THE ROLE OF EXPECTATIONS IN DETERMINING CAREGIVER WELL-BEING

by

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Abstract

In recent years there has been a growing body of literature regarding the experiences and well-being of people providing care to a relative with dementia. There is some evidence within this literature that sub-groups of caregivers respond differently to the caregiving situation. In particular, findings have tended to suggest that women caregivers experience more burden and distress than men (eg Gilhooly, 1984a; Gillear et al, 1984), and that spouses of the care recipient experience more burden and distress as carers than children (eg George & Gwyther, 1986; Gilhooly, 1984a). Various explanations have been postulated, one of which focuses on caregivers' expectations of themselves in providing care: it has been speculated that women may have higher expectations of themselves (eg Schnoover et al, 1988), due to a sense that in providing care they are fulfilling an appropriate or anticipated role. It is suggested here that a similar argument may be extended to spousal caregivers.

This study, then, aimed to investigate the levels of expectation of 27 caregivers, and any role this factor may play in determining levels of burden and distress. Differences between the expectations of women and men, and spousal and child caregivers were also investigated, as was the effect of expectations on the use of social support.

Contrary to hypotheses, it was found that expectation levels were inversely related to levels of burden, and there were no differences
between sub-groups. There was evidence of differential use of support for caregivers with different levels of expectation: those with higher expectations of themselves reporting the availability of more informal supports, but lower frequency of contact with services than those with lower expectations.

The results provide a characterisation of the more burdened caregivers being those who have lower expectations of themselves to provide care, who are less involved in caregiving and receive more support in the role. Potential explanations for these findings are discussed, limitations imposed by the methodology of the study are outlined and clinical implications of the present results are considered.
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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region based in Plymouth N.H.S. Trust and the research was conducted in collaboration with Plymouth Community Services N.H.S. Trust.

Signed ...K.J. Foole......

Dated ....3/12/98......
CHAPTER 1. INTRODUCTION

1. Caregivers in the Community: A Descriptive Profile

What we are witnessing in the 'developed' societies of today is something that has never existed before on the present scale in human history: it is the Survival of the Unfittest...Man, alone among the animals, is now provided with the means of survival in a state of unfitness. It is now normal for life to close, as it began, with a period of prolonged dependency; but whereas we have for long organized our society to care for the helpless infant and the developing child, we are only beginning to seek means of dealing with the problems created by dependency in old age. (Isaacs et al, 1972, p.3)

The trend of increasing numbers of elderly people in developed countries has been well-documented, and has been described as "a major problem of the late twentieth century" (eg Woods & Britton, 1985). As reflected in the quote above, this trend has massive implications for service providers and society as a whole, and Woods and Britton suggest "recent years have shown a slow but significant response" (1985, p.1). More recently, population trends have reflected a stabilisation in the number of people over the age of 65.
years, but within this age group there has been a shift in the age distribution, with the numbers of people aged 80+ years increasing. This has been referred to as an increase in the number of 'old old' (eg Woods & Britton, 1985). Again, this has implications for medical, psychological and social health providers as people facing the health and social problems associated with old age increase in number.

Dementia represents one such problem: estimates suggest that between the ages of 60 to 80 years, one in ten people suffer from dementia, but over the age of 80 the prevalence rises to one in four or five (eg Marshall, 1990). This increasing prevalence of dementia with increasing age, considered alongside the knowledge that the number of 'old old' is increasing, implies that the numbers of people presenting with dementia will grow.

This is set in a context of less institutional care, and an emphasis on community care in government legislation (see Marshall, 1990). The implication of these two trends seems clear: increasing numbers of people with dementia, increasingly supported within the community. It would seem important, then, to know something of their supporters. Stone et al (1987) report on data from an American survey: the 1982 National Long-Term Care Survey, designed to elucidate a profile of disabled non-institutionalised elderly people in the U.S.A.. The 'Informal Caregiver Survey' (ICS) formed a part of this work, and involved interviews with 1,924 caregivers representing 2.2 million people nationally. Whilst this work does not refer specifically to caregivers of people with dementia, some of the results are none-the-
less worth noting here. In accordance with previous research, Stone et al report the majority of caregivers (72%) to be women, with daughters and wives representing the two largest groups. As many as three quarters of caregivers were co-resident with their dependents. One third were sole providers of care ie they adopted main responsibility and reported no other help. One third were primary caregivers with informal help. Interestingly, less than 10% of caregivers reported using formal services, and those that did tended to be caring for the more impaired elderly people. Thus, they suggest, service use is seen as a last resort when the demands of caregiving become too great for the caregiver and their informal support network.

Unfortunately, there seems to be no study of the characteristics of caregivers of people with dementia which compares in size and detail to those conducted with caregivers of frail or disabled elderly. Houlihan (1987) reviewed findings from both populations: caregivers of frail and demented elderly. His reports of characteristics of the former group concur with those cited here: the majority of carers (60%) were women, and there was generally one primary caregiver who sought informal help from other family members. For the latter group he could report only that the majority were women, and that spouses were more likely to be co-resident than children. He suggests, however, that "no obvious difference of demographic characteristics are evident".

Finally, Gilhooly (1984b), in a review of research, cites evidence suggesting that 34 - 50% of people with dementia in the community
live alone. The remainder are co-resident with a spouse (17-23%),
adult child (12%) or other relative (10%).

Thus, it appears that people with dementia living in the community
are most likely to be cared for by spouses or adult daughters. These
caregivers will have primary responsibility for caregiving, but may
seek informal help from other family members, and a significant
proportion of them will be co-resident with their care recipient.

It has recognised for some time that these caregivers are themselves
in a vulnerable position, worthy of attention. The work of Grad &
Sainsbury in the 1960's is often cited as the first acknowledgement
of the burden resulting from the provision of care (eg see Morris et
al, 1988a; Vitaliano et al, 1991b), and since this time a body of
literature has evolved surrounding the situation and experiences of
caregivers. The impetus for this work, and assumptions behind it,
seem to stem from two sources (cf Montgomery, 1989):

First, strain or burden has been considered detrimental, either in
itself, or because of its negative implications for various aspects
of the caregivers' well-being (eg physical, psychological). One of
the objectives of caregiver research is therefore to elucidate the
prevalence of distress, the factors which influence the degree of
strain experienced by caregivers, and to identify those carers at
'high risk' in terms of their health status (Morris et al, 1988).

Second, the well-being of caregivers has a direct impact on the lives
of their care recipients. Strain on relatives accounts for a large
proportion of geriatric admissions (Isaacs, 1971) and thus, it is assumed, has the potential to affect their future caregiving capacity. Research has attempted to clarify the predictive potential of strain or burden, and to identify ways of supporting caregivers, and maintaining their ability to provide care (cf Cantor, 1983).

Although both lines of research should, to some extent, inform each other, it is the first body of literature which will form the focus of the present review. Before details of the findings of this research are outlined, some if its characteristics, confusions and limitations will be described.

2. Characteristics of Caregiver Research

2.1 Theoretical Frameworks

That strain among caregivers has been well-recognised has been noted above. Indeed it has been suggested that caregivers of people with dementia experience more strain than those caring for other dependent groups (eg Eagles et al, 1987b; Houlihan, 1987; Whittick, 1988). Research has therefore moved past the point of demonstrating this, to investigating the factors which influence the degree of strain experienced. However, throughout much of this literature there seems to be a lack of any theoretical framework guiding research (Dillehay & Sandys, 1990). The consequence of this seems to have been the publication of a large number of studies, investigating the correlation between burden or psychological well-being and an unwieldy array of variables, with little articulated rationale.
Much of the research has focused on identifying correlates which are assumed to be antecedents to levels of burden, i.e., those determining the "context of care" (Montgomery, 1989). These can be considered in three groups: characteristics of the care recipient, of the care provider, and of the situational and interpersonal context. Whilst findings from such studies may have contributed to an awareness of some of the factors which influence burden levels, the lack of a conceptual framework makes integration of the findings difficult.

More recently, theoretical models from the stress literature have been applied to the experience of caregivers (cf. Stephens & Zarit, 1989), and has generated a small, but growing, body of literature. Broadly speaking, the stress paradigm views stress as a process leading from external stressor, to individual experience of stress to health and adaptational outcome. This process is mediated by a number of intervening variables, such as social support, appraisal of the stressor, personality variables and coping strategies. Viewed within this framework, the care recipient's limitations constitute the caregiver's external stressor. The way in which this is appraised, and the meaning given to the caregiving situation will determine the level of stress the caregiver experiences. Thus, burden is "an example of an external demand or potential threat that has been appraised as a stressor" (Lawton et al., 1989c, p.61). The caregiver's adaptation to this stress will be influenced by the various mediating variable (see above).

There are a number of advantages to viewing caregiving within this framework (see Stephens & Zarit, 1989): The paradigm has already
generated much research, using other types of stressors, ranging from those that are durable and chronic to those that are acute (Chiriboga et al, 1990). It can therefore provide a useful indication to researchers of which variables may be important in determining caregiver burden and adaptation. It also provides a framework in which findings from caregiver research can be organised, and allows for conceptualisation of the complexity of the caregiving situation. Finally, it can account for the fact that some caregivers may adapt to caregiving: responses to stress are not necessarily negative and stressful situations can allow an individual to develop their coping resources, and can provide the opportunity for psychological growth.

However, use of the framework also has disadvantages. Within the stress literature, concern has been expressed about the degree to which measures of objective stressor, appraisals and subjective stress overlap (see Braithwaite, 1992). This problem is compounded when the framework is applied to caregiver research, since "caregiver burden" is itself an imprecise concept (discussed below). Measures of the key variable, then are confounded in caregiver research, and this limits any inferences that can be drawn from resulting correlations. A related dilemma concerns the range of stressors that should be included for study (Chiriboga et al, 1990) ie those directly pertaining to caregiving tasks versus broader stressors which may or may not be derived from the impact of caregiving, such as work or financial difficulties.
Whilst use of the stress framework, then, has benefits, it is associated with its own confusions and many questions remain unanswered.

2.2 Methodological Shortcomings

Several authors have commented on the various limitations in research methodologies in this area (eg Montgomery, 1989; Schulz, 1990; Raveis et al, 1990), which have limited generalisability and comparability of findings, and of the conclusions that can be drawn. First, the majority of studies employ cross-sectional designs, and correlational analyses. Not only does this limit inferences about directions of causality between related variables, but is also inappropriate for investigating changes in stress and burden as the care recipient's illness progresses. Thus, the need for longitudinal designs has been frequently cited. Second, some studies have employed comparison groups to determine the degree to which distress in caregivers is elevated above the level of distress found in non-caregiving samples, and this can present problems. In order to allow such comparisons, some researchers (eg Eagles et al, 1987a,b; Gilhooy, 1984) have used standardised measures of psychological disturbance, with pre-existing norms for general or psychiatric populations. However, these normative samples are likely to differ from a caregiving sample on a number of variables, such as employment status, income, and health, which may themselves influence levels of emotional distress.

Third, sampling methods have differed between studies, with each method introducing different biases to resulting data. For example,
samples tend to be drawn from only one source, and are not therefore characteristic of the population of caregivers. Caregivers are typically contacted through various service agencies, and caregivers known to these agencies may represent those with greater needs. In addition, those using different treatment settings are likely to differ.

Fourth, sample sizes of the studies tend to be small, which limits control of sociodemographic variables. Samples tend to be fairly homogenous, thus restricting generalisability of results, and it has been argued (eg Raveis et al, 1990) that caregivers from ethnic minorities, and male caregivers, have been under-represented.

Finally, criteria for defining 'caregivers' and 'dementia' have differed between studies, which will influence the population being sampled, and limits cross-study comparison.

2.3 Measurement of Outcome

There seems to have been little consensus in research in this area regarding which outcome variables should be employed, and there has been wide disparity.

One variable which is often considered relates to the stress associated with caregiving, but this has been given various labels, such as stress, strain, burden, impact or cost. This research seems to assume that the stress has negative implications in itself (cf Montgomery, 1989) whilst other researchers have attempted to measure
psychological well-being more directly, and variables considered have included morale (eg Gilhooly, 1984a), life satisfaction (Pett et al, 1988), psychiatric status (eg Eagles et al, 1987a,b) and depression (eg Morris et al, 1988).

In noting the range of outcome variables employed, Gilleard (1984) has highlighted the distinction between those which are situationally independent (eg morale, symptomatology) and those which are specific to the caregiving situation (eg burden). However, it seems that there is rarely any clear rationale for choice of outcome indicator, and this becomes problematic in reviewing the literature for two reasons.

First, different outcome variables may give different results (eg see Gilhooly, 1984a) thus limiting their comparability. Second, it is unclear how the various outcome variables relate to each other. For example, on the one hand it has been reported that depression may be an independent, antecedent factor, contributing to the stress of caring but not necessarily caused by it (Poulshock & Deimling, 1984). On the other hand, it has also been suggested that measures of burden should be shown to correlate with measure of psychological symptoms in order to demonstrate construct validity of the burden measure (Vitaliano et al, 1991b). Thus, we are left wondering "Is low morale...equivalent to severe strain, or marked depression, or severe burden?" (Gilleard,1984, p.77) and "...is morale determined by burden or burden determined by morale..." (Montgomery et al, 1985, p.148).
The situation is further confused when outcome indicators are extended to include physical health, financial resources and social participation (eg George & Gwyther, 1986).

Clearly, the understanding of 'outcome' in caregiver research is far from complete. There is no agreement about which are the critical indicators of outcome, or the relationship between these.

Turning now to consider selection of measures for the outcome variable chosen, the most unresolved area is the measurement of caregiver stress, or burden.

2.4 Conceptualisation and Measurement of Burden

'Burden' has been defined, conceptualised and measured in a multitude of different ways: definitions have varied from emotional consequences of caregiving to disruption in daily routine (see Poulshock & Deimling, 1984); burden has been conceptualised as unidimensional and, more recently, multidimensional (see Montgomery, 1989), and the measures developed have varied accordingly.

Research which has taken burden to be a unitary concept has developed a single summary measure, for example strain (eg Gilleard, 1987) or burden (eg Zarit et al, 1980). These typically present checklists of situations or concerns related to caregiving, and respondents are asked to rate each for its frequency of occurrence. This has been criticised for imprecision (eg Poulshock & Deimling, 1984). Montgomery and colleagues (1985, 1989) note the trend in research to
distinguish 'subjective' from 'objective' burden: they suggest that the former refers to impact on relationships and feelings, and the latter refers to objective infringements on time, money, and social activity.

Poulshock & Deimling (1984) claim that this distinction is not satisfactory, since identification of caregiving effects as 'subjective' or 'objective' is done in an inconsistent way. They go on to develop a model of burden, suggesting that the subjective, emotional response of caregivers mediates between elder impairment and the impact of caring on various aspects of the carer's life. This subjective response they label 'burden'. Thus:

Elder impairment $\rightarrow$ Subjective emotional $\rightarrow$ Impact of caregiving ('burden')

How does this model relate to other measures of burden? There is a large degree of overlap between Poulshock & Deimling's impact scales and items used by other researchers to measure subjective and objective burden (Montgomery, 1989). 'Burden', then, has been renamed 'impact'. Their new definition of burden is the subjective response to specific caregiving tasks, is narrower than previous definitions, and views burden clearly as a subjective concept. Whilst this could be viewed as a positive advance, it also presents difficulties (Braithwaite, 1992): burden, thus defined, does not take into account distress arising from the impact of caregiving on the carer's life eg distress from the care recipient's behavioural problems are included but distress from the social restrictions caused by caregiving are not. It has been argued that this is an
equally important element of burden, and the degree to which personal reactions to caregiving, and the effects of it can be empirically separated has been queried.

In an alternative proposal, Vitaliano et al (1991a,b) also separate caregiving experiences from the caregiver's subjective response to these experiences. The former they call 'objective burden', the latter 'subjective burden'. Their measure does, however, include items relating to both caregiving tasks and effects of caregiving. The main difficult with this measure (cf Braithwaite, 1992) seems to lie in the conceptual confusion between the 'objective' and 'subjective' scales. Items used to measure objective burden include those with an obvious subjective element, eg "I feel so alone...". In any case, this attempt at distinguishing experiences from their resultant distress, and suggesting that the former is an "objective" measure whereas the latter is a "subjective" one, has been criticised (eg Braithwaite, 1992; Schulz, 1990). The way in which an individual reports their experience will be influenced by their reaction to it, and both therefore reflect the caregiver's subjective perception of their situation.

In summary, there is general agreement that burden is a subjective phenomenon, involving distress in relation to caregiving and its consequences in the caregiver's life. It is this conceptualisation of the term that will be used in the present research. A number of increasingly complex models and measures have been proposed. However, there is, if anything, more confusion regarding the dependent variable of interest and the inter-relationship between
caregiver strain, distress, and situationally independent symptomatology. Burden, then, remains a broad, scientifically "fuzzy" and clumsy concept, which continues to pose problems for researchers attempting to measure it.

Despite these numerous difficulties, several patterns of findings have emerged within the research. It seems unsurprising that these patterns are rarely totally consistent, but an attempt will be made to review some of the emerging patterns, and to note some of the inconsistencies within the literature. As outlined above, research relating to correlates of burden will be reviewed in three groups: characteristics of the care recipient, care provider, and situational context. Research derived from use of the stress paradigm, and relating to other mediating variables will then be reviewed.

3. Characteristics of the Care Recipient

3.1 Age and Gender
The majority of studies have found no association between a range of background characteristics of the care recipient, such as age and gender, and burden or stress in the caregiver (e.g., Fitting et al., 1986; George & Gwyther, 1986; Zarit et al., 1980, 1986). An exception is reported by Gilhooly (1984a) who found care of a woman to be associated with better morale and mental health. This can be explained by taking into account the fact that male caregivers are normally spouses and represent a larger proportion of those caring for female dependents. It is possible, then, that the finding
reflects a difference between male and female caregivers, rather than being a direct result of the sex of the care recipient. (The differential experiences of male and female caregivers is considered more fully below). In short, it seems unlikely that the age or sex of the care recipient mediate the effect of caring on the provider.

3.2 Severity of Dementia

Several authors report no association between severity of dementia and emotional distress or burden, and this has been demonstrated with a range of measures of dementia severity, such as level of cognitive impairment, functional ability, type and frequency of problems (Zarit et al, 1980), a simple rating scale (Whittick, 1988) and researcher and hospital staff ratings (Gilhooly, 1984a).

Conversely, other authors have reported significant associations, most notably when measures of behavioural disturbance are used as indicators of dementia severity (eg Eagles et al, 1987b; Gilleard et al, 1984; Gilleard, 1987).

It seems possible then that discrepancies in the research regarding the relationship between severity of dementia and caregiver's burden and distress can be accounted for, to some extent, by the differences in measurement of dementia severity, with those studies finding some degree of association tending to use level of behavioural disturbance as the severity indicator. Indeed, Deimling & Bass (1986) explicitly compared the effects of self-care, cognitive, social and behavioural impairment of the dependent on caregiver stress. They report
cognitive impairment to have less direct effect on stress than any of the other three measures. Cognitive impairment was found to have mainly an indirect effect through its influence on behavioural and social functioning.

Behavioural disturbance, then, appears to have a greater influence on caregiver burden than dementia severity itself, and some researchers have investigated more specifically which behavioural problems cause strain and distress in the carer.

3.3 Type of Behaviours Presented
Sanford (1975), in a study of admissions to a geriatric hospital for non-medical reasons, asked caregivers about the frequency of a list of behaviour problems, and then enquired about which problems would need to be removed for the caregiver's situation to become tolerable. Using this method, he reports the most poorly tolerated problems as sleep disturbance, faecal incontinence, night wandering, shouting and micturition.

In a "partial replication" of this study, considering admissions to a psychogeriatric service, Argyle et al (1985) report similar results. They enquired about the presence/absence of a list of 22 behaviour problems and, where present, rated each problem on a three-point scale from coped with well (A) to not coped with, not tolerated (C). From this they suggest that "simple nursing problems", such as dressing and washing, to be relatively well tolerated. In contrast, the most poorly tolerated problems were physical aggression, verbal
abuse, wandering, inappropriate micturition and faecal smearing: "the problems that nobody likes to talk about".

In a literature review, Morris et al (1988a) suggest that there is good agreement between studies regarding the types of behaviours that caregivers find problematic. These, they suggest, fall into two categories: those that reflect aversive behaviours, and those that make constant daily demands of the caregiver eg constant supervision.

3.4 Summary
The only characteristic of the care recipient which appears related to caregiver strain and distress is the number and type of behavioural problems presented. Some problems appear to be experienced as particularly stressful by caregivers, and these include incontinence, sleep disturbance, and dangerous behaviour. However, whilst incidence of behaviour problems may contribute to strain, it does not account for all of the variance in this measure (see Gilhooly, 1984) and the effect of other variables has been examined.

4. Characteristics of the Caregiver

4.1 Gender
Several studies have suggested gender differences in response to caregiving, with women being reported to experience higher levels of burden and strain than men (eg Gilhooly, 1984a; Gilleard et al,
This difference has been observed in groups of spouses (e.g., Zarit et al., 1986) and children caring for an ageing parent (e.g., Robinson & Thurnher, 1979; Schoonover et al., 1988) or for a parent with dementia (e.g., Horowitz, 1985). It is suggested, then, that caregiving is a more stressful experience for women, and various explanations are postulated:

First, it has been speculated that men are less emotionally involved in caregiving (e.g., Gilhooly, 1984a) and adopt a more instrumental approach to their situation and problems (e.g., Zarit et al., 1986). Indeed, Fitting et al. (1986) suggest men and women may have different 'models' of caregiving, with women adopting a parent-child model, and men using a work-derived model focusing on delegation and recognition of limits. In agreement with this suggestion is the finding that men and women offer different types and levels of care, and this is discussed more fully below.

A second, and compatible, hypothesis proposes that caregiving is a "gender appropriate role" for a woman, and that there are greater demands of her to fulfil this role (e.g., Schoonover et al., 1988). Not only, then, does she adopt a different model of caregiving, but also feels more guilty for what she cannot do (e.g., Robinson & Thurnher, 1979).

Alternatively it is suggested that women experience more conflict associated with providing care, both in terms of competing demands from their own nuclear family and/or from work (Horowitz, 1985), and in terms of their preferred 'life trajectories' in which they may
desire to move away from the role of caregiver towards more personal autonomy (Fitting et al, 1986). Men, in comparison, are less likely to be required to fulfil multiple roles (Horowitz, 1985) and for them, caregiving is a new challenge (Fitting et al, 1986). This explanation becomes less attractive when results relating to 'other demands', suggesting that they do not contribute to levels of burden or stress, are considered (see below).

Finally, it is possible that the gender differences in perceived burden or strain reflect a gender difference in willingness to report burden or signs of distress (Dillehay & Sandys, 1990).

For completeness it should be noted that the finding has not always been replicated. For example, whilst Fitting et al (1986) report higher levels of depressive symptomatology in wives than husbands, they found no significant difference in levels of perceived burden. Similarly, Zarit et al (1986) report that initial differences in burden scores between husbands and wives had disappeared at two year follow-up. These findings are none-the-less indicative of a difference in the response of men and women to the caregiving situation.

4.2 Age

Again, findings relating to the role of age in determining caregiver outcome have been mixed (eg Fitting et al, 1986 vs Pett et al, 1988). However, this is a difficult variable to study in isolation, since it is confounded with other influential variables: younger caregivers
tend to be women and older caregivers tend to be spouses. The effect of age alone, then, is unclear.

4.3 Role in Caregiving
Caregivers differ in terms of their level of responsibility for providing care. Often studies report to involve only primary caregivers, but this is not always so, and in any case this description does not adequately define the amount of care being provided (Dillehay & Sandys, 1990). A number of studies, however, have explicitly addressed the issue of the role adopted by the caregiver in providing care, and of potential effects of this on the degree of strain and burden they experience.

Archbold (1983) identified two different caregiver modalities: care provider and care manager. The former identify the service needs of their dependent, and fulfil these personally; and the latter identify the dependent's service needs and organise and co-ordinate services to fulfil these. Care providers are thus more involved in direct, 'hands on' care than managers. It was found that the former perceive fewer benefits and more costs to caring than the latter. Archbold's sample included only women carers, but it seems possible that there may be sex differences in the caregiver modality adopted. Horowitz (1985) reports sons and daughters to differ in the type of care they provide: daughters were far more likely to provide 'hands on' care than sons, who tended to provide financial and organisational care. Montgomery (1989), in her literature review, notes a similar
difference for spousal and child caregivers: spouses are likely to provide more personal care for longer than children.

Interestingly, then, there is some evidence suggesting that the amount of direct care provided by the caregiver is related to the degree of disruption or negative impact on their life (Cantor, 1983) and to high levels of burden and low levels of life satisfaction (Pett et al, 1988).

4.4 Summary
The general weight of evidence available tends to suggest that men and women differ in their responses to the caregiving role. Women are likely to provide more direct care, and to experience more burden and distress. There is a smaller amount of evidence that the amount of care provided itself contributes to the experience of burden. However, the differential effects of gender on burden persist when amount of care provided is controlled for (Horowitz, 1985). In short, caregiving appears to be a more stressful experience for women, and explanations postulated have been outlined above.

5. Situational and Interpersonal Characteristics

5.1 Duration of Care
Given the gradual deterioration of people with dementia, and the stressful nature of caregiving, it would seem reasonable to suppose that the longer a person provides care, the more stress and burden
they would report (eg Townsend et al, 1989). However, the reverse seems to be true, ie either burden and well-being show no association with duration of care (eg Zarit et al 1980; George & Gwyther, 1986), or there is a tendency for subjective stress and psychological well-being to improve as caregiving progresses (eg Gilhooly, 1984a; Townsend et al, 1989).

5.2 Living Arrangements

The term 'caregivers' is used throughout the research to refer to people providing care in widely differing situations: community caregivers may be co-resident or non-resident with their dependent, or the dependent may be living in an institution. Some researchers have directly compared two of these groups. For example, Gilhooly (1984a,b) provides single case studies to demonstrate the way in which co-resident and non-resident community caregivers experience qualitatively different strains, but reports little quantitative difference in levels of morale and mental health.

Others have compared the three groups of caregivers, and have found co-residency to be associated with higher burden and lower levels of psychological well-being (eg George & Gwyther, 1986; Pett et al, 1988). However, co-resident caregivers are also found to differ from the other two groups with respect to numerous other factors. For example, they report lower levels of social support or participation, lower income, provision of a greater percentage of caregiving responsibilities, and different coping strategies; they are also older, less likely to be employed, and represent a larger proportion
of spousal and male caregivers (eg Gilhooly, 1984a, George & Gwyther, 1986; Pett et al, 1988). The independent effects of living arrangements itself is thus difficult to evaluate.

5.3 Blood/Role Relationship

Although some researchers have failed to find any difference between spousal and child caregivers (eg Zarit et al, 1980; Eagles et al, 1987b), the general weight of evidence suggests that spouses experience higher levels of strain and lower levels of well-being (eg Cantor, 1983; George & Gwyther, 1986; Gilhooly, 1984a). A potential explanation of the discrepant findings lies in the confounding of relationship with other variables. For example, men are likely to form a larger proportion of spousal than child samples, and the differential effects of gender on burden have been discussed above. Spouses are also likely to be older, and therefore predisposed to poorer health, lower income, and at greater risk of isolation (Cantor, 1983). However, the difference has been shown to remain significant when age is controlled for statistically (George & Gwyther, 1986).

The explanations postulated focus on the "centrality" of the relationship (Cantor, 1983) and the increased emotional involvement of the caregiver, as the distance of the relationship decreases (Gilhooly, 1984a).

Interestingly, the difference between spouses and children in the extent and type of care provided has been noted above. It thus seems
likely that spouses' and children's response to and experience of the caregiving role differs.

5.4 Quality of the Relationship
In addition to the nature of the relationship, it has also been suggested that the quality of the relationship between caregiver and recipient is important in determining caregiver well-being. In this regard, research suggests that the quality of the relationship prior to the onset of dementia is positively associated with caregiver strain and mental health (Gilleard et al, 1984; Morris et al, 1988b), although this finding has not always been replicated (eg Gilhooly, 1984).

The dementing illness itself is more likely to have a negative than a positive impact on the quality of the relationship (Fitting et al, 1986), and the results regarding change in quality of the relationship have been conflicting. Morris et al (1988) report greater loss of intimacy to be associated with higher levels of depression, whilst Morrisey et al (1990) claim negative impact of the illness on the marital relationship to be only weakly associated with depression.

An additional aspect of the qualitative nature of the caregiver-dependent relationship, which has recently received attention, is 'expressed emotion' (EE). This concept derives from literature on families of people with schizophrenia, and has been found to be predictive of relapse (eg Brown et al, 1972). Its components are
critical comments, hostility and emotional overinvolvement directed towards the care recipient, and as such provides a measure of the emotional atmosphere of the family (Brown et al, 1972).

In applying this concept to the situation of caregivers of people with dementia, it has been shown that lower EE is associated with less strain and distress, and more efficient coping (Bledin et al, 1990; Gilhooly & Whittick, 1989).

In short, it seems possible that a poor pre- or post-morbid relationship with the dependent, or greater loss of intimacy in this relationship, may serve to place the caregiver at risk of higher levels of strain and poor mental health, though this is not necessarily realised.

5.5 Other Demands
Brody (1981) outlines social trends, such as the increase in the number of elderly people and increased move of women to the workforce, which she suggests have produced a group of caregivers she refers to as "women in the middle", ie middle-aged, in middle generations and in the middle of a number of competing roles (eg caregiver vs paid worker). This multiplicity of roles has been called to account for the higher levels of burden amongst women caregivers (eg Horowitz, 1985) and there is evidence that employed caregivers protect and maintain their work and family responsibilities, at the expense of their own social and leisure participation (Cantor, 1983). However, the degree to which this
stereotype typifies the experience of women caregivers has been questioned (Spitze & Logan, 1990). In any case, evidence suggests that other demands, such as employment or responsibility for other dependents, do not result in higher levels of burden or lower morale or mental health (eg Gilhooly, 1984a; Pett et al, 1988).

It seems possible that whilst other demands may increase caregiver strain, they also serve a protective function, for example, employment may offer the caregiver more financial resources and a break from providing care (Pett et al, 1988). Indeed, Archbold (1983) suggests that for caregivers employed in socially valued careers, the delegation of caregiving tasks causes little internal conflict. This may not be so for those employed in less valued positions, and here the strain caused by conflict of roles may be greater.

5.6 Summary
Factors such as duration of care and presence of other demands, which might be expected to contribute to the burden of caregiving, do not appear to do so. The pre- and post-morbid quality of the relationship between caregiver and recipient has, however, been implicated. So, too, have co-residency status and being a spousal as opposed to a child caregiver. The confounding between these latter two factors has been noted, and their potential independent effects are considered more fully below.
6. Advances in the Literature

It seems clear that it is not simply characteristics of the care recipient and their level of disturbance which influence the degree of burden experienced by caregivers. Numerous other factors, relating to characteristics of the caregiver and of their situation, contribute to defining the "context of care" and it is this which is more critical in dictating burden levels. Indeed, Montgomery (1989) suggests that it is against this background that caregivers judge the degree to which caregiving is an infringement on their lives which is experienced as oppressive.

However, whilst it has been acknowledged that caregivers are not an homogenous group (eg Cantor, 1983; Gwyther & George, 1986) this recognition has not always been reflected in the research. As noted above, sample sizes are often relatively small, and they represent a mixture of co-resident vs non-resident, male vs female, and spousal vs child caregivers. It is only when the role of one of these factors is being investigated that it is given explicit attention. The situation is further complicated by the covariance between variables, noted throughout above (eg the confounding between spousal and co-resident status).

The use of correlational designs has precluded analysis of the causal relationship between factors, and for many of these, their antecedent status can only be assumed (Dillehay & Sandys, 1990). In addition, the use of univariate statistics has limited understanding of the inter-relationship between variables, and the degree to which they
have independent effects on burden. Montgomery (1989) suggests that a fuller understanding of the elements which are most important in defining caregiver context is needed.

There have been some advances in this direction. Harper & Lund (1990) describe a study in which, through the use of multivariate analyses, they attempt "to identify specific sets of variables that best explain the differential burden levels among caregivers" (p.241). They divided their sample into groups on the basis of living arrangements, sex of carer, and relationship to the care recipient, and found higher levels of burden for those living with the care recipient, intermediate levels for those whose relative was in a nursing home, and lowest levels for those whose relative lived elsewhere in the community. Within each 'living arrangement' category women had higher burden scores than men. They report significant main effects for both living arrangements and relationship to care recipient. They go on to explore the degree to which 18 variables were predictive of caregivers' burden, and found that caregivers in each sub-group had a different set of three to five variables explaining 25% to 68% of the variance in burden. It is suggested that new factors be sought, which may account for additional variance in this measure.

These findings are significant for the present concern for three reasons. First, they suggest that, independent of living arrangements, relationship to the care recipient is an important determinant of burden. Secondly, they confirm that women experience
more burden than men. Thirdly, it is suggested that new factors be sought, which may account for additional variance in this measure.

With regards to the latter point, the recent recognition, within models of burden, of the importance of considering the degree of subjective distress in response to the caregiving situation has already been mentioned, as has the use of the stress paradigm in understanding caregiver experience. Some research, then, has sought to address the role of various subjective responses and personal and social resources in determining caregiver burden.

7. Caregivers' Subjective Reactions and Resources

7.1 Cognitive Factors
As described above (see 2.4), cognitive processes are a major focus within the general stress paradigm. In any stressful situation, it is not simply the objective stressor that is involved in determining a person's adaptational outcome, but the meaning given to that stressor, and the individual's perceptions of their ability to cope. This conceptualisation of the stress process is best exemplified, within the general stress literature, by the stress model proposed by Lazarus & Folkman (eg 1985). According to this model, any potential stressor initiates in the individual a process of appraisal, during which they assess the extent to which the problem is a threat (primary appraisal) and their capacity to cope (secondary appraisal). It is this which will determine whether a potential stressor evokes subjective stress within an individual. Thus, "stress arises when
one appraises a situation as threatening or otherwise demanding and
does not have an appropriate coping response" (Cohen & Wills, 1985,
p.321).

While the importance of such cognitive processes have been recently
acknowledged within the caregiver literature (Stephens & Zarit,
1989), they have not been widely studied. This may be due partly to
the lack of conceptual clarity in the area of caregiver burden, and
the difficulty in defining and measuring "appraisal" in a way which
is not confounded with measurement of other variables, such as
objective stressor and subjective distress (see Lawton et al, 1989c).
This is clearly exemplified in a study by Borden (1991), who claims
to measure caregiver appraisals, but defines these as "distress in
appraisal of illness characteristics" and measures them as ratings of
the extent to which various care recipient symptoms elicit distress
in the caregiver. What is being measured, then, is "burden"
(Poulshock & Deimling, 1984) or "subjective burden" (Vitaliano et al,
1991b), but not appraisals.

In a conceptually clearer study, Haley et al (1987b) took objective
measures of the care recipient's cognitive, behavioural and self-care
limitations, and asked caregivers to rate each for its degree of
stressfulness (primary appraisal) and for their degree of confidence
in managing the problem (secondary appraisal). From this they report
appraisals to be significant predictors of caregiver outcome. More
specifically, they found caregivers' ratings of the stressfulness of
behavioural problems to be significantly related to depression, and
their appraisals of their own ability to deal with such problems to
be inversely related to depression. Thus, consistent with the stress literature, caregivers' perceptions of their situation and their own ability to cope with it seem important contributors to caregiver outcome.

In addition to appraisals, a person's attributional style, or the causal attributions that they make for uncontrollable negative events, has been proposed as a vulnerability factor for depression (Abramson et al, 1978). According to attributional theory, a person is prone to depression if they attribute negative events to internal, stable and global causes, since perceived loss of control will then result in an expectation of future uncontrollability of negative events. Alternative formulations have also suggested that perception of loss of control over personal reactions to such events (e.g. guilt) may contribute to resultant depression (see Morris et al, 1988a).

The situation of caregivers has recently been used by researchers to test the predictions of these models. This research has implicated perception of loss of control over the care recipient's behaviour and over personal reactions in contributing to levels of depression (Pagel et al, 1985). Internal attributions for upsetting events (Pagel et al, 1985), global attributions for a care recipient's behaviour, and global and stable attributions about a major life change caused by caregiving (Coppel et al, 1985) have similarly been shown to be associated with depression. Predictions from the model have thus received some confirmation within the caregiving situation.
The above studies, then, suggest that various cognitive processes play an important role in determining outcome in the caregiver situation, particularly with regards to levels of caregiver depression.

7.2 Coping Strategies

Coping has been defined as "any response to external life strains that serves to prevent, avoid or control emotional distress" (Pearlin & Schooler, 1978, p.2), and different researchers have categorised coping responses in different ways. For example, Pearlin & Schooler (1978) have suggested that coping responses fall into three types: those that directly modify the stressful situation, those that focus on controlling the meaning of the problem and those concerned with management of resultant distress, rather than being aimed directly at the problem itself. Alternatively, Folkman & Lazarus (1985) have suggested that coping is "emotion-focused" when it is intended to regulate the distressing emotions caused by the stressor, and "problem-focused" when it is directed towards changing the problem or stressful situation.

Other conceptualisations have been suggested, each resulting in differences of measurement. Again, then, there are problems in making direct comparisons between results from different studies, but a selection of findings will be briefly reviewed.

Research has, in general, suggested that coping strategies have a direct effect on caregiver well-being (eg Bledin et al, 1990;
Borden, 1991; Haley et al, 1987b; Pett et al, 1988). This research has tended to distinguish a priori effective or adaptive coping from ineffective or maladaptive coping, and to demonstrate that effective coping is correlated with measures of well-being. Although results are merely correlational and direction of causality cannot be inferred, it would seem that the use of active problem-solving coping, and of strategies which control the meaning of the problem are associated with higher levels of well-being (eg Borden, 1991; Haley et al, 1987b). Conversely, exclusive use of strategies aimed at avoidance or at emotional discharge are associated with lower levels of well-being (eg Borden, 1991; Pett et al, 1988; Haley et al, 1987b).

Further than this, it has been suggested (Borden, 1991) that coping strategies employed are affected by the caregiver's level of perceived social support, with higher levels of support being associated with greater use of active problem-solving, and less use of emotion-focused strategies. It seems clear that the relationships between stressor, well-being and mediating variables are complex, and although the roles of these variables may not be fully understood, it would seem that the coping strategies adopted by the caregiver will have some effect on their resultant well-being.

7.3 Social Support
Within the stress literature the role of social support in maintaining the well-being of individuals exposed to stress has been widely investigated. There has been controversy regarding the
process by which support can affect well-being, with a "main effect" model suggesting support has a positive effect on well-being irrespective of an individual's exposure to stress, and a "buffering" model suggesting that support buffers or protects an individual from the detrimental effects of stress, but has no independent effect for those not experiencing stress. Regardless of this, numerous studies document the beneficial effects of social support (cf Cohen & Wills, 1985).

Within the caregiving literature the role of two distinct forms of support in determining levels of well-being have been investigated: informal support (ie that provided by the caregiver's network of family and friends) and formal support (ie that provided by the support services).

**Informal Support:**
As with most other variables studied in relation to well-being, findings regarding the role of informal support have been mixed. For example, it has been reported that higher frequency of visits from family members is associated with lower levels of caregiver burden (Zarit et al, 1980), and that higher levels of network size, social activity and satisfaction with support are associated with higher levels of life satisfaction and perceived health (Haley et al, 1987b). Conversely, others have reported no correlation between extent of family support and levels of emotional distress (Gilleard et al, 1984); nor between assistance with caregiving tasks, presence of a confidante and caregiver burden (Pruchno, 1990).
Again, as with other variables, social support is considered to be a multidimensional concept and imprecision in the way in which support is defined and measured has been noted (eg Dillehay & Sandys, 1990). In this regard, one important distinction that has been identified is that between quantitative measures, such as network size or frequency of contact, and qualitative measures, such as caregivers' perceptions of the adequacy of support, or their satisfaction with it. It has been suggested that it is the latter that is more important in determining caregiver outcome (eg Gilhooly, 1984a) and ratings of perceived adequacy of support have been consistently found to be related to measures of burden and well-being (George & Gwyther, 1986; Scott et al, 1986).

It has also been suggested that distinctions should be made in measurement between different components of support. Fiore et al (1983) identify five components, and report "cognitive guidance", ie provision of information and advice, as the most predictive of caregiver depression. More importantly, these authors suggest a distinction is made between the supportive aspects of social networks, and the upset or stress concurrently received from them. In investigating caregivers' perceptions of the helpfulness and the upset provided by their networks, they report network upset to be predictive of depression, and network helpfulness to be unrelated to depression. This finding was replicated by Pagel et al (1987), who also demonstrated caregivers' ratings of satisfaction with support to be related to perceived upset, but not to perceived helpfulness. They suggest, then, that when caregivers rate themselves as satisfied with their support, they are simply reporting "that they have
relatively few complaints" (p. 802). It is the absence of these complaints that relate to outcome, rather than the support received itself.

In short, it would seem that informal support has a role in determining caregiver well-being, and that this role may be more dependent on the caregiver's perception of the adequacy of support, rather than the actual amount of support provided. This perception of adequacy may be shaped in part by caregivers' expectations of their network, and the upset caused when these expectations are not met (Pagel et al., 1987).

The process by which perceptions of informal support may affect caregiver well-being is complex and, as noted above (7.2), one proposal has considered the effect of support to be mediated by its effects on caregiver coping strategies (Borden, 1991). Whilst its precise role may not yet be thoroughly understood, the fact that informal support affects caregiver well-being is important, given that caregiving itself has negative consequences for the social involvement of caregivers (Cantor, 1983; George & Gwyther, 1986). Thus, the need to investigate ways of mobilising caregivers' informal support, and to offer alternative forms of support has been noted (eg Zarit et al., 1980; Zarit, 1989).

**Formal Support:**

A range of caregiver support services have been described within the literature, such as individual counselling, family meetings, support groups (Zarit & Zarit, 1982), and respite care (Lawton et al., 1989b).
One of the assumptions underlying much of the research on formal support is that intervention can reduce caregiver burden or strain, and that this will maintain their capacity to care for their dependent relative in the community (eg Zarit & Zarit, 1982). There has been some empirical evidence that strain or burden is predictive of caregivers' desire to institutionalise their relative (eg Morycz, 1985), and of their actual decision to institutionalise (eg Colerick & George, 1986). However, the degree to which strain is predictive of institutionalisation, independently of the care recipient problems causing the strain, has been doubted (Gilleard, 1985). In any case, the use of prevention of institutionalisation as a sole aim for caregiver interventions could be questioned, and a body of evaluative research has evolved, using other outcome criteria.

Most of the evaluative research has focused on support groups. These tend to focus on education and peer support (Gonyea, 1989), although the variability between functions of different support groups has been noted (Toseland & Rossiter, 1989). Much of the early research used caregiver ratings, such as satisfaction, as the outcome measure, and tended to show positive results (Toseland & Rossiter, 1989). However, when outcome criteria were extended to include measures such as well-being, coping and social functioning the results were more mixed. Some studies have shown that, even when support groups are rated positively by caregivers, there is little change in objective measures of well-being (eg Haley et al, 1987a; Haley, 1989). Others have found positive changes, following attendance at support groups, in measures of psychological well-being, size of informal support
network, and burden (eg Greene & Moriahan, 1989; Toseland et al, 1989).

Numerous methodological difficulties have been noted in research of this nature (eg Haley et al, 1987a; Haley, 1989; Zarit & Toseland, 1989). For example, it has been suggested that global measures of well-being are not sensitive enough to measure changes in caregiver functioning, that some of the beneficial effects may be preventative in the long-term but not immediately apparent, and that support groups may actually facilitate appropriate placement of the care-recipient.

Some researchers have taken a more focused look at support groups with specific, circumscribed functions, and using relevant outcome measures, have shown positive results. For example, Chiverton & Caine (1989) have demonstrated an increase in coping competence following a short educational programme. Sutcliffe & Larner (1988) have demonstrated a decrease in distress following a group focusing on emotional support, but an increase in knowledge alone following a group focusing on informational provision.

In short, it seems generally accepted that support groups are well-received by caregivers, and can be beneficial. However, questions concerning what type of support group is effective for which caregivers in which ways and at what point in the caregiving process remain.
Results from evaluative studies investigating other forms of support seem similar: ie caregivers express satisfaction, but the effect on objective measures of caregiver functioning are more equivocal. For example, Lawton et al (1989a), in a longitudinal study of respite care, report no beneficial gains in health, mental health nor burden relief. Again, Zarit et al (1987) found no difference in caregivers' levels of distress following individual and family counselling, or support group attendance, and a 'waiting list' control group. However, in a reanalysis of this data, using a statistical procedure that takes into account variability in initial distress score, Whitlatch et al (1991) report a significant reduction in distress following counselling, but equal probabilities of successful and unsuccessful outcomes for support group attenders. Predictably, then, caregivers show variability in the degree to which they benefit from interventions.

To conclude, it has been noted (eg Haley et al, 1987a; Lawton et al, 1989a) that caregivers have multiple needs, and it seems unsurprising that any single intervention is not sufficiently powerful to affect major changes in caregiver well-being. This is not to denigrate the potential role of any support service but simply underlines the fact that caregivers needs are great, and a clear understanding of the specific functions of specific services has not yet been achieved.

7.4 Summary
Consistent with the literature regarding stressors and mental health, a number of cognitive processes (appraisals, perception of control
and attributional style) have been demonstrated to play some role in determining caregiver well-being. So, too, have the coping strategies adopted by caregivers, and their perceptions of the adequacy of their informal support. However, the degree to which formal support services are effective in alleviating distress and facilitating well-being seems less certain from evidence currently available.

Given, then, that caregiving involves numerous costs to the caregiver and sources of hope for this being alleviated seem uncertain, why do people care?

8. Why Do People Care?

This question becomes more pertinent when one discovers that some caregivers have negative attitudes to caregiving, positive attitudes to institutionalisation, and that these factors are associated with higher levels of emotional distress (Whittick, 1989). Availability of institutional places is clearly a potential relevant factor, but cannot account for why so many people offer care to their relative with dementia for so many years. Some authors have even highlighted that, in addition to an interesting question, it is a potentially concerning one, since a proportion of these carers will themselves be old and physically vulnerable, and may resist allowing their care recipient to become institutionalised (Montgomery et al, 1989).
Less research attention has been paid to the question, but the explanations which exist within the literature range from psychological to sociological and socio-biological (Schulz, 1990).

Psychological explanations postulate motives such as "egoistic or self-serving" and "empathic and altruistic". The former refers to motives shaped by a person's anticipation of some gain from caregiving (eg financial, enhanced self-esteem, or social approval) and negative consequences from not providing care (eg guilt). Factors such as "a fruitless search for parental approval that has never been received..." (Brody, 1885, p.23) fall within this category. Alternatively, altruistic motives are shaped by the ability to empathise with the position of the care recipient. It has also been hypothesised that the need to provide care to a parent may activate "intra-psychic tensions", and viewed in this way "excessive caregiving may represent not emotional health, or heroism or love, but pathology" (Brody, 1985, p.23).

Sociological explanations focus on the role of social norms, and the expectation that family members should care for their own. Indeed, evidence suggests that values of family care still abound (Brody et al, 1983; 1984).

Answers to the question 'why do people care?', then, probably demand explanations at a number of levels of analysis. People's motives for caring are unlikely to be straightforward, and, as suggested above, rather than asking 'why?' researchers have tended to ask 'what contributes to a healthy outcome?' and 'how can we help?'.
9. Conclusions and Introduction to the Present Study

Whilst it is difficult to draw firm conclusions from the current literature, given its methodological and conceptual difficulties and resultant inconsistencies, one conclusion that is often highlighted is that caregivers are not homogenous, but there are sub-groups of caregivers, which can be expected to respond differently to the caregiving situation (Gwyther & George, 1986). In particular, one distinction which can be made is between men and women: women tend to show higher levels of burden and to adopt a different role in caregiving. This role in itself may affect burden levels, with those providing higher levels of direct personal care experiencing more burden. Another distinction that can be made is that between spousal and child caregivers, with the former tending to report more burden than the latter.

Although these findings are noteworthy, they cannot be useful in the design of interventions aimed at reducing caregiver burden, since variables such as gender and relationship to the care recipient are fixed. In this regard, findings derived from the use of the stress paradigm, suggesting various cognitive processes, coping strategies and satisfaction with social support are all influential in caregiver outcome, could be viewed as more useful. None-the-less, findings from intervention studies have not yet led to clear demonstrations of their effectiveness.

In considering the question 'Do we need another "Stress and Caregiver" study?' Zarit (1989) has suggested that research attention
be paid to caregiver interventions, that these interventions are unlikely to make a major impact on constructs as broad as coping or social support, and that the objective of these interventions can more easily become specific when the processes by which various factors can affect burden are better understood.

To return to the findings cited above regarding correlates of burden, ie that women and spouses tend to report more burden, one explanation revolves around caregivers' expectations of themselves in providing care. For example, the suggestion that women providing care are fulfilling a "gender-appropriate" role, and that there is more demand of them to act as "nurturers" has been cited within the literature (eg Brody, 1981; Gillear, 1984; Schnoover et al, 1988). Thus, it is hypothesised, women may have higher expectations of themselves to provide care (eg Schnoover et al, 1988) and feel more guilty about what they cannot do (Brody, 1985; Robinson & Thurner, 1979). Similarly, it has been suggested that "children end their caregiving careers at about the time spouses begin identifying themselves as caregivers" (Montgomery et al, 1989, p.463). It could be hypothesised, then, that one of the factors leading to increased levels of burden in spousal caregivers is, again, the higher expectations they have of themselves to provide care.

The corollary of the expectations caregivers have of themselves in providing care is their receptivity to support in this role. Again, it has been suggested, at least within the literature on formal support, that there may be differences between sub-groups of caregivers in how likely they are to accept help. For example, it
has been suggested that men use formal services more often than women (Chiverton & Caine, 1989), and has been hypothesised that this may reflect a reluctance of women to use help, a sense that they should be providing care themselves, and guilt about not doing so (eg Chiverton & Caine, 1989; Morycz, 1985). Similarly, it has been suggested that spouses are more reluctant than children to place their care recipient in a nursing home (Montgomery et al, 1989; Colerick & George, 1986) and this may reflect an "expectational set" that they alone are responsible for caring for their spouse (Pruchno, 1990), and that nobody can provide the same quality of care as themselves (Chiverton & Caine, 1989).

These hypotheses are all consistent with the characterisation within the literature of the burdened caregiver who cannot set limits to their caregiving role (Pett et al, 1988) and who needs help accepting what they cannot do (Brody, 1985). If this characterisation proves true, it will have clear implications for caregiver interventions. This study, then, aims to investigate caregivers' expectations of themselves in the caregiving role (which will be referred to as 'perceived personal responsibility') and their receptivity to support, with the following hypotheses:

1) Perceived personal responsibility (PPR) and receptivity to social support (RSS) will be inversely correlated, and can be combined to provide an overall 'expectations' score, with high expectations referring to high PPR and low RSS.
2) Expectation scores will be positively correlated with caregiver burden and stress.

3) Women will have higher expectation scores than men.

4) Spouses will have higher expectation scores than children.

5) Expectation scores will be inversely correlated with levels of social support.

Additional differences between caregivers with high and low expectations will be examined in an exploratory fashion, with no specific hypotheses made.
CHAPTER 2: METHOD

1. Design

A cross-sectional design was employed in the present study. Measures of caregivers' expectations, burden, distress and various demographic and background variables (see Table 1, p.63) were taken from each participant. The relationship between expectations and burden, distress and social support was then investigated using correlational analyses. In addition, participants were divided into two groups on the basis of their gender (women vs men), and into two groups on the basis of their relationship to the care recipient (spouse vs child). Mean expectation scores could thus be compared between the two groups, for each division.

Finally, caregivers were divided on the basis of their expectation scores into 'high', 'medium' and 'low' groups. (Operational definitions of these three categories are given in the 'Results' section). Comparisons of caregivers' scores for each of the background variables were then made between those categorised as 'high' and those categorised as 'low' expectation scorers.

2. Participants

Interviews were initially arranged with 30 caregivers. Three subsequently cancelled their interview. One of these was a spouse
caring for her husband, and he became physically ill and was hospitalised shortly prior to the arranged interview. Two were daughters caring for their mothers. One of these was unable to keep the scheduled interview because of her mother's appointment with her doctor, and no reason was obtained for the other cancellation.

The final sample, then, consisted of 27 caregivers. Of these, 15 were women, and 12 were men. Of the female carers, seven were spouses of the care recipient, five were adult children, one was a niece, one a sister, and one a daughter-in-law. Of the male carers, ten were spouses, and two were adult children. The mean age of participants was 67.0 years (range 44 to 84 years). These caregivers were caring for relatives, 20 of whom had a primary diagnosis of Alzheimer's Disease, and seven of whom were reported to have other primary diagnoses eg "senile dementia", "multi-infarct" or "arteriosclerotic" dementia. The mean age of care recipients was 77.1 years (range 59 to 92 years). The mean length of time in caring was 5.1 years (range 1 to 15 years).

They were contacted through various sources. The final sample consisted of 11 caregivers contacted via one of three day hospitals, six caregivers contacted via one of two day centres, and ten caregivers contacted via the Alzheimer's Disease Society. Inclusion criteria for participation in the study were as follows: (1) the participant had to be the primary caregiver (2) co-resident with the care recipient (3) and to be a relative of the care recipient (4) the care recipient had to have a primary diagnosis of dementia.
3. Measures

3.1 Measurement of Caregivers' Expectations

Development of Caregivers' Expectations Scale (CES):
Caregivers' expectations are defined here as their suppositions about what they should be doing in the care-giving role, and their level of expectations is defined as how much they suppose they should provide in their caregiving role. One approach to measurement of expectations could therefore involve surveying which of a range of caregiving tasks (e.g., feeding, toileting, taking out) they believe they should personally be providing. However, there are problems with measuring levels of expectations behaviourally: such a measure may provide a good indication of the range of caregiving tasks a carer expects to provide, but does not provide a continuous scale, since one cannot assume that different tasks are equivalent in terms of intensity or demand. For this reason, levels of expectation were measured using an attitudinal type scale.

As outlined above, two factors were identified as contributing to caregivers' expectations:
1) perceived personal responsibility for care (PPR)
2) receptivity to social support (RSS).

A 14-item questionnaire was developed to reflect caregivers' levels of expectations of themselves in providing care, with seven items relating to each factor (see Appendix I). Each item presented a statement and participants were requested to indicate the degree to which they endorsed the statement on a five-point scale, from
strongly agree to strongly disagree. The items were selected in the following way:

The literature regarding attitudes to filial responsibility, caring for a dependent, institutional care and receptivity to formal support was reviewed (Brody et al, 1983; 1984; Whitrick, 1989). Items pertaining to one of the above two factors were selected and adapted as necessary. For example, the statement "I think it is a family's duty to care for a disabled relative at home" (Whitrick, 1989) is a question pertaining to values of family care. In adapting it for use in the present study, such that it related to perceived personal responsibility, it became "I think it is my duty to care for my relative at home".

Additional items were developed, such that questions regarding receptivity to support covered a range of supportive services, from institutional care to home care services.

The questionnaire developed thus differed from any used in previous work in that items were personal rather than general statements; it was designed to be applicable to any relative caring for a person with dementia but no item related specifically to those caring for other dependent groups; and items related directly to the above two factors, with no item relating to general feelings or attitudes about caring for a dependent relative (e.g. "I would rather look after my relative than do anything else", Whitrick, 1989).
The questions were worded in such a way that they avoided unidirectionality, for example, a caregiver with a high perceived personal responsibility would need to respond 'strongly agree' to some PPR items, and 'strongly disagree' to others. This minimises the influence of acquiescence on the score obtained.

Finally, the questionnaire was piloted on seven trainee clinical psychologists. Comments regarding layout, wording and relevance of the questions were taken into account. It was subsequently piloted on four people who were caring, or who had been caring for a dependent relative. Two of these caregivers were husbands of the care recipient: one had been caring for his wife with dementia until she moved into hospital care, and one was currently caring for his wife with depression. The remaining two participants were daughters who had provided care to their mothers: one of these care recipients had subsequently moved to hospital care, and one was deceased. Again, comments regarding the wording and relevance of the questions were elicited and taken into account in the final version of the questionnaire, which appears in Appendix I.

Scoring of the CES:

**PPR items:** these were scored from -2 (low level of PPR) to +2 (high level of PPR). For items 2, 6, 12, 13 and 14 then +2 indicated "strongly agree" and -2 indicated "strongly disagree". Scoring was reversed for items 1 and 4.

**RSS items:** these were again scored from -2 (low level of RSS) to +2 (high level of RSS). For items 7, 8, 9 and 10 then +2 indicated
"strongly agree" and -2 indicated "strongly disagree". Scoring was reversed for items 3, 5 and 11.

For each participant there were two scores: level of perceived personal responsibility, derived by summing scores from the PPR items, and level of receptivity to support, derived by summing scores from the RSS items. A single score was derived thus:

Level of expectation = PPR score - RSS score

The range of possible scores was therefore -28 to +28. A score of -28 would indicate the lowest level of expectation ie a low PPR score and high RSS score. Conversely, a score of +28 would indicate the highest level of expectation ie a high PPR score and a low RSS score. Scores towards the middle of the scale, indicating medium levels of expectation, could be derived in various ways: medium PPR and RSS scores; high PPR and RSS scores, or low PPR and RSS scores, although this latter combination would be difficult to imagine in practice.

3.2 Measurement of Outcome

**Burden:**

The 22-item Zarit Burden Index (BI) (Zarit et al, 1980) was used. This is a self-report inventory, designed to assess the degree of burden felt by caregivers, as a result of their caregiving role. It consists of 22 statements about potential feelings, and asks respondents to rate how often they feel this way, on a scale from zero (never) to four (nearly always). The areas covered by the index include health, finances, social life and interpersonal
relationships. An overall score is derived by summing ratings to individual items, and can therefore range from zero (low burden) to 88 (high burden). A copy of the BI appears in Appendix II.

Vitaliano et al (1991b), in a review of burden measures, cites evidence of the BI's high internal consistency (alpha= .91) and test-retest reliability (alpha= .71). They note it has content validity, but concurrent validity is difficult to establish in any burden measure, given the uncertainty regarding the relationship of the concept to other psychological criteria. These authors also report the broad scope of the BI as one of its major strengths. Indeed, it includes items covering both 'subjective' and 'objective' burden as defined by Montgomery (1989) i.e. impact on relationships and emotions, and on finances and social restrictions. In addition, through the wording of the statements, it focuses on the affective response of the respondent, and thus covers 'objective' and 'subjective' burden, as defined by Vitaliano et al (1991a,b) i.e. caregiving experiences and distress in relation to these experiences. Although it is not possible to distinguish the two types of burden in the final score, this was not considered too limiting, since differential hypotheses had not been made.

Finally, whilst other forms of the BI exist (the 20 and 29 item versions), the 22-item BI has been widely used in previous research (Harper & Lund, 1990).

In short, the BI was selected for use here since it is a wide-ranging burden measure, with demonstrated reliability, it is easy to
understand and administer, and its use is consistent with much previous research.

**Psychological Well-being:**
The General Health Questionnaire (GHQ) was included as a situationally independent outcome measure. This is a self-administered scale which aims to detect psychiatric morbidity in non-psychiatric or community settings. The scale presents a series of 30 questions relating to a variety of symptoms and behaviours which are indicative of psychological disturbance. The respondent rates the occurrence of each on a four-point scale, ranging from "less than usual" to "much more than usual". A copy of it appears in Appendix III.

Rationale for selection of the GHQ-30, and for the scoring method adopted here is given in Appendix IV. In brief, the GHQ-30 was employed because it is short and easy to understand and administer, it is of demonstrated reliability and validity, and its use is consistent with previous research in this area.

**3.3 Additional Information**
A structured interview was devised (see Appendix V) to elicit information about participants' demographic details and about a number of factors which have been suggested to relate to burden. The factors included in this interview are shown in Table 1. Full details regarding their measurement are given in Appendix VI, but will be briefly outlined here:
Duration of care was recorded to the nearest year, and participants themselves located the point at which they began providing care to their dependent relative.

Three potential sources of 'other demands' on the caregiver were enquired about: employment status, number of other dependents in the household, and additional stressors identified by the participant.

The impairment level of the care recipient was measured using the Behaviour Rating Scale (BRS) of the Clifton Assessment Procedures for the Elderly (CAPE). The BRS is an 18-item rating scale designed to measure behavioural competence of elderly people, and to be completed by a familiar person. Each item is rated on a three-point scale, with higher scores indicating a higher level of disability. A total behavioural disturbance score is obtained by summing scores from the individual items, with possible values ranging from zero (low) to 36 (high).
In brief, it was chosen for use in the present study, since it has been demonstrated to have satisfactory reliability and validity, it is relatively short and easy to administer, and has been used in previous studies of this nature (e.g. Gilleard et al., 1984; Eagles et al., 1987b).

In order to operationalise both the qualitative and quantitative nature of support, three measures of both formal and informal support were employed: First, participants were asked to list the number of people/services who were available to help them in their caregiving tasks. Second, they were asked for their frequency of contact with each person/service listed, and this was totalled as the number of contacts with any supportive person/service per month. Third, they were asked to give an overall rating of the perceived adequacy of their informal/formal support, on a five-point scale. (This rating scale is shown in Appendix VII). Thus, for each participant there were six support scores: number, frequency and adequacy of informal and formal supports. This was chosen as a brief, cursory measure, and was considered to be an adequate reflection of support, and to be more appropriate than a lengthy standardised questionnaire.

Finally, involvement in caregiving was operationalised here as the percentage of care provided personally by the caregiver, and was self-rated on a scale from zero to 100% (see Appendix VII for a copy of the scale).
4. Procedure

Contact was made with key professional working in a number of services for people with dementia in and around the Plymouth area, including three day hospitals, one psychogeriatric respite ward, two day care centres, and a home care organiser. In addition, contact was made with the Regional Manager of the Alzheimer's Disease Society. The nature of the project was explained to these professionals, and caregivers who met the inclusion criteria were contacted in one of several ways, depending on the preference of the service organiser. Some caregivers were sent a letter directly from the researcher, with or without a covering letter from the service organiser, explaining the nature of the project and inviting them to return a tear-off slip indicating whether or not they were prepared to be interviewed (a copy of this letter appears in Appendix VIII). Others were contacted through carer support groups, where the researcher was invited to talk directly to caregivers about the project, and request their participation. In these cases, interested people were asked to identify themselves after the meeting, at which time the letter cited above was given and either an appointment was made, or they were left to return the tear-off slip should they choose. Finally, some caregivers were contacted directly by the service organiser, using the letter cited above.

Participation in the project was voluntary, with no details requested nor offered to service providers regarding (non)responders.
Given the variable way in which caregivers were contacted, there is no information available regarding total number of people contacted nor characteristics of non-responders.

Caregivers who responded to the initial letter, indicating that they were prepared to be interviewed, were contacted by telephone, and an interview time arranged. All interviews were conducted in the caregiver's home. Participants were requested to sign a consent form (see Appendix IX), after ensuring that they had understood the nature of the research. The interview then began with the Background Interview schedule, which took between 20 and 90 minutes to administer (mean = 47 minutes). Participants were then asked to complete the CES, BI and GHQ-30, but were offered the option of having these read aloud by the researcher should they prefer. The researcher was available in all cases throughout completion, to answer queries about the questionnaires. Completion time ranged from five to 60 minutes (mean = 32 minutes). The total interview time therefore ranged from 25 to 130 minutes (mean = 79 minutes).

At the end of the interview, any questions regarding the research were answered, and questions regarding services to people with dementia were answered within the researcher's knowledge base. Where such questions could not be answered immediately, the relevant information was sought out by the researcher and passed back to the participant. Having thus debriefed participants, the researcher offered to send a summary of the results to the study once these became available. All participants accepted this offer. In addition, the CES reliability study was described and their
participation requested. Those who agreed to participate were posted another CES form approximately one week following the first interview, with a covering letter (see Appendix X). Finally, it was ensured that participants had a contact address for the researcher, should any comments or queries regarding the research subsequently emerge.

5. Ethical Considerations

Care was taken at each stage of the project to ensure that caregivers understood the voluntary nature and something of the content of the research. The consent form was designed to reiterate this.

Where participants showed signs of undue distress during interview, their desire to contact additional services (e.g. the Psychology Department) was explored during debriefing. The case was then discussed with the field supervisor, and appropriate action taken. In addition, the leaving of a contact address was designed to ensure that any repercussions from the research could be dealt with.

In short, it was considered that the well-being of participants was attended to in the project design.

The project received ethical approval from Plymouth Local Research Ethics Committee (Trial Number 275).
CHAPTER 3: RESULTS

1. Comment on Key Variables

1.1 Caregiver Expectation Scale (CES)
Given that this scale has been newly developed, it was considered important to investigate some of the characteristics of the sample distribution.

CES scores ranged from -18 (lowest possible score -28) to +15 (highest possible score +28). This measure, then, provided a reasonable range of scores, with no floor nor ceiling effects. The mean score was 3.26 (s.d.8.35), and the median score was 3. A measure of the skewness of the sample distribution is given in Table 2. This indicated a slight negative skew, which does not reach a significance level of \( p=0.05 \). The data was thus assumed to have parametric properties for the purpose of data analysis (ie to be interval data, normally distributed).

1.2 Social Support Measures
Six measures of social support were used: for both formal and informal support, a measure was taken of the number of supportive people/services mentioned, the frequency of contact with supports, and the perceived adequacy of the support. The last of these was clearly an ordinal variable, but for the previous four it was again considered important to investigate some of the characteristics of the distribution of these scores.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Skewness</th>
<th>S.E. Skew</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>CES score</td>
<td>-.6523</td>
<td>.4479</td>
<td>1.456</td>
</tr>
<tr>
<td>Informal social support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>number mentioned</td>
<td>.2623</td>
<td>.4479</td>
<td>.5856</td>
</tr>
<tr>
<td>frequency of contact</td>
<td>.9745</td>
<td>.4479</td>
<td>2.1758*</td>
</tr>
<tr>
<td>Formal support services</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>number mentioned</td>
<td>-.0730</td>
<td>.4479</td>
<td>-.1758</td>
</tr>
<tr>
<td>frequency of contact</td>
<td>.9406</td>
<td>.4479</td>
<td>2.100*</td>
</tr>
</tbody>
</table>

*p< 0.05, 2-tailed test

Table 2: Measure of skewness of the distribution of key variables

Number of supports:
For informal support, the number of people mentioned ranged from 0 to 6; mean 2.81 (s.d. 1.36); median 3. A measure of the skewness of the distribution is given in Table 2. This indicates little skew, and the data appeared approximately normally distributed.

For formal support, the number of services mentioned ranged from 0 to 6; mean 3.03 (s.d. 1.32); median 3. Again, the data appeared to approximate to a normal distribution, and there was no significant skew (see Table 2).

In short, this data was approximately normally distributed. However, it covered only a small range of values (0 to 6), and for this reason was assumed non-parametric for the purpose of data analysis.
Frequency of contact:
For informal support, frequency of contact with supporters ranged from 0 to 60 contacts per month; mean 15.47 (s.d. 16.76); median 10. There appeared to be a strong positive skew in the distribution of scores, and this was statistically significant (see Table 2).

For formal support, frequency of contact with services ranged from 0 to 50 contacts per month; mean 18.27 (s.d. 13.13); median 15. Again, there appeared to be a slight positive skew in the data which was statistically significant (see Table 2).

In short, this data was not normally distributed, and non-parametric tests were employed during data analysis.

1.3 Caregiver Outcome
Two outcome measures were taken: Burden Index (BI) scores (measuring caregiver burden; with 22 items; range of possible scores, 0 to 88) and GHQ scores (measuring psychological distress; with 30 items; range of possible values 0 to 90). The mean BI score for this sample was 27.59 (s.d. 13.02). This mean is relatively low in comparison to that cited in other studies. For example, Pett et al (1988) cite a mean BI score of 41.6 (s.d. 15.7). Similarly, Harper & Lund (1990) cite a mean of 42.9 (s.d. 15.2). These studies have used caregivers of varying characteristics, with respect to living arrangements, gender, relationship to care recipient and so on. The difference is thus difficult to interpret. In addition, normative data for the BI have not been established, and it can only be noted here that the burden levels of this sample seem relatively low.
The two outcome measures were found to be significantly correlated \((r=0.59, n=27, p<0.001)\). Although the nature of the relationship between burden and distress is unclear, this correlation suggests that, as may be expected, caregivers' reports of distress increase as their reports of burden increase.

<table>
<thead>
<tr>
<th></th>
<th>BI scores</th>
<th>GHQ scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n=12)</td>
<td>23.00</td>
<td>9.71</td>
</tr>
<tr>
<td>Women</td>
<td>31.27</td>
<td>14.43</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouses</td>
<td>25.18</td>
<td>9.15</td>
</tr>
<tr>
<td>(n=17)</td>
<td>36.00</td>
<td>16.42</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n=7)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p=0.05, 2-tailed test

Table 3: BI and GHQ scores by gender and relationship

As noted above (see 'Introduction') it has been suggested that women report higher levels of burden and distress in the caregiving situation than men, and similarly spouses report higher levels than children. In order to determine whether these results have been replicated with the present sample of caregivers, mean BI and mean GHQ scores were examined by gender and relationship (see Table 3). Observation of these means suggests that the same pattern of results have emerged here for gender. However, unrelated t-tests reveal
that these differences were not statistically significant (t=-1.70, df=25, p=0.05). Conversely, the pattern of results for spouses and children appear reversed ie mean BI and GHQ scores are higher for child than spousal caregivers. This difference is statistically significant for BI scores (t=-2.08, df=22, p=0.05).

2. Validity and Reliability of the CES

2.1 Reliability

There are a number of forms of reliability, and the most relevant form for any given measure will depend on its nature and purpose. For the CES, test-retest reliability was considered most relevant.

Test-retest reliability:

This provides a measure of the test's stability over time, ie the degree to which it will provide the same score on two separate occasions, given no change in caregiver's level of expectation. In order to assess this, all participants were asked to complete a second CES approximately one week after the first administration. Twenty-four participants agreed to be sent a second CES, and all of these returned the questionnaire. Mean return time was 7 days (range 2 to 28 days).

A Pearson's product-moment correlation coefficient was computed for total scores and the two sub-scale scores ('perceived personal responsibility [PPR], with 7 items; and receptivity to social support [RSS], with 7 items) on the first (CES1) and second (CES2)
administration. This demonstrated the total score derived from the CES to be highly reliable \(r=0.85, n=27, p<0.001\). Both sub-scale scores were also reliable (PPR: \(r=0.85, n=27, p<0.001\); RSS: \(r=0.79, n=27, p<0.001\)).

**Internal consistency:**

This provides a measure of the degree to which all items on a scale are measuring a single concept, i.e., the degree to which scores on individual items covary. The most commonly used indice is Cronbach's alpha, which represents the mean of all possible split-half reliability coefficients.

Cronbach's alpha was calculated for the two sub-scales of the CES. Two sets of data had been collected (CES1 and CES2), and the analysis was run separately for each, thus providing two estimates of the internal consistency of the sub-scales. The results were as shown in Table 4.

<table>
<thead>
<tr>
<th></th>
<th>CES1 (n=27) alpha value</th>
<th>CES2 (n=24) alpha value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPR</td>
<td>0.73</td>
<td>0.86</td>
</tr>
<tr>
<td>RSS</td>
<td>0.62</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Table 4: Internal consistency of the sub-scales of the CES

Taking 0.80 as the cut-off point, below which the scale cannot be considered internally consistent, these results demonstrate an acceptable degree of internal consistency for the PPR sub-scale, but
cast doubt on the internal consistency of the RSS sub-scale. For the purpose of the present study the internal consistency of the sub-scales was considered acceptable, but it seems likely that some items of the RSS sub-scale are tapping a different concept. Further development of the scale would require identifying these items, and omitting them, or developing the measurement of the concept further.

2.2 Validity
Again, there are various forms of validity. The CES was assumed to have face validity given its acceptability during piloting. It was assumed also to have content validity, given that it was based on a review of the literature regarding attitudes to caregiving and to support services: no obvious omissions were apparent. Criterion related validity was difficult to establish, given the absence of an existing criterion measure. Finally, construct validity represents an attempt to define the construct which the scale purports to measure, and to assess the degree to which it does so.

As stated above, caregivers' levels of expectation were defined here as how much they supposed they should provide in their caregiving role. Two elements were identified: PPR and RSS. In this regard, hypothesis (1) stated that:

PPR and RSS will be inversely correlated, and can be combined to provide an overall 'expectations' score.
In order to test this hypothesis a Pearson's product-moment correlation coefficient was calculated for PPR and RSS scores, for both CES1 and CES2 data sets. This revealed a negative correlation between PPR and RSS scores. This was non-significant for CES1 data ($r = -0.46$, $n=27$, $p > 0.01$), but was significant for CES2 data ($r = -0.64$, $n=24$, $p < 0.001$).

In order to determine the validity of combining the two sub-scales into a single scale, the internal consistency of the overall scale was computed for CES1 data (with scoring for RSS items reversed). This demonstrated the scale to have some degree of internal consistency (Cronbach's alpha=0.75).

Hypothesis (1) was therefore accepted, and PPR and RSS scores will thus be combined into a single summary measure for the remainder of data analysis.

3. Test of Main Hypotheses

Hypothesis (2) stated that:

expectation scores will be positively correlated with caregiver burden and stress.

In order test this hypothesis, a Pearson's product-moment correlation coefficient was computed for both CES and BI scores and CES and GHQ scores. This analysis revealed a modest but significant correlation
between CES and BI \((r = -0.54, n=27, p < 0.01, \text{1-tailed test})\). It was, however, in the opposite direction to that predicted ie as level of expectation increased, level of burden decreased. This relationship is depicted in Figure 1. There was no significant correlation between CES and GHQ \((r = -0.36, n=27, p > 0.01, \text{1-tailed test})\). However, the trend again was for an inverse relationship ie there was a tendency for GHQ scores to decrease as level of expectation increased.

Hypothesis (2) was therefore rejected.

**Hypothesis (3)** stated that:

women will have higher expectation scores than men.

Mean CES score by gender is given in Table 5. From this it would appear that men have higher expectation scores than women. However, an unrelated t-test revealed this difference to be statistically non-significant \((t=0.92, df=25, p > 0.05, \text{1-tailed test})\).

<table>
<thead>
<tr>
<th></th>
<th>Men (n=12)</th>
<th>Women (n=15)</th>
<th>Spouses (n=17)</th>
<th>Children (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CBS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.92</td>
<td>1.93</td>
<td>2.71</td>
<td>5.43</td>
</tr>
<tr>
<td>S.D.</td>
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<td>9.46</td>
<td>7.74</td>
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</tr>
<tr>
<td>(t)</td>
<td>0.92 (df=25)</td>
<td>-0.83 (df=22)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5: CES scores by gender and relationship to care recipient
Figure 1: Relationship between burden (BI score) and level of expectation (CES score)
Hypothesis (4) stated that:

spouses will have higher expectation scores than children.

Mean CES scores by relationship are also given in Table 5. From this it would seem that children have higher expectation scores than spouses. However, an unrelated t-test again revealed this difference to be non-significant \( t = -0.83, \text{df}=22, p > 0.05, \text{1-tailed test} \).

Gender and relationship were, however, confounded in the present study (eg 59% of spouses were men, and 71% of child caregivers were women). The effects of either factor in isolation could thus be obscured. A one-way ANOVA was therefore conducted to determine whether there were significant differences between CES scores of daughters, husbands and wives (see Appendix XI). No significant differences were revealed \( F [2,19] =0.56, p>0.05 \).

Hypotheses (3) and (4) were therefore rejected.

Hypothesis (5) stated that:

expectation scores will be inversely correlated with levels of social support.

Kendalls Tau c correlation coefficients were calculated for CES and each support measure (see Table 6). This revealed only two significant correlations: a positive correlation between CES scores
and number of informal supports mentioned (\(\tau_c = 0.35, n=27, p< 0.005, 1\text{-tailed test}\)), and a negative correlation between CES scores and frequency of contact with formal support services (\(\tau_c = -0.31, n=27, p< 0.005, 1\text{-tailed test}\)). Thus, the higher a caregiver's expectations, the more family members and friends they report to be available for support, and the lower their frequency of contact with support services. There appears, however, to be no relationship between expectation levels and number of support services mentioned, nor frequency of contact with informal supports, nor perception of adequacy of formal and informal support.

<table>
<thead>
<tr>
<th>CES by</th>
<th>(\tau_c)</th>
<th>ASEI</th>
<th>(t) value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal support</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>number</td>
<td>0.349</td>
<td>0.097</td>
<td>3.586*</td>
</tr>
<tr>
<td>frequency of contact</td>
<td>0.090</td>
<td>0.125</td>
<td>0.721</td>
</tr>
<tr>
<td>perceived adequacy</td>
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<td>0.138</td>
<td>1.372</td>
</tr>
<tr>
<td>Formal support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>number</td>
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<td>0.123</td>
<td>-0.704</td>
</tr>
<tr>
<td>frequency of contact</td>
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<td>0.094</td>
<td>-3.275*</td>
</tr>
<tr>
<td>perceived adequacy</td>
<td>0.044</td>
<td>0.121</td>
<td>0.361</td>
</tr>
</tbody>
</table>

*\(p< 0.005, df=25, 1\text{-tailed test}\)

Table 6: Relationship between CES and support measures

The findings regarding hypothesis (5), then, are mixed and the concept of 'levels of support' is more complex than this hypothesis implies.
4. **Background Factors**

Data was collected on a variety of additional factors (see Table 1). In order to determine whether caregivers with high and low expectations differed on any of these factors, the sample was first classified on the basis of their CES scores, thus:

- **High expectations:** CES = 7 or above  \( n = 11 \)
- **Medium expectations:** CES = 1 to 6  \( n = 7 \)
- **Low expectations:** CES = 0 or below  \( n = 9 \)

Those caregivers classified as having high or low expectations were then compared for each factor. This necessarily involved a large number of comparisons within the data, and a number of these may be significant by chance at \( p=0.05 \). Caution is therefore required in interpreting these results. A selection of factors are shown in Table 7.

<table>
<thead>
<tr>
<th>Low expectations (( n = 9 ))</th>
<th>High expectations (( n = 11 ))</th>
<th>( t )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
</tr>
<tr>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>BRS score</td>
<td>17.00</td>
<td>6.29</td>
</tr>
<tr>
<td>Age of caregiver</td>
<td>65.77</td>
<td>10.63</td>
</tr>
<tr>
<td>Percentage of care</td>
<td>76.11</td>
<td>15.57</td>
</tr>
<tr>
<td>Years caregiving</td>
<td>3.89</td>
<td>3.22</td>
</tr>
</tbody>
</table>

*\( p<0.05 \), 2-tailed test

**Table 7:** Comparison of a selection of background factors for caregivers with high and low expectations
4.1 Characteristics of the Care Recipient

**Impairment level:**
Mean Behaviour Rating Scale (BRS) scores of care recipients for caregivers with high and low expectations are given in Table 7. The difference between them was small and non-significant (t = -0.17, df=18, p > 0.05, 2-tailed test).

4.2 Characteristics of the Caregiver

**Age:**
Mean age of caregivers of high and low expectations are given in Table 7. Observation of these means reveals little difference between them, and an unrelated t-test showed the difference to be non-significant (t = -0.25, df=18, p > 0.05, 2-tailed test).

**Gender:**
A 2 x 2 contingency table was constructed for gender by expectations (see Appendix XII). A Fisher's exact probability test revealed no significant difference between the frequency of the cells (p = 0.670, 2-tailed test). This indicates that proportions of men and women do not differ in high and low expectation categories, and is consistent with results cited above regarding the lack of a relationship between gender and expectation level.

**Involvement in caregiving:**
Mean self-rated percentage of care provided by caregivers with high and low expectations are given in Table 7. It would seem that those
with high expectations report more involvement in caregiving, and an unrelated t-test revealed this difference to be statistically significant (\(t = -2.32, \text{df}=18, p<0.05, \text{2-tailed test}\)).

4.3 Situational Characteristics

Duration of care:
Mean number of years spent in caregiving for those with high and low expectations are shown in Table 7. There appeared to be a tendency for those with high expectations to have cared for longer, but this was non-significant (\(t = -1.72, \text{df}=18, p>0.05, \text{2-tailed test}\)).

Relationship:
A 2 x 2 contingency table was constructed for expectations by relationship (spouse or child) (see Appendix XIII). Again, a Fisher's exact probability test revealed no significant difference between the frequency of the cells (\(p=1.000, \text{2-tailed test}\)). This is again consistent with results cited above regarding the lack of a relationship between relationship and expectation level.

Other demands:
A Fisher's exact probability test revealed that proportions of caregivers employed versus not employed outside the home did not differ significantly for those with high and low expectations (\(p=0.566, \text{2-tailed test}\)) (see Appendix XIV). In addition, the 'number of other dependents' ranged from 0 to 2, and was therefore treated as a nominal variable. A Chi-square analysis (see Appendix XV) indicated that the proportion of caregivers with 0, 1 or 2
additional dependents does not differ for those with high and those with low expectations (Chi-square=3.363, df=2, p> 0.05). However, caution is required in interpreting these results, as the minimum expected frequency of the cells was very low (0.450), two-thirds of the cells had an expected frequency of less than 5, and 2 cells had an observed frequency of zero.

Finally, the 'number of additional stressors' mentioned by participants ranged from 0 to 4. This was therefore treated as an ordinal variable, and a Mann-Whitney U test revealed no significant difference between the number of stressors reported by those with high and those with low expectations (U=40.5; n=11, n=9; corrected Z= -0.737; p> 0.05; 2-tailed test).

In short, other demands did not appear to differ between those with high and low expectations.

4.4 Social Support
Mann-Whitney U tests were employed to examine the difference between caregivers with high and low expectations, for each social support measure (see Table 8). Two significant differences were revealed: those with high expectations reported significantly more informal supports (U=21.5; n=11, n=9; corrected Z= -2.21; p< 0.05; 2-tailed test), and significantly fewer contacts per month with formal support services (U=19.0; n=11, n=9; corrected Z= -2.32; p< 0.025; 2-tailed test) than those with low expectations. These results are consistent with the correlations reported between these measures (see above).
Table 8: Comparison of social support for caregivers with high and low expectations

<table>
<thead>
<tr>
<th></th>
<th>Low expect. (n = 9)</th>
<th>High expect. (n = 11)</th>
<th>U</th>
<th>corrected Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean rank</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>number</td>
<td>7.39</td>
<td>13.05</td>
<td>21.5</td>
<td>-2.21*</td>
</tr>
<tr>
<td>frequency contact</td>
<td>10.33</td>
<td>10.64</td>
<td>48.0</td>
<td>-0.11</td>
</tr>
<tr>
<td>perceived adequacy</td>
<td>9.11</td>
<td>11.64</td>
<td>37.0</td>
<td>-1.04</td>
</tr>
<tr>
<td>Formal support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>number</td>
<td>11.22</td>
<td>9.91</td>
<td>43.0</td>
<td>-0.51</td>
</tr>
<tr>
<td>frequency contact</td>
<td>13.89</td>
<td>7.73</td>
<td>19.0</td>
<td>-2.32**</td>
</tr>
<tr>
<td>perceived adequacy</td>
<td>10.00</td>
<td>10.91</td>
<td>45.0</td>
<td>-0.40</td>
</tr>
</tbody>
</table>

*p< 0.05, 2-tailed test  **p< 0.025, 2-tailed test
CHAPTER 4. DISCUSSION

This study aimed to investigate the relationship between caregivers' expectations (of themselves and of their social support) and their burden and well-being. Caregivers with high expectations were defined as those having a high level of perceived personal responsibility for providing care, and low receptivity to support. It was hypothesised that those with higher expectations would report higher levels of burden and distress; that women and spouses would have higher levels of expectation than men and child caregivers; and that those with higher expectations would report less use of social support. None of these hypotheses were substantiated. Interestingly, the data here suggests that it is those caregivers with lower levels of expectation who report more burden. Although there were no significant differences between sub-groups of caregivers, there was a tendency for it to be women and spousal caregivers who reported lower expectations. And whilst these burdened caregivers had more contact with support services, they also had a lower number of informal supports. Finally, they reported a lower involvement in caregiving than those with higher expectations.

Thus, the characterisation of the burdened caregiver, who is heavily involved in caregiving, cannot set limits to the role and cannot accept what they are unable to provide receives no support from this study. If anything, the reverse seems to be true: that the more
burdened caregiver is the one who is less involved in providing care, and receives more support services. These findings will be considered in more detail below, but first the methodological limitations of this study, and the restrictions these impose on the interpretation of these findings will be outlined.

1. Methodological Limitations

One of the most important factors to consider in interpreting the present results concerns the validity and reliability of the Caregiver Expectation Scale (CES) as a means of operationalising caregivers' expectation levels. As noted above (see 'Results') the CES shows evidence of good test-retest reliability, indicating that the questions were understood by participants, and they were able to respond to them consistently over time. Used as a single scale, the CES also shows evidence of fair internal consistency. However, the 'receptivity to social support' (RSS) sub-scale was less internally consistent than the 'perceived personal responsibility' (PPR) sub-scale, and it is possible that the RSS items were not all measuring the same construct. It may be, for example, that participants responded differentially to questions pertaining to institutional versus home care services. Further psychometric development of the CES would thus necessitate investigating this possibility further. Ideally, a principle component analysis would be used to provide a more thorough exploration of the number of identifiable factors that were being measured. However, the small number of participants
employed in this study, relative to the number of items of the CES (2:1) would render the factors extracted by this method unstable.

The various forms of validity of the CES are discussed above (see 'Results'). As hypothesised, PPR and RSS scores were negatively correlated. In addition, the results provide some evidence that participants' responses to the CES were reflected in their actual behaviour: those with higher expectations reported themselves to provide a higher percentage of their dependent's care, and to have a lower frequency of contact with support services. Although the relationship between caregivers' expectations and their behaviour would not be expected to be direct, but may be expected to be influenced by additional factors (e.g., availability of support services, their perception of social norms, pressure from others to [not] provide care) the fact that there is some degree of correspondence between the two suggests again that the CES has some degree of validity.

However, there are a number of limitations to the CES. First, caregivers' level of expectation was defined as how much they supposed they should be doing in the caregiving role, and PPR and RSS were identified as two contributory factors. The CES does not, however, also cover respondents' receptivity to informal support. This becomes important when one considers the differential results obtained for receipt of formal and informal support (those with higher expectations had lower contact with services but more informal supports available). Not only would it be interesting to discover the relationship between receptivity to formal and informal
sources of support, but it may also be that adding a measure of the latter to the CES would increase the sensitivity of the scale. For example, on the present scale, those who were receptive to informal but not formal support would not be differentiated from those who expected to provide all care themselves with no form of support at all.

Secondly, while the CES provides a measure of caregivers' level of expectation, the definition of this precludes measuring the nature of these expectations, ie precisely what caregivers suppose they and their supporters should be doing. This would provide interesting information but was not part of the present study of expectations.

Limitations are also imposed on the results by the sampling method employed. First, the sampling criteria specified that care recipients should be co-resident with participants. Thus, caregivers whose dependents were living alone in the community or who were institutionalized were not included. This is significant since it is possible that caregivers in these categories will have differential expectation levels. For example, those with very low expectations may be more likely to be found amongst the institutionalized category.

Second, caregivers were contacted through various service agencies. Indeed, those who were finally interviewed had been contacted through day hospitals, day centres or through the Alzheimer's Disease Society. It may be that caregivers drawn to such services differ in some way from the total caregiver population. In
addition, those caregivers who were not in contact with services were not sampled. Again, this is significant since it is possible that these caregivers differ in important ways from the present sample. For example, those with very high expectations would, by definition, be unlikely to be in contact with support services. This provides one explanation for the present lack of evidence to corroborate the characterisation of the burdened caregiver who is reluctant to accept help. It may be accurate in a community sample, but these caregivers simply may not be found in service samples. In short, the present results apply to co-resident caregivers in contact with service agencies, and there is no evidence that the results generalise to all caregivers.

In addition to a sample bias, it is possible that there is a respondent bias. For example, the burden level found in the present sample seemed relatively low, thus raising the possibility that caregivers who responded to the request for participation in this study were those who felt less burdened. However, as noted above (see 'Method'), no information is available for non-responders, and it is not possible to know how they differed from current participants.

Finally, with regards to the sample of this study, the sample size employed here was very small, which has two implications. First, control of extraneous variables was difficult, which is particularly significant in research in an area such as this where so many factors have been implicated in determining levels of burden. Second, it has implications for the statistical analysis of the
results. The use of multivariate statistics was precluded. Thus, extraneous variables could not be controlled for statistically, nor could their relative influence, and the inter-relationship between them be evaluated. When the sample was divided into sub-groups (e.g., men vs women) the numbers were very small. The validity of a number of the statistical tests employed was thus challenged (e.g., see 'other dependents' in the 'Results'). Results were also sensitive to individual variability in scores. Finally, the use of univariate statistics to compare differences between those with high and low expectations on a variety of background factors necessitated using a relatively large number of comparisons. As previously noted, in such situations, one in 20 of these may reach significance by chance, at a probability level of 0.05.

Limitations are also associated with the design of the study: its cross-sectional nature and correlational analyses preclude implications being drawn about the causal relations between correlated variables.

In short, the CES used as a means of measuring level of expectations seems reliable, and shows some evidence of validity. However, this study has many of the methodological shortcomings that characterise research in this field. The limitations regarding generalisability of the results have been noted, and the present results should be viewed as indicative rather than conclusive. Interpreted in this way they raise interesting possibilities and questions regarding the situation of caregivers.
2. Expectations and Caregiver Outcome

The finding that expectations are negatively correlated to caregiver burden seem, initially, difficult to explain. The literature suggesting that caregivers who provide more direct care also report more burden has been reviewed above (see 'Introduction'). It did seem to be the case that those with higher expectations reported fulfilling a higher percentage of caregiving duties than those with lower expectations, and for this reason alone, then, one might expect their burden levels to be higher. In addition, factors such as feelings of guilt about what they were not able to provide were expected to raise their burden levels further.

The finding becomes more understandable if expectations are seen as forming part of the "caregiving context": Montgomery (1989) suggests that the caregiving context is determined by numerous characteristics of the care recipient, caregiver and of the caregiving tasks. She claims that it is against this background that a caregiver will "make a subjective judgement about the extent to which his or her caregiving activities are an infringement that is oppressive" (p.213). It is this, rather than absolute levels of care provided, that is the critical determinant of burden. Caregivers' expectations may be seen as forming part of this context, ie they may be viewed as contributing to the 'yardstick' against which caregivers judge their own caregiving situation. It could then be argued that those caregivers with high expectations are simply fulfilling their expectations: they are doing what they suppose they should be doing in the caregiving role and therefore do
not judge their duties as an oppression. Conversely, those with low expectations perceive their own responsibility to provide care as being lower, and thus judge their caregiving duties as more oppressive.

Seen from this point of view it seems possible that, rather than caregivers' expectations levels, it is the degree of match between these and the reality of their situation that is critical in determining burden. It may be that caregiving duties are only judged to be oppressive when they are in excess of the duties the caregiver expects to perform. Caregivers with low expectations who are none-the-less providing care to their dependent relative would then be more likely to report burden. This argument could be extended to the converse situation, in which a caregiver is not providing as much care to their dependent relative as they expect they should be (eg a caregiver with high expectations, whose relative has been institutionalised). Again, the mismatch between expectations and actual behaviour may lead to burden, through feelings of guilt and a sense of having failed. Sampling limitations in this study (excluding institutionalised care recipients) preclude further consideration of this proposal. It is, however, worthy of further investigation since, if one potential contributor to burden is the mismatch between caregivers' expectations and their reality, then interventions aimed at altering one of these two factors would be indicated.

The discussion so far has assumed that expectations are an antecedent to burden. However, the relationship is merely
correlational, and it is also possible that burden levels are a
determinant of expectations. Seen in this way, high burden levels
may lead a caregiver to have lower expectations of themselves to
provide care. It may be, for example, that as burden increases, so
the caregiver disengages from caregiving, becomes less personally
involved and draws in service support. It is not possible to infer
direction of causality from the present findings.

The significant negative correlation found between expectations and
burden was not also observed between expectations and psychological
distress, measured by the GHQ. The relationship here was similarly
in a negative direction, ie those with increasingly higher
expectations reported increasingly less distress. However, the size
of the correlation was small and not significant.

As noted at several points above, there is no clear agreement about
the nature of the relationship between measures specific to the
caregiving situation, such as burden, and situationally independent
measures of psychological well-being. The fact that caregivers are
at risk of burden is clear. However, there have been discrepancies
in the literature regarding the prevalence rates of psychological
distress in this population ie the degree to which burden results in
psychological health problems. Whilst some research with caregiver
samples has revealed high levels of both situationally dependent
'strain' and distress, measured via the GHQ (eg Gilteard et al,
1984), other research has reported 'strain' to be high, but distress
low (eg Eagles et al, 1987a,b).
The two measures were found to be correlated in the present sample, as may be expected. However, it seems clear that the relationship is not straightforward, and it is likely that a number of factors will intervene in the process leading from caregiver burden to psychological distress. This is consistent with the conceptualisation of stress and health found within the stress literature (eg Cochrane, 1985) which, as noted above, sees the process leading from subjective stress (or 'strain') to health and adaptational outcome as being mediated by variables such as coping responses and social resources. Thus, it is being argued, whether or not a burdened caregiver will experience distress and show signs of psychological disturbance will depend on the influence of a number of intervening variables.

In short, it seems that caregivers' expectations may play some role in determining their levels of burden. However, their role in influencing caregivers' psychological health seems less direct.

3. Expectations and Caregiver Sub-groups

It was hypothesised here that women and spousal caregivers would have a higher level of perceived personal responsibility and lower level of receptivity to support, due to a sense that providing care is, for them, an anticipated role and that they may feel guilty for what they cannot do. However, the obtained results did not substantiate these suggestions: expectation scores for men and child caregivers actually exceeded those of women and spousal
caregivers, although neither of these differences were statistically significant. There are various possible explanations.

The most obvious explanation is that there is actually no difference in expectation levels between caregivers of different gender, or different relationship to the care recipient. Levels of expectation may be shaped by factors additional to sex role expectations or those related to the caregivers' relationship with their dependent. These may include factors such as adherence to values of family care, and individual motives for caring (reviewed in 'Introduction'). Levels of expectation, then, may contribute to burden levels, but play no part in understanding differences between sub-groups in the experience of caregiving. However, there is evidence that these results should be treated with caution.

Hypotheses formulated in the present study were based on previous reports that women and spousal caregivers experience more burden and distress in the caregiving role. These findings were not, however, replicated in the current sample. With regards to gender, the results were in the expected direction, but were non-significant. It may be important, then, that the current sample size was relatively small, rendering results sensitive to the effects of extraneous variables, which could not be controlled for, and of individual variability in burden and distress level. It may also be significant that two of the women caregivers were more distant relatives of the care recipient than spouses or children (ie niece and daughter-in-law). If burden increases with "centrality" of the relationship (Cantor, 1983: see 'Introduction') then the effect of
inclusion of these caregivers may have been to decrease the mean burden score of the female sample. Finally, the possibility of a respondent bias has also been noted above, and it may be that the more burdened (women) caregivers did not participate.

With regards to the caregivers' relationship to their care recipient, the results were in the opposite direction to that expected, and this difference was significant for burden scores. It may be worth noting that previous findings relating to the effect of relationship on burden have not been totally consistent, and some research has failed to find any effect of this variable on burden. One explanation that has been offered for the discrepancy is the confounding of relationship with other variables eg co-residency status (eg George & Gwyther, 1986). In this study, all participants were co-resident with their dependent. However, gender and relationship were confounded, with 59% of the spousal sample being men, but only 29% of the child sample. Given the potential difference in burden levels between men and women, the effect of this may have been to lower the mean burden level of the spousal sample, and raise it for the child sample. This in itself could explain the obtained pattern of burden scores. In addition, the small sample size and the resultant sensitivity of results to individual variability in scores has been noted above.

In short, given the small sample size, confounding of key variables, and lack of control for other extraneous variables, it seems likely that the present results regarding differences between sub-groups are not robust. With this in mind, it seems possible that, using a
more rigorous design and larger sample size, a clearer pattern of
differences between the expectations of sub-groups would have
emerged.

Similar conclusions could be reached when one considers suggestions
from previous research that women and spousal caregivers make less
use of support services. Although not investigated directly, the
lack of relative sub-group differences imply that it is unlikely
there will be differences in receptivity to or use of services in
the present sample. This, again, would seem inconsistent with
previous findings and suggests the present results may not be
characteristic of caregiver populations.

There was, however, a relationship between expectation levels and
use of support, and these will now be considered in more detail.

4. Expectations and Social Support

The findings regarding the relationship between expectations and
support levels differ between formal and informal sources of
support, and these will therefore be considered separately.

Formal support:
There is some evidence to support the hypothesis that caregivers'
expectations are inversely correlated to the level of support they
receive, when the latter is operationalised as frequency of contact
with support services. However, the direction of causality in this
relationship cannot be conclusively inferred. It may be that those with lower expectations seek and accept more services. Alternatively, it could be argued that those in receipt of more services lower their expectations accordingly. Gilleard (1985) prefers the latter explanation. In investigating factors which are predictive of the outcome residential placements of people with dementia she reports a high level of professional care whilst the care recipient is living in the community to be one of the factors predicting an institutional outcome six months later. From this she suggests that caregivers receiving high levels of formal support begin to believe that they should not be expected to be able to care at home.

This situation seems difficult to imagine in practice. The explanation assumes that caregivers' level of formal support is dictated solely by the level of services offered, with the caregiver playing no role in accepting, refusing or choosing how to use what has been offered. Interestingly, in this study, caregivers' expectations were not found to be related to the number of services with which they had contact. To suggest that they played no role in deciding how frequently to use these services, but that this is dictated to them and that they shift their expectations accordingly, seems unlikely. The explanation preferred here, then, is that expectation levels play some role in determining frequency of service use.

The situation becomes more complex when the finding that those with lower expectations also report more burden is taken into account.
Research suggesting that those caregivers in receipt of more formal support experience more burden has been reported before (e.g. see Morris et al., 1988a). One explanation that has been offered is that support services are reactive to caregiver burden. If this is the case, then it becomes difficult to speculate on the nature of the relationship between burden, support and expectations, and which comes first in any potential causal chain. For example, is it the case, as being suggested here, that lower expectations result in higher burden and in higher levels of support. Or is it the case that higher burden results in higher levels of support which result in lower caregiver expectations, and so on.

The results here regarding caregivers' ratings of the adequacy of their formal support shed little clarifying light. Adequacy ratings did not differ significantly with expectation levels. In some ways this seems surprising. One might have expected those with higher receptivity to support to rate its adequacy as lower. Indeed, one of the explanations given above for the higher levels of burden for those with lower expectations suggests that these caregivers' behaviour did not match their expectation level, and that they were doing more than they supposed they should. The implication is that these caregivers suppose others should be doing more to support them, and thus would rate their support as being less adequate.

There are several explanations for the lack of any significant relationship. First, it may be that caregivers' perceptions of the adequacy of their formal support did not actually differ with expectation level. However, if this is the case then it becomes
more difficult to explain why levels of burden were negatively related to expectations. Alternatively, it may be that caregivers did not want to be seen to be criticising the services they received. The tendency for service consumers to consistently rate themselves as satisfied with service provisions has been noted in other areas of research (e.g., Justice & McBee, 1978). It may be, then, that participants valued the services they did receive, and thus rated its adequacy at similar levels. Caution is therefore required in interpreting these results.

**Informal support:**

The finding that caregivers with lower expectations had a higher level of formal support was not obtained for measures of informal support. Here, those with lower expectations reported a smaller number of supportive family and friends than those with higher expectations. Again, direction of causality cannot be inferred. It may be that those with fewer family and friends available for support expect more from the services, and less of themselves. Alternatively, those with lower expectations may not get family and friends involved in providing care, or may be surrounded by family members who, equally, have low expectations of themselves to support the caregiver.

With regards to the latter explanation, it seems possible that values of family care may be one factor shaping caregivers' levels of expectations (with those adhering to such values having higher expectations) and that these values will be shared amongst family members. It is interesting that caregivers with higher expectations
were as receptive in practice to informal support as those with lower expectations. This was not found for formal support and it could be speculated that caregivers with high expectations are more receptive to informal than formal support because its use is consistent with values of family care. It would be interesting to determine the validity of this speculation since, if it were the case, then it may be that interventions for these caregivers which aimed to facilitate their use of informal support networks may be more effective in alleviating burden than formal support services. It would also be interesting to determine the way in which caregivers integrate their formal and informal support networks, ie whether they serve different specific functions, or whether they may substitute for each other.

As with formal support, when burden is introduced into the equation, the situation becomes more complex. It was found here that those with higher expectations reported a larger number of informal supports, lower level of formal support, and lower burden levels. This is consistent with previous findings (eg see Morris et al, 1988a) that those caregivers with more informal support report less burden. The inter-relationship between expectations, burden and informal support, and the nature of causality in these relationships is, however, unclear.

The discrepancy between formal and informal support in their relationship to burden (ie that formal support is associated with higher, and informal support with lower burden) is interesting. As described above, this discrepancy has been explained by suggesting
that the former is reactive to burden (and the latter presumably is
not). From the present results, however, an alternative explanation
is possible: that the relationship between support and burden is
mediated in both cases by a third variable, ie expectation level.
Whilst this is not such a parsimonious explanation, it seems
plausible that expectations will shape both burden levels and
caregivers' use of support and the adequacy of any of these
explanations remains unclear.

Interestingly, as with formal support, caregivers' ratings of the
perceived adequacy of their informal support were not associated
with their expectation level. Previous findings (see
'Introduction') have suggested that it is this perception, rather
than the actual amount of support received, that is critical in
determining burden. Further, it has been suggested (Pagel et al,
1987) that one of the most important factors in determining
perception of adequacy is the degree of upset a person receives from
their support network, which may be caused in part by their
expectations of the network not being met. Again, then, one might
have expected those with lower expectations (and higher receptivity
to support) to rate the adequacy of their support as lower. Two
explanations for the lack of any difference seem possible.

As previously mentioned, the CES did not include a measure of
caregivers' receptivity to informal support. Thus, it is possible
that caregivers' expectations of their informal support network are
similar, regardless of their receptivity to formal support. If this
were the case, then one might expect their perceptions of the adequacy of their informal support to be similar. Alternatively, the lack of any relationship between the two variables may simply indicate that all caregivers valued their informal networks, and did not want to be seen to be criticising them.

In summary, it is being suggested on the basis of the present findings, that caregivers' expectation levels precede, and play a role in determining, both their levels of burden and their use of formal and informal support. Given the correlational nature of the present research, this suggestion requires further investigation. In addition, caregivers' preferences for source of support, and the way in which they integrate their formal and informal support networks would be fruitful areas for research, given their implications for the design of caregiver interventions.

5. Expectations and Background Factors

Previous research has suggested that numerous factors may play a role in influencing levels of burden (see 'Introduction'). Determining the way in which these are related to expectations is important in considering the way in which expectations may be shaped, or the nature of the relationship between expectations and burden.

In this respect, gender, relationship to the care recipient and social support have been discussed above. Additional factors which
have been considered by previous researchers include impairment level of the care recipient, age of the caregiver and other demands placed upon them (eg other dependents, employment outside the home). This work has been unclear in elucidating their relationship to burden, and in the present study these variables were not, in any case, found to differ significantly between caregivers with high and low expectations. They do not, then, contribute to an understanding of the relationship observed between expectation levels and reported burden.

One finding that seems somewhat clearer from previous research relates to duration of care: that burden is maintained at similar levels or decreases as duration of care increases. In an attempt to explain this finding it has been argued (eg Gilhooly, 1984a; Townsend et al, 1989; Zarit et al, 1986) that people simply adapt to the increasing demands of their dependent, as the dementia progresses or that they find more effective ways of coping. It is also possible that those people who are very strained by caregiving and are unable to cope, are progressively filtered out of samples of community caregivers by the institutionalisation of their care recipients. Gilhooly (1984a) refers to this as "the survivor effect".

Consistent with this, current findings suggest that those with higher expectations (and lower burden) had been caring for longer, although this difference was not significant. The direction of this relationship, however, raises the possibility of similar lines of reasoning. It seems plausible that people raise their expectations...
of themselves in the caregiving role over time, as they become more familiar with what the role entails. Alternatively, it may be that those with lower expectations do not continue to care for as long, and given their higher receptivity to support this seems likely. Clearly, longitudinal studies would be needed to investigate these sorts of possibilities, and the need for this kind of design in caregiver research has been called for (eg Montgomery, 1989).

Interestingly, one factor which did differ significantly between caregivers with high and low expectations was the percentage of their dependent's care they reported providing personally: those with higher expectations (and lower burden) reported providing more care. These results seem in conflict with those that would be predicted from previous research, which has suggested that those who provide more direct personal care experience more burden. Some caution is required in interpreting this finding, since the measure of involvement in caregiving was based on self-report, and it is possible that those with higher expectations wished to believe they were providing more care, and perceived themselves as doing so. However, the result also suggests that subjective factors play a role in determining burden, and that these may be as or more important than the caregiver's actual caregiving behaviour.

This suggestion is not new. As described above (see 'Introduction'), cognitive factors such as the caregiver's perception of control, appraisals of caregiving tasks and their ability to cope, and attributions of the care recipient's behaviour and negative consequences of caregiving have all been implicated in
determining caregiver well-being. In addition, Whittick (1989) reports attitudes to caring to be associated with emotional distress, in that those with more negative attitudes to caring and more positive attitudes to institutionalisation report higher levels of distress. If expectation levels are viewed as another measure of caregivers' perception of their situation, then it would seem interesting to consider the relationship between these factors, and to determine which is the most predictive of caregiver burden. For example, it is possible that caregivers with lower expectations in providing care are those who emerged in Whittick's study as "reluctant caregivers" with negative and pro-institutional attitudes to caring. Likewise, it may be that caregivers with higher expectations appraise caregiving tasks as less demanding and as not exceeding their capacity to cope. It would be informative to know the way in which these factors interact in shaping caregivers' perceptions of their situation, and with this knowledge interventions which target these perceptions as a means of reducing burden could be more effectively designed.

Finally, a number of factors were not explored in the present study, but investigation of their relationship to caregiver expectations would be informative in a similar way. These factors include the quality of the caregivers' relationship to their care recipient, their motives for providing care and the coping strategies they employ.

In summary, the majority of background factors investigated in this study did not differ significantly between those with high and low
expectations, and thus provide little additional information regarding the way in which expectations are shaped, nor their relationship to burden. It is, however, possible that expectations may change over time. In addition, it is being suggested that expectations may form part of the caregivers' perception of their situation, and the way in which expectation levels interact with other subjective factors would be interesting to explore.

6. Clinical Implications and Directions for Future Research

Reference has been made throughout the above discussion to the implications that the present findings have for the design of interventions aiming to reduce caregiver burden, and to potentially fruitful areas for future research. Given that studies evaluating interventions ranging from caregiver counselling and support, to respite care have, to date, left questions regarding which interventions may be most beneficial to which caregivers in which ways, it seems worth considering the implications arising here in more detail.

The main finding in this study was that caregivers' levels of expectation were negatively correlated with their levels of burden. If it is the case, as has been suggested here, that the match between expectation levels and the reality of the caregiver's situation is a causal antecedent to burden, then two interventions are implicated.
First, interventions aiming to raise caregivers' levels of perceived personal responsibility and/or lower their levels of receptivity to support may be effective in reducing their experience of burden. This is consistent with previous descriptions of, or recommendations for, interventions aiming to directly target the caregiver's experience of their situation. For example, Whittick (1989) has suggested attitude change, encouraging the caregiver to see the positive side of caring, as a potential intervention. Alternatively, Oliver & Bock (1985) have described the use of rational-emotive therapy in alleviating caregivers' "maladaptive" emotional responses to their situation, such as self-pity and anger.

There are, however, several disadvantages to this suggestion. As noted above, it would be desirable to know the way in which expectations relate to other factors affecting caregiver burden for an intervention of this nature to be effectively designed. For example, it may be that targeting expectations directly may be ineffective, without also considering an individual's appraisals, attitudes or available coping resources. In addition, the ethics of such an intervention would need to be considered, as would the political role it would infer upon the therapist. Attempting to change an individual's beliefs regarding the role they should adopt in the provision of care to an elderly dependent relative may be neither desirable nor effective, and could be considered to contravene an ethic of the therapist ensuring "that their intervention does not unreasonably impose their own values nor those of the institution or organisation upon the client" (B.P.S., 1990, p.4).
The second clinical implication is that caregivers should be offered a level of support that matches their expectations for help. This seems equivalent to suggesting that interventions should be led by the needs and preferences of the individual caregiver. It may be, then, that future research which aims to survey these needs and preferences could provide an important source of information regarding the type of caregiver interventions that could usefully be offered.

The finding that those with higher expectations have less contact with services supports but similar levels of contact with informal supports as those with lower expectations may be relevant in this consideration. It raises the possibility that caregivers will differ in their preferences for sources of support, and these preferences may dictate the effectiveness of support received. For example, if a caregiver would prefer to receive support from their informal network, then formal support may be less effective in reducing burden, perhaps through evoking guilt at 'failing to cope'.

In addition, no analysis was undertaken here to determine whether caregivers differed in their preferences for the nature of support they received (eg informational, practical, emotional), from either their formal or informal networks. Such preferences, and the way in which the two networks are integrated by caregivers, remain interesting research questions.

Finally, recent critiques of the caregiving literature have suggested that burden alone does not adequately characterise the experience of caregiving, and that interventions should not aim only
to reduce burden or stress, but should consider the quality of life, basic needs and welfare rights of caregivers (Abel, 1990; Braithwaite, 1992). As Braithwaite has suggested "Tinkering with individual psyches and patterns of interaction are not sufficient to improve the quality of life of caregivers. We must focus on structural changes that broaden caregiving options and spread the responsibility of care if we are to make caregiving burden less of a reality" (p.23). The present research, in investigating the effect of expectations on caregiver burden is guilty of adopting this limited perspective on the caregiver situation. However, the suggestion being made here, that attempts should be made to offer caregivers levels of support which match their expectations, and that future research considers caregiver preferences for nature and source of support, seems more consistent with this argument than investigating the design of individual interventions aiming to manipulate caregivers' perceptions of their situation.

As suggested at the very outset of this report, the increasing number of people with dementia in the Western world has implications, not just for individual caregivers, but for society more generally. Although many of the caregiver interventions that have been developed and evaluated focus on personal change in individual caregivers, Abel (1990) suggests "The overriding issue is...not how to relieve stress, but how to organize society to make care for the dependent population more just and humane" (p. 147). This is not to dismiss the potential benefits of individual interventions, nor to imply that they should not be sought nor developed. It does, however, suggest that it is unlikely that
sufficient solutions will be found in this way alone. The opening quote here (p.1) claims "we are only beginning to seek means of dealing with the problems created by dependency in old age" (Isaacs et al, 1972). Twenty years on, this claim still seems relevant, and there is clearly much to learn about the caregiving situation and ways of supporting both the dependent elderly and those providing them with care.
APPENDIX I

CAREGIVERS' EXPECTATIONS SCALE

I am interested in what you think about caring for your relative, and what you think about care from the services. I would like to point out that there are no 'right' or 'better' answers: please answer each question as honestly and frankly as possible.

Please read each statement, then indicate whether you agree or disagree with it by ticking the relevant box.

1) I can foresee a time in the future when caring will become too much for me.

[ ] [ ] [ ] [ ] [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

2) I think it is my duty to care for my relative at home.

[ ] [ ] [ ] [ ] [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

3) I think that no institution could offer as much care and affection as I can.

[ ] [ ] [ ] [ ] [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

4) I think there is a limit to how much care I can provide single-handedly for my relative.

[ ] [ ] [ ] [ ] [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree
5) Even if there was a place available now in a good institution I would prefer that my relative stays at home.

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

6) I would feel guilty if I did not provide all the care my relative needs.

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

7) If there were enough government or private programs to help people with dementia, my relative could get most of what he/she needs without having to rely on me for it.

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

8) I think the State should do more to help me in caring for my relative with dementia.

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

9) If I had a job, I think it would be better to pay someone to take care of my relative than to leave my job to take care of him/her myself.

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree
10) I think that there are some things that my relative needs that are better done by the services than by myself.

[ ]  [ ]  [ ]  [ ]  [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

11) I would prefer not to get a professional to do things for my relative, but would rather do everything myself.

[ ]  [ ]  [ ]  [ ]  [ ]  [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

12) I think it is very important for me to be available for my relative to depend on.

[ ]  [ ]  [ ]  [ ]  [ ]  [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

13) I think it is my responsibility to take care of my relative in whatever way necessary.

[ ]  [ ]  [ ]  [ ]  [ ]  [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree

14) I think it is my obligation to do everything for my relative that he/she needs.

[ ]  [ ]  [ ]  [ ]  [ ]  [ ]

Strongly Agree  Agree  Don't Know  Disagree  Strongly Disagree
APPENDIX II

BURDEN INDEX

Below is a list of things which some people find difficult when caring for a person with dementia. Please read the following statements, then ring the answer which is relevant to your situation:

1) I feel resentful of other relatives who could but who do not do things for my relative.

0 | 1 | 2 | 3 | 4
---|---|---|---|---
Never | Rarely | Sometimes | Often | Nearly always

2) I feel that my relative makes requests which I perceive to be over and above what s/he needs.

0 | 1 | 2 | 3 | 4
---|---|---|---|---
Never | Rarely | Sometimes | Often | Nearly always

3) Because of my involvement with my relative I don't have enough time for myself.

0 | 1 | 2 | 3 | 4
---|---|---|---|---
Never | Rarely | Sometimes | Often | Nearly always

4) I feel stressed between trying to give to my relative as well as to other family responsibilities, job etc.

0 | 1 | 2 | 3 | 4
---|---|---|---|---
Never | Rarely | Sometimes | Often | Nearly always

5) I feel embarrassed over my relative's behaviour.

0 | 1 | 2 | 3 | 4
---|---|---|---|---
Never | Rarely | Sometimes | Often | Nearly always
6) I feel guilty about my interactions with my relative.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always

7) I feel angry about my interactions with my relative.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always

8) I feel nervous or depressed about my interactions with my relative.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always

9) I feel that my relative currently affects my relationships with other family members and friends in a negative way.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always

10) I feel resentful about my interactions with my relative.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always

11) I feel pleased about my interactions with my relative.

0 __________ 1 __________ 2 __________ 3 __________ 4

Never Rarely Sometimes Often Nearly always
12) I feel useful in my interactions with my relative.

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<td>Rarely</td>
<td>Sometimes</td>
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13) I feel strained in my interactions with my relative.

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<td>Rarely</td>
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14) I feel that my health has suffered because of my involvement with my relative.

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<td>Rarely</td>
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15) I feel that the present situation with my relative doesn't allow me as much privacy as I'd like.

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<td>Never</td>
<td>Rarely</td>
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16) I feel that my social life has suffered because of my involvement with my relative.

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<td>Never</td>
<td>Rarely</td>
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17) I wish that my relative and I had a better relationship.

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<td>Never</td>
<td>Rarely</td>
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18) I feel uncomfortable when I have friends over.

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<tr>
<td>Never Rarely Sometimes Often Nearly always</td>
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19) I feel that my relative tries to manipulate me.

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<tr>
<td>Never Rarely Sometimes Often Nearly always</td>
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20) I feel that my relative seems to expect me to take care of him/her as if I were that only one s/he could depend on.

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<tr>
<td>Never Rarely Sometimes Often Nearly always</td>
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21) I feel that I don't have enough money to support my relative in addition to the rest of our expenses.

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<tr>
<td>Never Rarely Sometimes Often Nearly always</td>
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22) I feel that I would like to be able to provide more money to support my relative than I am able to now.

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<tr>
<td>Never Rarely Sometimes Often Nearly always</td>
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**GENERAL HEALTH QUESTIONNAIRE**

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, over the past few weeks. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

### HAVE YOU RECENTLY:

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
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</thead>
<tbody>
<tr>
<td>1 - been able to concentrate on whatever you’re doing?</td>
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<td>2 - lost much sleep over worry?</td>
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<td>3 - been having restless, disturbed nights?</td>
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<td>4 - been managing to keep yourself busy and occupied?</td>
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<td>5 - been getting out of the house as much as usual?</td>
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<tr>
<td>6 - been managing as well as most people would in your shoes?</td>
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<tr>
<td>7 - felt on the whole you were doing things well?</td>
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<tr>
<td>8 - been satisfied with the way you’ve carried out your task?</td>
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<tr>
<td>9 - been able to feel warmth and affection for those near to you?</td>
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<tr>
<td>10 - been finding it easy to get on with other people?</td>
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<tr>
<td>11 - spent much time chatting with people?</td>
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<tr>
<td>12 - felt that you are playing a useful part in things?</td>
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<tr>
<td>13 - felt capable of making decisions about things?</td>
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Please turn over.
<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
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<tbody>
<tr>
<td>HAVE YOU RECENTLY:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 — felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>15 — felt you couldn’t overcome your difficulties?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>16 — been finding life a struggle all the time?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>17 — been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>18 — been taking things hard?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>19 — been getting scared or panicky for no good reason?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>20 — been able to face up to your problems?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less able than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>21 — found everything getting on top of you?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>22 — been feeling unhappy and depressed?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>23 — been losing confidence in yourself?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>24 — been thinking of yourself as a worthless person?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>25 — felt that life is entirely hopeless?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>26 — been feeling hopeful about your own future?</td>
<td>More so than usual</td>
<td>About same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>27 — been feeling reasonably happy, all things considered?</td>
<td>More so than usual</td>
<td>About same as usual</td>
<td>Less so than usual</td>
<td>Much less than usual</td>
</tr>
<tr>
<td>28 — been feeling nervous and strung-up all the time?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>29 — felt that life isn’t worth living?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>30 — found at times you couldn’t do anything because your nerves were too bad?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
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APPENDIX IV

Rationale for Use of the General Health Questionnaire 30 in the present study

The General Health Questionnaire (GHQ) was included as a situationally independent outcome measure. This is a self-administered test which aims to detect psychiatric morbidity in non-psychiatric or community settings. The test presents a series of 30 questions relating to a variety of symptoms and behaviours which are indicative of psychological disturbance. The respondent rates the occurrence of each on a four-point scale, ranging from "less than usual" to "much more than usual". A copy of it appears in Appendix III.

There are several versions available: the GHQ-60, from which has been derived shortened versions: the GHQ-30, GHQ-28 and GHQ-12. The GHQ-30 was selected for use in this study, since it is less time-intensive to complete than the GHQ-60, and it has previously been used in research with this population of respondents (e.g. Gilheard et al, 1984; Whittick, 1988; 1989).

The GHQ-30 has been shown to have good internal consistency (reports of Cronbach's alpha ranging from .84 to .93; Goldberg & Williams, 1988). Reports of its criterion validity, when validated against a standardised psychiatric assessment, such as the Clinical Interview Schedule (CIS), have ranged from .45 to .77. This, however, rises when one assumes the standardised assessment is not error-free
(Goldberg & Williams, 1988). The use of the GHQ-30 in identifying "caseness" in caregivers of people with dementia has been validated (Gilleard et al, 1984). The present study, however, did not use the GHQ as an indicator of morbidity, but as a measure of severity of psychological disturbance. Thus, no assumptions were made regarding the 'threshold' score for identifying cases.

There are a number of ways of scoring the GHQ (see Goldberg & Williams, 1988). The 'GHQ' scoring method involves scoring the first two points of each response scale as zero and the second two as one. Resultant scores thus reflect only the number of symptoms/behaviours experienced. An alternative is given by the 'Likert' scoring method, in which the four points of the response scale are scored sequentially from zero to three. This provides additional information about the intensity of each symptom/behaviour experienced, and results in a less skewed distribution of the data (Goldberg & Williams, 1988). This was therefore the scoring method chosen here.

In short, the GHQ-30 was employed because it is short and easy to understand and administer, it is of demonstrated reliability and validity, and its use is consistent with previous research in this area.
BACKGROUND DETAILS: INTERVIEW SCHEDULE

I will start by asking a few general questions about yourself, the relative you are caring for, other members of your household, and any help you may receive.

1) Gender of carer

   Male  Female

2) Gender of person with dementia

   Male  Female

3) Is your relative your:

   |   | mother/father
   |   | husband/wife
   |   | other (please specify)

4) How long have you been caring for your relative?

   ..........................................................
5) Are you

|   | employed full-time outside the home
|   | employed part-time outside the home
|   | retired
|   | left job to care
|   | homemaker

6) I would now like to ask some questions about what your relative is like at the moment (ie within the last fortnight).

INSERT 'BEHAVIOUR RATING SCALE' (Pattie & Gilleard, 1979).

7) Can you tell me how many of your friends or relatives help you with caring for your relative with dementia (list these). How often do you have contact with (ie see or speak to) each of these people?

<table>
<thead>
<tr>
<th>Friend/relative</th>
<th>Frequency of contact</th>
</tr>
</thead>
</table>

8) HAND RATING SCALE 1 TO PARTICIPANT
On a scale of 0-4, how would you rate the help or support that you get from your family and friends?

.......................
CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

Behaviour Rating Scale

Name: ........................................ Date of birth: ................................

Current address/placement: ..............................................................

Please ring the appropriate number for each item

1. When bathing or dressing, he/she requires:
   - no assistance 0
   - some assistance 1
   - maximum assistance 2

2. With regard to walking, he/she:
   - shows no signs of weakness 0
   - walks slowly without aid, or uses a stick 1
   - is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side 2

3. He/she is incontinent of urine and/or faeces (day or night):
   - never 0
   - sometimes (once or twice per week) 1
   - frequently (3 times per week or more) 2

4. He/she is in bed during the day (bed does not include couch, settee, etc):
   - never 0
   - sometimes 1
   - almost always 2

5. He/she is confused (unable to find way around, loses possessions, etc):
   - almost never confused 0
   - sometimes confused 1
   - almost always confused 2

6. When left to his/her own devices, his/her appearance (clothes and/or hair) is:
   - almost never disorderly 0
   - sometimes disorderly 1
   - almost always disorderly 2

7. If allowed outside, he/she would:
   - never need supervision 0
   - sometimes need supervision 1
   - always need supervision 2

8. He/she helps out in the home/ward:
   - often helps out 0
   - sometimes helps out 1
   - never helps out 2

9. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc):
   - almost always occupied 0
   - sometimes occupied 1
   - almost never occupied 2

10. He/she socialises with others:
    - does establish a good relationship with others 0
    - has some difficulty establishing good relationships 1
    - has a great deal of difficulty establishing good relationships 2

11. He/she is willing to do things suggested or asked of him/her:
    - often goes along 0
    - sometimes goes along 1
    - almost never goes along 2

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12. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
   - understands almost everything you communicate 0
   - understands some of what you communicate 1
   - understands almost nothing of what you communicate 2

13. He/she communicates in any manner (by speaking, writing or gesturing):
   - well enough to make him/herself easily understood at all times 0
   - can be understood sometimes or with some difficulty 1
   - can rarely or never be understood for whatever reason 2

14. He/she is objectionable to others during the day (loud or constant talking, pilfering, soiling furniture, interfering with affairs of others):
   - rarely or never 0
   - sometimes 1
   - frequently 2

15. He/she is objectionable to others during the night (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc.):
   - rarely or never 0
   - sometimes 1
   - frequently 2

16. He/she accuses others of doing him/her bodily harm or stealing his/her personal possessions — if you are sure the accusations are true, rate zero, otherwise rate one or two:
   - never 0
   - sometimes 1
   - frequently 2

17. He/she hoards apparently meaningless items (wads of paper, string, scraps of food, etc.):
   - never 0
   - sometimes 1
   - frequently 2

18. His/her sleep pattern at night is:
   - almost never awake 0
   - sometimes awake 1
   - often awake 2

Eyesight:
(tick which applies)
   - can see (or can see with glasses)
   - partially blind
   - totally blind

Hearing:
(tick which applies)
   - no hearing difficulties, without hearing aid
   - no hearing difficulties, though requires hearing aid
   - has hearing difficulties which interfere with communication
   - is very deaf

Rated by: ........................................ Date: .................................

Staff/Relative

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Fourteenth impression 1992

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The published edition of this Report Form is printed in a coloured ink: please contact the publishers if your copy is printed in black.
9) Can you tell me about which services you receive now in helping you care for your relative (e.g., meals on wheels, respite, carer support group, day hospital) (list these). How often do you receive each of these services?

<table>
<thead>
<tr>
<th>Services</th>
<th>Frequency of use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10) **HAND RATING SCALE 1 TO PARTICIPANT**

On a scale of 0-4, how would you rate the help or support that you get from the services?

.................................................

11) **HAND RATING SCALE 2 TO PARTICIPANT**

On a scale of 0-100%, how much of your relative's care would you say you provide personally, and how much is provided by other people? (The 2 scores should add to 100%).

Self: ........................................

Other: ......................................

12) Who else lives at home with you? (list first names and/or relationship to carer).

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship to carer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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13) Does anyone in the household, apart from your relative with dementia, suffer from any disability or chronic illness?

____ Yes      ____ No

If YES, who is this and what is their disability/illness?

14) Have there been any major upsets in your life over the last year? (eg financial difficulties, illness of yourself or someone close to you, loss of someone close to you).

____ Yes      ____ No

If YES, what was the upset?

15) What is the date of birth of your relative with dementia?

..........................

16) What is your date of birth?

..........................
CHECKLIST

1) Do you live with your relative? [ ] [ ]
   YES       NO

2) What is his/her primary diagnosis? .................

3) Are you the primary carer? [ ] [ ]
   YES       NO

4) Do you want a summary of the results when these become available? [ ] [ ]
   YES       NO

5) Debreifing: contact left [ ]

6) Are you prepared to be contacted for reliability check (explain what this entails)? [ ] [ ]
   YES       NO

7) Further action required? [ ] [ ]
   YES       NO
   What?.................

COMMENTS

IMPRESSIONS

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Details of Measurement and Scoring of 'Background Factors

Duration of care:
This measure was chosen in preference to time since diagnosis or duration of illness (e.g. Zarit et al, 1980). If it is the case that levels of burden do not change during the illness, but sources of burden shift, and caregivers adjust to their situation (see literature review above) then duration of care would seem a more critical variable. This was measured to the nearest year, and participants themselves located the point at which they began providing care to their relative.

Other Demands:
Employment status codes were collapsed into two categories during scoring: employed or not employed outside the home.

Other dependents were defined as children under the age of 18 years, living at home, or any other person with disability living in the household. This item was scored as the total number of other dependents mentioned.

Concurrent stressors were described to participants as "major upsets", and again were scored as the total number mentioned.
Impairment level of care recipient:

This was measured using the Behaviour Rating Scale (BRS) of the Clifton Assessment Procedures for the Elderly (CAPE). Behavioural disturbance was used as a measure of the impairment level of the care recipient, in preference to any cognitive measure of the impairment level of the care recipient, since there is some suggestion that behavioural disability is more influential in determining burden levels in the caregiver (see literature review above).

The BRS is an 18-item rating scale designed to measure behavioural competence of elderly people, and to be completed by a familiar person. The items cover four areas of disability: physical disability (Pd), apathy (Ap), communication difficulties (Cd), and social disturbance (Sd). Each item is rated on a three-point scale, with higher scores indicating a higher level of disability. Scores can be obtained for the individual sub-scales (Pd, Ap, Cd, and Sd). A total behavioural disturbance score is obtained by summing scores from the individual items, with possible values ranging from zero (low) to 36 (high).

Inter-rater reliability has been shown to be satisfactory for individual items, and sub-scale scores, across a series of five studies (Pattie & Gilleard, 1979). The scale has been shown to have concurrent validity (higher BRS scores were found for people living in accommodation with more support) and predictive validity (BRS scores discriminate between people with differing outcomes in groups
of acute elderly psychiatric, and elderly mentally infirm) (Pattie & Gilleard, 1979).

It is relatively short and easy to administer, and has been used in previous studies of this nature (e.g. Gilleard et al, 1984; Eagles et al, 1987b).

**Formal and Informal Support:**

As noted above (see literature review above), social support is a multi-dimensional concept, which has been conceptualised and measured in a variety of ways with little agreement about its basic elements (e.g. Sarason et al, 1983). In measurement, distinctions have been made between structural and functional elements (i.e. existence of a supportive network vs. type of support provided) and between emotional and practical support (e.g. Norbeck et al, 1981; Power et al, 1988). The importance of considering an individual's perception of the availability and adequacy of support has also been noted (e.g. Power et al, 1988; Sarason et al, 1983). Finally, it has been suggested that the over-provision, as well as under-provision, of different types of support should be measured (Power et al, 1988).

Throughout the caregiver literature, measures of formal and informal support have varied, from the use of standardised questionnaires (e.g. see Borden, 1991) to number of visits from various professional (e.g. Gilhooly, 1986). Harper & Lund (1990) report the use of a simple scale, measuring informal network size and quality. The former was addressed via totalling the number of people
caregivers reported to be readily available to help with caregiving tasks, and the latter was addressed in questions about the ease and frequency of contact with supporters, and perceived satisfaction with support. The scale was devised by Diamond et al (1987) and shown to have high internal consistency (alpha = .81) when used with a sample of caregivers (Caserta et al, 1987). Insufficient details were provided in these papers to use the scale in its original format here. However, the elements of it were employed to address both formal and informal support of caregivers. Thus, participants were asked questions about the size (number of people/services reported to be available) and quality (frequency of contact with each person/service; and perceived adequacy) of support. Information concerning the specific function of each supportive relationship was not sought.

**Scoring:** The number of people reported to be available to help with caregiving was totalled. This total included those people mentioned to be available if asked, but who had not yet been asked. The number of services received in relation to caregiving was also totalled. This total did not include non-specialist help (e.g. cleaner, gardener), but did include caregiver support groups. Where more than one type of service was provided by the same place (e.g. respite care and day care at a hospital), this was scored as two separate services.

Frequency of contact with informal supporters and formal support services was scored as the total number of contacts per month. Where contact was continuous over several days (e.g. one week...
respite) this was scored as a new contact each day, to provide some reflection of the degree of support. Further than this, no attempt was made to weight scores for duration of contact.

Perceived adequacy of support was rated by the participant on a five-point scale (see Appendix VII) ranging from "much less than adequate" to "much more than adequate", for both formal and informal support.

Thus, for each participant there were six support scores: number, frequency and adequacy of informal and formal supporters. This was chosen as a brief, cursory measure of support which reflected both size and perceived quality of support networks. It was considered to be an adequate reflection of support, and more appropriate than a lengthy standardised questionnaire.

Involvement in Caregiving:
In previous research, this has been operationalised in various ways, including rating of involvement on a 12-point scale (Horowitz, 1985), proportion of caregiving duties assumed by the caregiver (Pett et al, 1988) and caregiver's hours of contact with care recipient. In this study it was operationalised as the percentage of care provided personally by the caregiver, and was scored on a rating scale (see Appendix VII) by the participant.
APPENDIX VII

Rating Scale 1

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not</td>
<td>Not</td>
<td>Enough</td>
<td>Slightly</td>
<td>Much more</td>
</tr>
<tr>
<td>nearly</td>
<td>quite</td>
<td>enough</td>
<td>more than</td>
<td>than enough</td>
</tr>
<tr>
<td>enough</td>
<td>enough</td>
<td>enough</td>
<td>enough</td>
<td></td>
</tr>
</tbody>
</table>

Rating Scale 2

<table>
<thead>
<tr>
<th>0</th>
<th>10</th>
<th>20</th>
<th>30</th>
<th>40</th>
<th>50</th>
<th>60</th>
<th>70</th>
<th>80</th>
<th>90</th>
<th>100%</th>
</tr>
</thead>
</table>

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Dear

I am a Trainee Clinical Psychologist studying at the University of Plymouth. I am currently engaged in research with people who are caring for a relative who is suffering from dementia, such as Alzheimer's Disease. In particular I am looking at the expectations that people have of themselves in caring for a relative, and how this may affect their experiences of care-giving. I know that many people find caring for a relative can be a demanding and stressful task, and it is important to understand the things that might contribute to this. The research aims to study this.

I understand that you are caring for a relative and I would be extremely grateful if you would be prepared to be interviewed. The interview can be arranged at a time and place of your convenience, and any information that you give me will be confidential: no-one will try to identify you on the basis of what you say.

If, at any time, you have questions or concerns about the research, or if you want to talk with me before making your decision, then please do not hesitate to contact me on Plymouth (0752) 233161 or at the address above.

Please could you fill in the slip below to let me know of your decision. This can be returned to me in the enclosed stamped addressed envelope. It would be very helpful to me if you could return this as soon as possible.

Thank you for your help.

Yours sincerely

Kate Foote
Trainee Clinical Psychologist

__________________________________________________________

I am/am not * willing to be interviewed for the research (* Please delete as applicable)

NAME .................................. TEL. NO. .............................
ADDRESS .................................. DATE .............................
.................................................. SIGNED ..........................
The research for which your participation has been requested aims to study the expectations that people have of themselves in caring for a relative with dementia, and how this may affect the impact of care-giving.

The research interview starts by asking some questions about yourself, the relative you are caring for, other members of your household and any help you may receive in care-giving. It then asks you to complete three questionnaires. One of these is concerned with your expectations in providing care, one is concerned with the impact of care-giving on you and some of the things about care-giving which you may find difficult, and the third is concerned with your recent health.

If at any stage you want to stop the interview then you will be free to do so, and you will not have to state a reason unless you wish to.

The information that you provide for the research will be kept completely anonymous.

If, at any time, you have questions or concerns about the research, then you can contact Kate Foote, Clinical Teaching Unit, University of Plymouth. Tel: Plymouth 233161.

Your decision about whether or not to participate in the research has no effect on any of the services you may receive in relation to caring for your relative.

--INFORMED CONSENT--

I have read and understood the above, and agree to be interviewed for this research.

Name..............................................

Signed.......................................... Date.............
Dear

Thank you for your help in participating in my research project, and for agreeing to be sent another questionnaire which you will find enclosed.

The questionnaire can be returned to me in the stamped addressed envelope provided. Please just fill in the questionnaire as honestly as possible, based on what you think about caring today.

Once again, many thanks and best wishes.

Yours sincerely

Kate Foote
Trainee Clinical Psychologist

Enc
**APPENDIX XI**

**Summary table of Analysis of Variance to test for differences in CES scores between husbands, wives and daughters**

Mean CES score:

- **husbands** (n = 10): 4.20
- **wives** (n = 7): 0.57
- **daughters** (n = 5): 4.20

<table>
<thead>
<tr>
<th>Source of Variance</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F-ratio</th>
<th>Significance of F</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main Effects</strong></td>
<td>62.84</td>
<td>2</td>
<td>31.42</td>
<td>0.56</td>
<td>0.58</td>
</tr>
<tr>
<td>RELN</td>
<td>62.84</td>
<td>2</td>
<td>31.42</td>
<td>0.56</td>
<td>0.58</td>
</tr>
<tr>
<td><strong>Explained</strong></td>
<td>62.84</td>
<td>2</td>
<td>31.42</td>
<td>0.56</td>
<td>0.58</td>
</tr>
<tr>
<td><strong>Residual</strong></td>
<td>1076.11</td>
<td>19</td>
<td>56.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>1138.96</td>
<td>21</td>
<td>54.24</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX XII

Contingency table for gender by CES score category

<table>
<thead>
<tr>
<th>Gender</th>
<th>CES Score</th>
<th>Count</th>
<th>Expected Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>5</td>
<td>4.4</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td></td>
<td>6</td>
<td>5.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6</td>
<td>6.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>

Fisher's Exact Test:

Two-tail \[ p = 0.670 \]
Contingency table for relationship by CES score category

<table>
<thead>
<tr>
<th>Count</th>
<th>CES Score</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
<td>TOTAL</td>
</tr>
<tr>
<td></td>
<td>Expected Frequency</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td>5.6</td>
<td>6.4</td>
</tr>
<tr>
<td>Reln.</td>
<td>Child</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2.4</td>
<td>2.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>(%)</td>
<td></td>
<td>(47.1%)</td>
<td>(52.9%)</td>
</tr>
</tbody>
</table>
Contingency table for employment status by CES score category

<table>
<thead>
<tr>
<th>Employment status</th>
<th>CES Score</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low (7)</td>
<td>High (10)</td>
</tr>
<tr>
<td>Not Employed</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Employed</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>9 (45%)</td>
<td>11 (55%)</td>
</tr>
</tbody>
</table>

Fisher's Exact Test:
Two-tail \( p = 0.566 \)
### APPENDIX XV

Contingency table for number of other dependents by CES score category

<table>
<thead>
<tr>
<th>Count</th>
<th>CES Score</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Expected Frequency</td>
<td></td>
</tr>
<tr>
<td>Zero</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>7.7</td>
<td>9.4</td>
</tr>
<tr>
<td>One</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>0.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Two</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>0.5</td>
<td>0.6</td>
</tr>
<tr>
<td>TOTAL</td>
<td>9 (45%)</td>
<td>11 (55%)</td>
</tr>
</tbody>
</table>


-149-


