | | |
| **If someone annoys me, I'm apt to tell him / her how I feel** | | | | |
| **I control my angry feelings** | | | | |

Appendix H

## SATISFACTION WITH LIFE SCALE.

**Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below indicate your agreement with each sentence by placing the appropriate number alongside each sentence.**

**Please be open and honest in your responding.**

**7 - Strongly agree**
**6 - Agree**
**5 - Slightly agree**
**4 - Neither agree nor disagree**
**3 - Slightly disagree**
**2 - Disagree**
**1 - Strongly disagree**

**_____ In most ways my life is close to my ideal.**

**_____ The conditions of my life are excellent.**

**_____ I am satisfied with my life.**

**_____ So far I have got the important things I want in life.**

**_____ If I could live my life over, I would change almost nothing.**

# THE SCREEN FOR CAREGIVER BURDEN (SCB)

by

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For each of the following statements, please indicate (check) the degree to which you believe the experience/event has caused you distress (such as upset, nervousness). If the event has not occurred please check "did not occur".

| Experience or Event | did not occur | occurred but caused no distress | mild distress | moderate distress | severe distress |
|---|---|---|---|---|---|
| 1. My spouse continues to drive when he/she shouldn't. | | | | | |
| 2. I have little control over my spouse's illness. | | | | | |
| 3. I have little control over my spouse's behavior. | | | | | |
| 4. My spouse is constantly asking the same questions over and over. | | | | | |
| 5. I have to do too many jobs/chores (feeding, shopping) that my spouse used to do. | | | | | |
| 6. I am upset that I can not communicate with my spouse. | | | | | |
| 7. I am totally responsible for keeping our household in order. | | | | | |
| 8. My spouse doesn't cooperate with the rest of our family. | | | | | |
| 9. I have had to seek public assistance to pay for my spouse's medical bills. | | | | | |
| 10. Seeking public assistance is demeaning and degrading. | | | | | |
| 11. My spouse doesn't recognize me all the time. | | | | | |
| 12. My spouse has struck me on various occasions. | | | | | |
| 13. My spouse has gotten lost in the grocery store. | | | | | |

| | did not occur | occurred but caused no distress | mild distress | moderate distress | severe distress |
|---|---|---|---|---|---|
| 14. My spouse has been wetting the bed. | | | | | |
| 15. My spouse throws fits and has threatened me. | | | | | |
| 16. I have to constantly clean up after my spouse eats. | | | | | |
| 17. I have to cover up for my spouse's mistakes. | | | | | |
| 18. I am fearful when my spouse gets angry. | | | | | |
| 19. It is exhausting having to groom and dress my spouse everyday. | | | | | |
| 20. I try so hard to help my spouse, but he/she is ungrateful. | | | | | |
| 21. It is frustrating to find things that my spouse hides. | | | | | |
| 22. I worry that my spouse will leave the house and get lost. | | | | | |
| 23. My spouse has assaulted others in addition to me. | | | | | |
| 24. I feel so alone - as if I have the world on my shoulders. | | | | | |
| 25. I am embarrassed to take my spouse out for fear he/she will do something bad. | | | | | |

On the line below please write in which of the above experiences provides the most distress for you?

______________________________________________

Appendix J

# THE SCREEN FOR CAREGIVER BURDEN.

For each of the following statements, please indicate (by ticking) the degree to which you believe the experience / event has caused you distress (such as upset, nervousness). If the event has not occurred please tick "did not occur".

| EXPERIENCE OR EVENT | DID NOT OCCUR | OCCURRED BUT CAUSED NO DISTRESS | MILD DISTRESS | MODERATE DISTRESS | SEVERE DISTRESS |
|---|---|---|---|---|---|
| 1. My parent continues to drive when he/she shouldn't. | | | | | |
| 2. I have little control over my parent's illness. | | | | | |
| 3. I have little control over my parent's behaviour | | | | | |
| 4. My parent is constantly asking me the same questions over and over. | | | | | |
| 5. I have to do too may jobs/chores (feeding, shopping) that my parent used to do. | | | | | |
| 6. I am upset that I cannot communicate with my parent. | | | | | |
| 7. I am totally responsible for keeping the household in order. | | | | | |
| 8. My parent doesn't cooperate with the rest of our family. | | | | | |
| 9. My parent doesn't recognise me all the time. | | | | | |
| 10. My parent has struck me on various occasions. | | | | | |
| 11. My parent has been wetting the bed. | | | | | |

| EXPERIENCE OR EVENT. | DID NOT OCCUR | OCCURRED BUT CAUSED NO DISTRESS | MILD DISTRESS | MODERATE DISTRESS | SEVERE DISTRESS |
|---|---|---|---|---|---|
| 12. My parent throws fits and has threatened me. | | | | | |
| 13. I have to constantly clean up after my parent eats. | | | | | |
| 14. I have to cover up for my parent's mistakes. | | | | | |
| 15. I am fearful when my parent gets angry. | | | | | |
| 16. It is exhausting having to groom and dress my parent everyday. | | | | | |
| 17. I try so hard to help my parent, but he/she is ungrateful. | | | | | |
| 18. It is frustrating to find things that my parent hides. | | | | | |
| 19. I worry that my parent will leave the house and get lost. | | | | | |
| 20. My parent has assaulted others in addition to me. | | | | | |
| 21. I feel so alone - as if I have the world on my shoulders. | | | | | |
| 22. I am embarrassed to take my parent out for fear he/she will do something bad. | | | | | |

ON THE LINE BELOW PLEASE WRITE WHICH OF THE ABOVE EXPERIENCES PROVIDES THE MOST DISTRESS FOR YOU.

# RECORD OF INDEPENDENT LIVING.

**Patient's name** ____________________ **Date** ____________

**Rater** ____________________

How often do you see the patient (Circle one)

Daily

Several times a week

Once a week

Less than once a week

DO NOT WRITE BELOW

---

A. Activities
Total of Ratings ____________
Total Number of Items Rated ____________
Score ____________

B. Communication
Total of Ratings ____________
Total Number of Items Rated ____________
Score ____________

C. Behaviour
Total ____________

**1A. ACTIVITIES. Since the illness, how much assistance is required to perform each of the activities cribed below ?**

**ructions: For each activity, circle the number which best describes how the patient accomplishes the . If you do not know, circle the column marked "D.K."If the activity is not applicable, circle the mn marked "N/A".**

| | Does not need help, performs at same level as before illness. | Has trouble but can do alone. | Has trouble needs spoken or written assistance. | Has trouble needs physical assistance. | No longer Does it. | Don't Know. | Not applicable |
|---|---|---|---|---|---|---|---|
| g | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ing & ming | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| toilet | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ng d | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ing | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| g the | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| hold p, interior rior | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| nsibility sonal ings | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ity, bourhood | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| public ort | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| g | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ing & ng cash | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |

| | Does not need help, performs at same level as before illness. | Has trouble but can do alone. | Has trouble needs spoken or written assistance. | Has trouble needs physical assistance. | No longer Does it. | Don't Know. | Not applicable |
|---|---|---|---|---|---|---|---|
| ng | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| ion<br>isations | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| he<br>ne | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| tion | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |
| n<br>of<br>ment | 0 | 1 | 2 | 3 | 4 | D.K. | N/A |

**B. COMMUNICATION. Since the illness, have there been any changes in the patient's ability mmunicate ?**

**ctions: Mark the way in which each category is performed. If you don't know, circle the column d "D.K." If the activity is not applicable, circle the column "N/A".**

| | Does not need help, performs at same level as before illness | Has trouble but does not need help | Has trouble; needs assistance | No longer does it or has great difficulty | Don't Know | Not applicable |
|---|---|---|---|---|---|---|
| g | 0 | 1 | 2 | 3 | D.K. | N/A |
| standing | 0 | 1 | 2 | 3 | D.K. | N/A |
| g | 0 | 1 | 2 | 3 | D.K. | N/A |
| g | 0 | 1 | 2 | 3 | D.K. | N/A |

## CHECKLIST OF BEHAVIOURAL SYMPTOMS.

| AVIOUR | Present before illness | | Present now. | |
|---|---|---|---|---|
| | YES | NO | YES | NO. |
| Tends to be tired; does not take the initiative to start activity | | | | |
| Does not join in on ongoing activities | | | | |
| Can't complete a project once started; stops in the middle | | | | |
| Does not take pride in work or appearance is sloppy | | | | |
| Looks or talks about feeling sad | | | | |
| Feels guilty about being a burden on others or blames him/herself for bad things that happen | | | | |
| Tends to cry a lot | | | | |
| Seems anxious or worried most of the time | | | | |
| Is irritable; gets annoyed easily | | | | |
| Is excited and restless | | | | |
| Is suspicious of others | | | | |
| Gets hostile or violent | | | | |
| Does things in public that are embarrassing | | | | |
| Has poor social graces - is not polite or friendly | | | | |
| Makes inappropriate sexual innuendoes or advances | | | | |
| Behaves inappropriately with strangers | | | | |

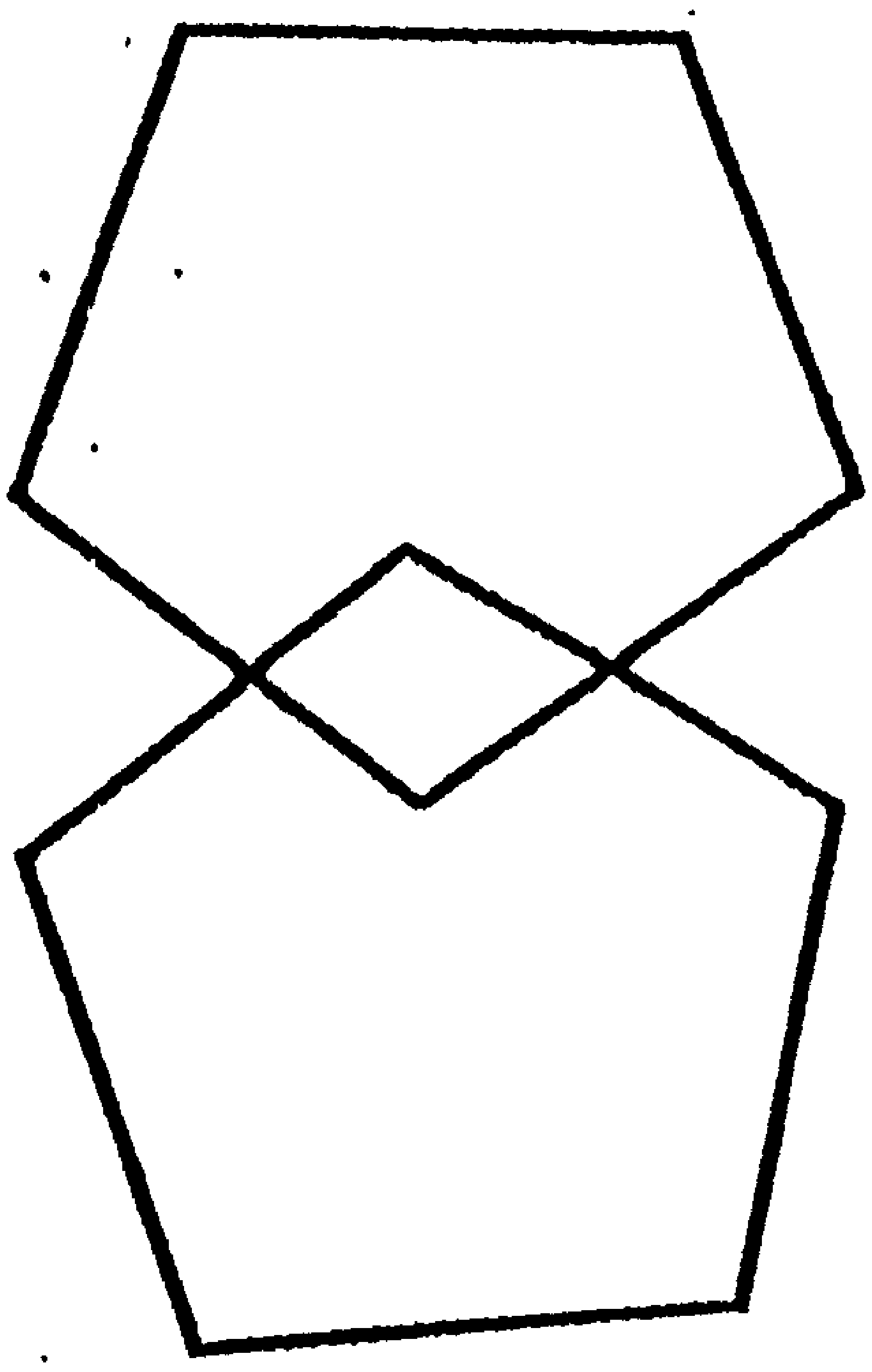
Project No   Patient id ______________________ (please enter)   **Appendix L**

# MINI MENTAL STATE EXAMINATION

Lead: *Some of the questions I'm going to ask you may seem a bit strange. You may think some of them don't apply to you but please try to answer them because we have to ask everybody the same questions..........*

1 = correct   0 = incorrect

1. What day of the week is it? ☐
2. What date is it? (correct day of the month +/- one) ☐
3. What month is it? ☐
4. What season is it? ☐
5. What year is it? ☐
6. Name the place/hospital we are in ☐
7. Name two nearby streets ☐
8. What is the name of this town? ☐
9. What district/county are we in? ☐
10. What floor of building are we on? ☐
11. Serial 7's   (or Spell WORLD backwards) ☐
12. What is this? (pencil) ☐
13. What is this? (watch) ☐
14. Repeat "No ifs ands or buts" ☐
15. I am going to give you a piece of paper. When I do, take it in your right hand, fold it in half and put it on your lap (max 3) ☐
16. Please read this card and do what it says ☐
17. Repeat the following words: apple penny table (repeat up to five times) (max=3) ☐
18. Write any complete sentence ☐
19. Copy the drawing (interlocking pentagons) ☐
20. Can you remember those three words I said? (max 3) ☐



CLOSE YOUR EYES

Appendix M

## Dementia - The Burden of Care on the Carers.

**Researcher -** Emma Shlosberg, Trainee Clinical Psychologist. Supervisor Alison Marriott; Consultant Clinical Psychologist.

**Contact Numbers** Work - 274 4173.

## Research Aims.

To investigate the links between subjective and objective burden with a range of psychological, coping and sociodemographic variables.

## Purpose of Research

Family caregivers literally perform invaluable services in home health care. To keep the emotional and physical costs of these family members, and simultaneously the financial costs of health care within acceptable levels, family caregivers will have to be adequately supported by professional caregivers.

It is essential to identify patients effects on caregivers which may be putting home care at risk. This will require insight into the relationship between objective and subjective burden with more distal indicators of distress.

It is hoped that such knowledge would enable specific interventions to be designed for distressed caregivers.

## Suitable Participants

### Inclusion Criteria

☐ Care recipients with a diagnosis of dementia.
☐ Primary caregiver being either the adult son or daughter
☐ Care recipient cared in the community. Caregivers either living with the care recipient or living within a five mile radius are suitable.

### Exclusion Criteria

☐ Care recipients living in residential care
☐ Caregivers and care recipients who experience difficulties speaking English
☐ Caregivers who are unable to read

## Procedure

1. Psychiatrist or other professional to briefly outline the aims and purpose

of the research, either over the telephone or whilst visiting, to suitable participants and ask them if they wish to participate in the study.

4. The researcher will contact those caregivers agreeing to take part in the study and will organise a convenient time and location to meet.

5. The researcher will only need to meet with the caregiver and care recipient on one occasion.

6. Caregivers will be asked to complete a number of different questionnaires. Interviews should take no longer than one hour.

7. The researcher will also ask the care recipient some questions. This should take no longer than $\frac{1}{2}$ an hour.

ALL THE INFORMATION PROVIDED WILL BE COMPLETELY CONFIDENTIAL.

SHOULD YOU REQUIRE ANY ADDITIONAL INFORMATION THEN PLEASE DO NOT HESITATE TO CONTACT ME.

THANK YOU FOR YOUR CO-OPERATION

Appendix N

# *Information Sheet.*

## *Dementia - The Burden of Care on the Carers.*

*y name is Emma Shlosberg. I am A trainee Clinical Psychologist working with Alison larriott (Consultant Clinical Psychologist).*

*vould like to ask you to take part in a study looking at the stresses or burdens linked ith caring for someone with dementia.*

*his will involve arranging to meet you and your parent with dementia at a time and cation suitable to you both.*

*vill only need to meet with you on one occasion and the appointment will last for out half an hour.*

*vill be asking you some questions from a questionnaire about what it is like to care for ur parent with dementia. I will also be asking your parent some questions.*

*u will have the chance to talk to me about any questions or concerns that you may ve.*

*any concerns are raised, then with your consent, I shall endeavour to inform the propriate person/ service and the concern will be dealt with accordingly.*

*formation from the questionnaires will allow psychologists and other professionals to nsider ways of helping carers in the future.*

*l the information you give me will be completely confidential ... no names will be ached to the discussions we have.*

*e decision to take part in this study is up to you. If you would prefer not to take part if you change your mind at any point it will not affect your own or your parents atment in the future. You are welcome to drop out at any point without giving a ison.*

*rou require any further information then please do not hesitate to contact me on 0161 8 9681 (outside working hours).*
*rou would like to take part in the study then please let your Psychiatrist / Key worker myself know within one week after receiving this letter.*

*Thank you for your cooperation.*

# Research Consent Form.

## Dementia - The Burden on The Family Carers.

Hospital / Institution ..................................................................

Subject's Surname ..................................................................

Other names ................................................

Date of Birth ........................

Sex (Please Tick) MALE FEMALE

---

| | |
|---|---|
| Name of Investigator | Emma Shlosberg |
| Speciality | Trainee Clinical Psychologist<br>Elderly Speciality |

I confirm that I have explained the nature of this research and have supplied the subject's relative with an information sheet and a leaflet explaining the subject's rights in this study in terms which in my judgement are suited to their understanding.

Signature ........................................ Date ..............................

## *Patient's Relatives* *(This part to be completed by the patient's relative / carer).*

## *Please read this form very carefully.*

*If there is anything that you don't understand about the information sheet or you wish to ask any questions please speak to the investigator named on this form.*

*Please check that all the information on the form is correct. If it is and you understand the explanation then sign the form below.*

*I ..................................................................................(relative / carer confirm)*

| | |
|---|---|
| | *Please delete as necessary.* |
| *I have been given a written explanation of the study by the investigator named on this form.* | *YES / NO* |
| *I have had a chance to ask questions about the study.* | *YES / NO* |
| *Do you understand that you are free to pull out yourself or your relative from the study* | |
| *A. At any time* | *YES / NO* |
| *B. Without having to give a reason* | *YES / NO* |
| *Do you understand that all the information collected in the study will be held in confidence.* | *YES / NO* |
| *I therefore agree that ............................................ will take part in this study* | *YES / NO* |

*Signed* ....................................................... *Date* ..................

# *Research Consent Form.*

## *Dementia - The Burden on The Family Carers.*

*Hospital / Institution* ..........................................................

*Subject's Surname* ..........................................................

*Other names* ..........................................

*Date of Birth* ...................

*Sex (Please Tick)* *MALE* *FEMALE*

---

*Name of Investigator* *Emma Shlosberg*

*Speciality* *Trainee Clinical Psychologist*
*Elderly Speciality*

*I confirm that I have explained the nature of this research and have supplied the subject's relative with an information sheet and a leaflet explaining the subject's rights in this study in terms which in my judgement are suited to their understanding.*

*Signature* .................................. *Date* ...........................

## *Patient's Relatives* *(This part to be completed by the patient's relative / carer).*

## *Please read this form very carefully.*

*If there is anything that you don't understand about the information sheet or you wish to ask any questions please speak to the investigator named on this form.*

*Please check that all the information on the form is correct. If it is and you understand the explanation then sign the form below.*

*I .......................................................................... (relative / carer confirm)*

| | <u>*Please delete as necessary.*</u> |
|---|---|
| *I have been given a written explanation of the study by the investigator named on this form.* | *YES / NO* |
| *I have had a chance to ask questions about the study.* | *YES / NO* |
| *Do you understand that you are free to pull out yourself or your relative from the study* | |
| A. *At any time* | *YES / NO* |
| B. *Without having to give a reason* | *YES / NO* |
| *Do you understand that all the information collected in the study will be held in confidence.* | *YES / NO* |
| *I therefore agree that ............................................. will take part in this study* | *YES / NO* |

*Signed* ....................................................... *Date* ...................

Dear Dr

Thank you for the referral of ....................................... to the research project "Dementia - The Burden of Care on the Carers".

I saw ............................. and their carer on ................................

Yours sincerely,

Emma Shlosberg
Trainee Clinical Psychologist, under the supervision of
Alison Marriott,
Consultant Clinical Psychologist

Dear Dr

This letter is to confirm that your patient........................................... has been referred to participate in the study "Dementia - The Burden of care on the Carers".

The details of the study are outlined on the information sheet enclosed.

The research has been ratified by the research ethics committee and will only be carried out with the informed consent of the adult child acting as primary caregiver.

Should you require any further information, then please do not hesitate to contact me on ............................

Yours sincerely,

Emma Shlosberg,
Trainee Clinical Psychologist, under the supervision of
Alison Marriott,
Consultant Clinical Psychologist.

## Appendix R

## Table of Skewed and / or Kurtosed Variables

| | SKEW | | KURTOSIS | |
|---|---|---|---|---|
| | **Statistic** | **Std Error** | **Statistic** | **Std Error** |
| **Background & Contextual Factors** | | | | |
| Caregiver gender | -1.021 | 0.325 | -0.996 | 0.639 |
| Premorbid relationship | -1.867 | 0.325 | 2.682 | 0.639 |
| Residency | -0.638 | 0.325 | -1.655 | 0.639 |
| Length of Practical Care | 3.047 | 0.325 | 11.223 | 0.639 |
| **Objective Stressors or Demands** | | | | |
| Activities | -1.089 | 0.325 | 2.475 | 0.639 |
| Communication | -0.762 | 0.325 | -0.261 | 0.639 |
| Depression | -0.020 | 0.325 | -1.488 | 0.639 |
| Hostility | -0.105 | 0.325 | -1.416 | 0.639 |
| Social Inappropriateness | 1.371 | 0.325 | 1.012 | 0.639 |
| **Mediators** | | | | |
| Isolation & Resignation | 0.928 | 0.325 | -0.749 | 0.639 |
| Formal Social Support | 0.890 | 0.325 | 0.215 | 0.639 |
| **Outcomes** | | | | |
| Anger Out | 0.715 | 0.325 | 0.379 | 0.639 |
| Anxiety | 1.035 | 0.325 | -0.383 | 0.639 |
| Self Perceived Coping | 0.463 | 0.325 | -1.642 | 0.639 |

$$t = (r_{12} - r_{13}) \sqrt{\frac{(N-1)(1+r_{23})}{2\left(\frac{N-1}{N-3}\right)|R| + \frac{(r_{12}+r_{13})^2}{4}(1-r_{23})^3}}$$

where

$$|R| = (1 - r_{12}^2 - r_{13}^2 - r_{23}^2) + (2r_{12}r_{13}r_{23})$$