

---

**CAUSAL ATTRIBUTIONS, KNOWLEDGE OF DEMENTIA  
AND PSYCHOLOGICAL WELL-BEING IN  
CAREGIVERS OF PEOPLE WITH DEMENTIA**

**FIONA ROBERTS**

D.Clin.Psy 1999

University College London

---

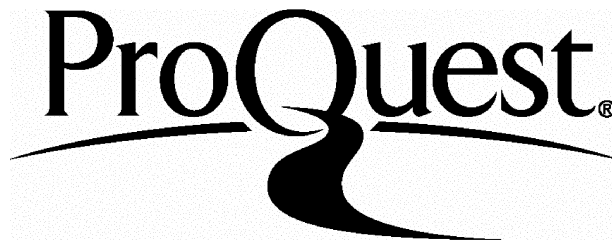
ProQuest Number: U642757

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U642757

Published by ProQuest LLC(2015). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.  
Microform Edition © ProQuest LLC.

ProQuest LLC  
789 East Eisenhower Parkway  
P.O. Box 1346  
Ann Arbor, MI 48106-1346

635161

---

“...there is no knowledge that is not power...”

(Ralph Waldo Emerson)

---

**INDEX**

	<b>Page</b>
<b>Abstract</b>	<b>7</b>
<b>Acknowledgements</b>	<b>8</b>
<b>Chapter One: Introduction</b>	<b>9</b>
1.1    Meaning and cause.	10
1.2    Causal attribution and psychological distress.	12
1.3    Caregiver distress and attributional models.	17
1.4    Causal attributional style and caregiver distress.	23
1.5    Attributions and knowledge.	26
1.6    Psycho-educational groups.	28
1.7    Knowledge and distress in caregivers.	34
1.8    The research questions.	37
<b>Chapter Two: Method</b>	<b>39</b>
2.1    Participants	39
2.2    Procedure	41
2.3    Assessments	41
2.4    Data analysis	47
<b>Chapter Three: Results</b>	<b>49</b>
3.1    Demographic Description of the Sample	50

---

<b>Chapter Three : Results Continued...</b>		<b>Page</b>
3.2	Dementia knowledge, caregiver well-being and causal attributions.	60
3.3	Interactions	73
3.4	Analysis of the role of causal attributions in mediating between caregiver knowledge and well-being.	79
<b>Chapter Four: Discussion</b>		<b>80</b>
4.1	Summary of the main research findings.	80
4.2	Discussion of the findings and previous research.	82
4.2.1	The main findings.	82
4.2.2	Caregivers characteristics within the sample.	96
4.2.3	Other factors in care giving distress.	100
4.2.4	How the findings fit with existing models of caregivers stress: Pearlin's Stress Process Model Of Caring.	104
4.3	Methodological difficulties	106
4.4	Clinical and research implications of the current study.	113
<b>References</b>		<b>120</b>
<b>Appendices</b>		<b>133</b>
<b>Tables</b>	Table 3.1 Demographic data on caregivers.	51
	Table 3.2 Caregiver's socioeconomic data.	52

---

## Tables continued...

## Page

Table 3.3	Demographic data on care recipients.	53
Table 3.4	Caregivers's ratings of their relative's behaviour.	55
Table 3.5	Amount of help received x socioeconomic status.	59
Table 3.6	GHQ scores	60
Table 3.7	GHQ x BMD	62
Table 3.8	SASS x length of time caring.	63
Table 3.9	DKQ scores	67
Table 3.10	Scoring of DKQ individual items.	68
Table 3.11	Causal attributions about dementia.	70
Table 3.12	Causal attributional style.	72
<b>Figures</b>		
Figure 1.1	Premises of the attributional reformulation of depression.	14
Figure 1.2	Attributional relationship.	27
Figure 3.1	Types of task being carried out by caregiver.	55
Figure 3.2	Length of time caring.	57
Figure 3.3	Relative contributions of support services to caregivers.	57
Figure 3.4	Sources of information identified by caregivers.	64
Figure 3.5	Most and least helpful sources of information.	65

Figures continued...	Page
Figure 4.1 The stress process model of caring.	105

**Appendices**

Appendix I Consent form	134
Appendix II Information sheet given to participants.	135
Appendix III Ethics committee forms.	136
Appendix IV Demographic details	139
Appendix V ASQ (Adapted Version)	143
Appendix VII Attributions about dementia care giving.	147



**ABSTRACT**

Clinical work with older people often involves the provision of information to those who care for a relative with dementia. Caregivers who have a greater understanding of dementia in general have been shown to experience lower levels of depression but higher levels of anxiety. However, studies have frequently found that information groups on their own fail to reduce caregiver distress. This study explored the relationship between information and caregiver distress. It also examined a possible factor which may mediate between the two; pessimistic causal attributional style, on the basis that this factor has been shown to be predictive of later distress in caregivers. Quantitative measures were used in a quasi-experimental design to explore the relationships between these variables within a group of 37 caregivers for individuals with dementia. The results indicated that dementia knowledge does have some relationship to the well-being of caregivers in terms of lower scores on the GHQ and SASS. The research identified that knowing about the aetiology of dementia may be particularly important in moderating caregiver distress. The results did not support the hypothesis that causal attributions may mediate between knowing about dementia and caregiver well-being, but did find some correlations between the measures of causal attribution and caregiver well-being. The discussion makes some recommendations about how the effectiveness of information giving strategies might be improved in the light of these findings.

**ACKNOWLEDGEMENTS**

I would first of all like to thank all those caregivers who gave their time and goodwill to this project, and to express my gratitude to Stephen Davies and Val Curren for supervising this study. I am also very grateful to all those who assisted me in the recruitment of a sample including; everyone at the Alzheimer's Disease Society in Dunmow, Harlow and Epping; and Workers at Herts and Essex NHS Trust services for Older Adults and Enfield Older Adults Psychology Service. Finally I would like to thank my tolerant family and friends for their boundless energy in supporting me in the completion of this project over the last two years.

## CHAPTER ONE: INTRODUCTION

### **Overview**

In 1996 in England and Wales it was estimated that around 665,000 people aged 65 and over were suffering significant impairment as a result of dementia (House of Commons Hansard, 4/11/97 col 103W), a number that is set to rise (Zarit & Edwards, 1996). As there is no cure at present for this degenerative condition, sufferers need increasing amounts of support up until their death (Stillwell, Hassall & Rose 1984). Relatives, usually wives and daughters, are the group who often care soonest and longest (Zarit & Edwards, 1996), with many studies revealing that they are the most important source of support (Shanas, 1979; Cantor, 1983; Johnson, 1983). In the UK there is an emphasis on community care of the elderly, mirrored by ongoing reductions in residential placement provision, making this a trend unlikely to be reversed (Age Concern, 1998).

In recent years considerable time and effort has been expended on educational programmes for those who care for a relative with dementia. This has probably been a result of a growing awareness of caregiver distress and a wish to reduce it. Unfortunately beyond the general idea that knowledge is empowering, little attention has been paid to exactly how knowing about dementia could be beneficial to caregivers.

This study examines the role of knowing about dementia in caregiver well being and explores a possible mechanism that may underlie this relationship; meaning in the form of causal attributions. This introduction intends to provide an account of the formulation of the research question, as well as placing the research within the context of the dementia care giving literature. As a starting point it seems important to consider whether meaning in the form of causal attributions could cause distress.

### 1.1 Meaning and Cause

Historically there has been friction between the scientific paradigm and consideration of the causal role of meaning, with logical positivists and their sympathisers critical of metaphysical doctrines. This friction has continued perhaps mainly because of the seemingly subjective nature of understanding (Bolton & Hill, 1997). This has led to a general acceptance of the separation of meaning from cause within the scientific paradigm.

Cognitive behavioural theorists have challenged this standpoint, declaring that cognitive states *are* implicated in the regulation of behaviour (e.g., Gardener, 1985; Baars, 1986). They propose that meaning, in the form of semantic information about organism-environment interactions (both correct and incorrect) is encoded in the acting being, influencing their behaviour. Cognitive behaviourists seek not only to understand behaviour, but also to predict it, presenting meaning as intrinsically causal. They state

that meaning must be causal, as the physical environment alone accounts for little of the variation in human behaviour. They suggest that difference can only be explained in terms of different personal understanding of the environment. They have argued strongly against the idea that only physical objects can be causes. Bolton & Hill (1997) for example, highlight the case of cognitive patterns. Living organisms are sensitive to and react to high order, complex, cognitive patterns although they do not map onto an exact physical object. An example of this can be seen in how an individual decides whether something is a toxin or a food. The individual makes the decision not by the physical presentation, but by the cognitive pattern which divides foods from non foods. Bolton & Hill (1997) suggest that "...if we want the best scientific explanation of human behaviour - not just to understand the behaviour, but to give causal predictive explanations - then we have to take on board, find out about, the system of beliefs, and world pictures, which guide and regulate behaviour..." (p.23). This is sometimes termed 'lay model'.

Accepting that meaning can equate with cause could prove helpful in understanding disordered psychological states. Personal meaning may explain why individuals react in certain ways to aversive stimuli or events. This conceptualisation goes beyond models which only look at 'low level'(or simple) appraisal, such as that formulated by Lazarus & Folkman (1984). Their stress model suggests that an individual appraises the potential for threat when a potential stressor is detected. On the basis of this appraisal the individual defines the situation as a stressor or non-stressor, and then evaluates their

---

ability to cope. The model suggests that distress occurs when the individual's appraisal of threat outweighs their perceived ability to cope. The model does not consider personal meaning and higher level processing which constructs more complex strategies to solve problems.

The model, though helpful, fails to give an account of the exact mechanism by which an individual reaches the decision of whether or not a situation can be coped with. It can be supposed that this is influenced by individual factors, such as the personal meaning of the situation to the individual. This necessitates an understanding of higher level processing. One form of such higher level processing (and there are others) is thought to be causal attributional style. Causal attributional style has been described as the way in which an individual answers the question "What causes the observed event?" (Jones, Kannouse, Kelley, Nispert, et al., 1972) and has been a highly influential concept on models that describe the genesis of psychological distress (Power & Brewin 1997).

## **1.2 Causal Attributions and Psychological Distress**

One of the most well known applications of causal attributional style in the understanding of psychological distress is within Abramson, Seligman & Teasdale's (1978) Attributional Reformulation of Depression. The theory is based upon the group's earlier Learned Helplessness Theory (Seligman 1974), which proposed that when an individual is faced by an uncontrollable stressor they become helpless and hopeless of

controlling stress in the future. The later reformulation of the theory (Abramson, Seligman & Teasdale, 1978) was developed in response to criticisms that the original theory lacked distinction between outcomes that were controllable for some and outcomes that were not controllable for anyone, and that it did not take account of specific or general conclusions made by the individual.

The reformulated theory combined the idea of learned helplessness with the self control theory developed by Rehm (1977). The reformulation suggested that individuals react differently to a stressor depending upon the meaning that they place upon it (**Figure 1.1**). The theory considers one particular type of meaning; ‘causal attribution’, and hypothesised that a depressed person may show a particular causal attributional style which can be termed ‘pessimistic’. The authors hypothesised that a depressed individual would tend to attribute negative outcomes internally (blame themselves) and attribute positive outcomes externally. The theory considered that they would be even more vulnerable to depression if they tended to over-generalise the effects to other situations and to consider the outcome as stable and unchangeable.

Investigations of the role of causal attributions in depressed and non-depressed individuals have delivered contradictory outcomes (see Robins & Hayes, 1995 for a review). Concurrent studies, looking at present relationships between depression and causal attributions for hypothetical negative events, have generally provided consistent

**I**

Expectancy of aversive or non rewarding outcome.

**II**

Expect that outcome will be beyond his / her control.

**III**

Individual has a maladaptive attributional style;

- Negative events are attributed to internal stable and global causes.
- Positive events are attributed to external unstable and specific causes

**IV**

The greater I and II,  
The greater the motivational and cognitive deficits,  
The greater the importance to the individual of the uncontrollable event,  
The greater the effective and self esteem disruption.

**Figure 1.1 :** Premises of the Attributional Reformulation of Depression  
After Abramson, Seligman & Teasdale (1978)



and strong evidence for the role of explanatory style (e.g. Robins, 1988; Eaves & Rush, 1984), but little or no relationship has been found when naturally occurring negative events are considered (e.g., Cochran & Hammen, 1985; Robins & Block, 1989). However, these studies tend not to look at individuals with ongoing negative life events. Those that do, indicate that a pessimistic attributional style correlates with depressed affect (e.g. Metalsky, Halberstadt, & Abramson, 1987). Studies rarely consider whether a pessimistic explanatory style for *positive* events correlates with depression. Those that have suggest that there is a concurrent relationship between pessimistic explanatory style and positive events (e.g., Sweeney, Shaeffer & Gollin, 1982), but there is little evidence for a prospective relationship between the two (e.g., Seligman, Peterson, Kaslow, Tannenbaum et al., 1984).

Robins & Hayes (1995) have proposed that much of the variability in findings is probably as much to do with extraneous factors as with a weakness in the theory. They point towards insufficient power of statistical analyses to detect modest relations and insufficient testing of the whole model. Sweeney, Anderson & Bailey (1986) conducted a meta analysis of 104 studies of this type. Their review concluded that there was a strong link between pessimistic attributional style for negative events and depression, and a weak to moderate link between positive attributional style, positive events and depression. As Williams (1992) states - as "...maladaptive attributions do occur in some patients, their role in all depressed patients must be looked for..." (p.32).

After reviewing these findings it appears that there could be an argument for suggesting that negative attributional style for adverse events may herald later depression. Once someone is already depressed, they may become more negative about positive events too.

Cognitive behaviour therapy has also highlighted the role of maladaptive cognitions (which can be understood in terms of a pessimistic attributional style) in anxiety as well as in depression (Mineka, Pury & Luten, 1995). There is little research looking into the relationship of anxiety to pessimistic attributional style, but studies have found that a pessimistic explanatory style seems to be associated with anxiety in non-clinical populations (e.g. Nezu, Nezu, & Nezu, 1986). Similar correlations have been found in clinical populations, although with less clear cut results. Agoraphobics, for example, have been shown to have a pessimistic explanatory style for negative events, whilst often demonstrating less pessimistic styles for positive events (e.g., Hoffart & Martinsen, 1990). Mineka et al. (1995) speculate that perhaps it is this non-pessimistic attributional style for positive events which prevents the onset of more severe depression. It certainly appears likely that causal attributions have some role to play in the aetiology of anxiety.

Summarising the research looking into the relationship between pessimistic attributional style and depression or anxiety, certain patterns of pessimistic attributions seem to be apparent. A pessimistic attributional style for negative events and not for positive events seems to relate to anxiety, and may be characterised by a sense of uncontrollability, and

pessimism for the outcome of negative events in the future. If however pessimistic attributions about positive events are also evident individuals seem more likely to be depressed.

### **1.3 Caregiver Distress and Attributional Models**

This present study is concerned with how attributional style may relate to the distress (mainly depression and anxiety) frequently seen in dementia caregivers (e.g., Coen, Swanwick, O'Boyle, & Coakley, 1997; Donaldson, Tarrier & Burns, 1998; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998). To understand whether a pessimistic attributional style (and hence these models) could have anything to contribute to our understanding of psychological distress in dementia caregivers, it is vital that several basic premises of the reformulated attributional theory are met. Firstly the individual must be faced with a negative event or situation. This means that caring for someone with dementia must be recognised to be a stressor. Secondly this stressor must cause psychological distress. Finally this distress must only be experienced by some of the caregivers, with severity of objective burden being unable to wholly account for the variance. There would be no need to evoke the mediating influence of attributional style if the degree of objective burden alone could account for the difference.

In order to consider whether caring can be considered a stressor it is necessary to understand the nature of what it is like to care for someone with dementia. Dementia can

be described as sustained loss or change in at least three of the following areas; cognition (the ability to manipulate old information), memory (the ability to learn new or retrieve old information), visuoperceptual function, language, and social behaviour (Cummings and Benson 1986). However, this description fails to express the challenge of caring for someone with dementia.

The consequences of the disease are both far reaching and unpredictable. Even when a diagnosis is established, and it often is not, the course of the disease generally remains a matter for speculation (Toseland, Rossiter, & Labrecque, 1989a). To add to the confusion there are many different types of dementia each characterised by a cluster of symptoms presenting an array of challenges to caregivers. The lack of prognostic clarity often means that the only clear pattern that can be seen across individuals is caregivers providing increasing amounts of care.

In general, most people with dementia show little deterioration during the early stages of the disease (Livingston & Hinchcliffe, 1993). At this point symptoms may include memory and word finding difficulties with caregivers beginning to step in to take control of household management and organisation of everyday life. This can be difficult for the caregiver. They may be simultaneously assimilating the implications of the diagnosis and attempting to assist an individual who may fail to recognise their reduction in abilities and who may be hostile to receiving help. Caregivers, particularly those caring for a parent, may also be finding it very difficult to adjust to the reversal of roles within their

relationship. Later in the disease process caregivers may provide more personal care including tasks like bathing, feeding and toileting. The care recipient usually becomes increasingly confused, finding it difficult to understand what is said to them, and may fail to recognise family and friends.

The care recipient might wander or place themselves at risk by attempting familiar tasks they can no longer carry out safely. If the disease affects their frontal lobes there may be changes in personality perhaps with accompanying aggressive or dis-inhibited behaviour. A recent study revealed that 15% of all those with dementia had been violent in the year following diagnosis (Paveza, Cohen, Eisdorfer, Freels, et al., 1992). Eventually the individual may become totally dependent on others, being unable to toilet, feed, wash or dress themselves. Even if an individual is admitted to a residential unit caregivers may continue to be highly distressed, perhaps feeling lonely because their partner is no longer with them, or guilty that they cannot provide care at home (Aneshensel, Pearlin & Schuler, 1993; Buck, Gregson, Bamford, McNamee, et al., 1997).

Changes in the care recipient are often described by caregivers as being both tiring and upsetting. Caregivers may become isolated as social contacts are reduced, and their own physical health may deteriorate as the burden of care increases. If their relative is admitted to residential care the caregiver usually continues to provide support by visits, remaining the main point of liaison for other family members (Rosenthal & Dawson,

1992). The term 'living bereavement' (Zarit & Edwards, 1996) clearly expresses the quandary of being a dementia caregiver.

Considering the task of care giving it appears that caring for someone with dementia involves a good deal of uncontrollable stress. Many of the care recipient's behaviours are may seem unamenable to change and the pressures on caregivers can fluctuate wildly with little warning. This certainly seems to match the kind of uncontrollable stressor described by Abramson and his colleagues (1978) and it would almost seem surprising if caregivers did not become distressed. A number of studies have shown that levels of strain and depression are high amongst caregivers (Buck et al., 1997; Morris, Morris, & Britton, 1989a). Dura, Haywood-Niler, & Kiecolt-Glaser's (1990) longitudinal study of spousal caregivers found that although caregivers exhibited no higher levels of depression than matched controls during the year prior to the start or in the first stages of their relative's disorder, during follow up over 30% had experienced a depressive disorder in comparison to only 1% in the matched controls.

A relationship has also been demonstrated between care giving and physiological changes, including changes in sleep pattern (Golodetz, Evans, Heinritz, & Gibson, 1969) or immune functioning (Pomara, Deptula, Gallow, LeWitt et al., 1987; Kiecolt-Glaser, Dura, Speicher, Trask et al., 1991; Vitaliano, Scanlan, Krenz, Schwartz, et al., 1996). Kiecolt-Glaser et al. (1991) demonstrated that these negative physiological consequences may remain, even after the care recipient is institutionalised. Dementia caregivers visits

their General Practitioners twice as often and take up to 86% more prescribed medication than the population as a whole (Katon, Kleinman, & Rosen, 1982).

Not all studies have found such relationships (Eagles, Craig, Rawlinson, Restall, et al., 1987), and caution must remain as there has been a tendency to select samples from groups who present for help and may therefore be, by definition, more distressed. Many of the recent studies have sought to overcome such sampling biases and it does appear that there is a relationship between caring and psychological distress. Longitudinal studies suggest that this is as a result of the care giving process.

Despite the high rate of morbidity among caregivers, many do not become distressed and severity of the objective burden on its own is inadequate to account for the variance (Hooker, Frazier, & Monahan, 1994; Morris et al., 1988b; Light & Lebowitz, 1989). Although Rabins, Mace, & Lucas (1982) found that the degree of dementia related to distress, many other researchers have found no direct connection between the two (Duijnste, 1992; Gilleard, Belford, Gilleard, Whittick, et al., 1984; Eagles et al., 1987; Gilhooly, 1984). Several separate behavioural symptoms in the care recipient have been shown to partly explain why only some caregivers become distressed. Behavioural disturbance appears to be particularly distressing for caregivers (Aneshensel et al., 1995; Absher & Cummings, 1994; Donaldson et al., 1998; Gilleard et al., 1984, Morris, et al., 1988a; Pruchno & Resch., 1989; Teri, Truax, Logsdon, Zarit, et al., 1992) and distress appears to positively correlate with the length of time the caregiver has been providing

care (Grad & Sainsbury, 1963). Interestingly the degree of cognitive impairment itself has not been found to relate to caregiver distress (Coen et al., 1997). Some authors (e.g. Duijnste, 1992; Kramer, 1997a) have suggested that the discrepancy is due to methodological difficulties within these studies, each measuring slightly different criteria. Others have highlighted the circular argument of predicting distress by caregiver ratings of behaviour. This is based on the finding that distressed caregivers make significantly higher ratings of difficulties in comparison with independent judges than do non-distressed caregivers (Coen et al., 1997; Pruchno, Burant, & Peters, 1997). This later point also demonstrates that how the caregiver views caring may be as important as the task itself. That is, it is not just how many stressors the caregiver faces that are important, but also how they understand them, in that case, whether they rate them as being a 'difficulty'.

In conclusion, it appears that caring for someone with dementia meets all the main criteria for the Reformulated Attributional Theory of depression (Abramson, Seligman & Teasdale, 1978). It can be considered as an ongoing stressor, that correlates with distress. A stress appraisal model is insufficient to account for why only some caregivers become distressed and so there must then be some other mediating factor. The Reformulated Attributional Theory of Depression proposes that causal attributions are this factor. According to the Abramson, Seligman & Teasdale (1978) and the attribution research carried out, the repeated inability to change the situation coupled with internal attributions for negative events and external attributions for positive events could cause



depression in some caregivers, whilst leaving others unaffected. This would be particularly the case if they viewed their situation as unchangeable and all engulfing.

#### **1.4 Causal Attributional Style and Caregiver Distress**

Only two studies have examined the relevance of the pessimistic attributional style to psychological distress in dementia caregivers. The first study (Coppel, Burton, Becker, & Fiore, 1985; Pagel, Becker, & Coppel, 1985) looked at 68 spouse caregivers (aged 37 to 85 years) of individuals with Alzheimer's disease, using a two wave assessment schedule. There was a ten month delay between the first and second wave.

The study found, like other studies, that the severity of the stressor did not fully account for depression at follow up. A positive correlation between depression and pessimistic attributional style about a self nominated distressing behaviour of the care recipient was found, although no relationship was found between pessimistic attributional style and anxiety symptoms. Pagel et al. (1985) recognised that the measure used to assess anxiety (The Anxiety Sub-scale of the Symptom Checklist-90; Derogatis, Rickels, & Rock, 1976) was less powerful than that used to assess depression (a principle component analysis of three measures of depression; Beck Depression Inventory; Hamilton Depression Rating Scale; and the depression sub scale of the SCI-90 - Beck & Beamesderfer, 1974; Hamilton, 1967; Derogatis et al., 1976 respectively), and hence may have been unable to detect the relationship.

Looking more specifically at what kinds of attribution about the distressing behaviour linked with caregivers reporting depressive symptoms, the research revealed that in line with part (II) of Abramson, Seligman & Teasdale's (1978) reformulation, loss of control was significantly related to depression. Furthermore, this relationship was found to increase as a function of the caregiver's tendency to make internal attributions, that is blame the self. Caregivers who both felt their spouses behaviour to be out of control, and who blamed themselves showed, more depressive symptoms and were most likely to be depressed at the 10 month follow up.

The findings were less conclusive than the other two features of the pessimistic attributional style described by Abramson, Seligman & Teasdale (1978; **Figure 1.1**, part III); whether or not the relative's distressing behaviour is attributed to stable and global causes. Of the two, only whether the relative considered the behaviour to be all pervasive (global), related to depression. Coppel et al.(1985) comment that in the case of individuals with Alzheimer's disease this is not necessarily surprising, as the degenerating nature of the condition means that caregivers are constantly faced with a far from stable situation.

The researchers also examined the relationship between caregivers causal attributions about changes in their own lives and depressive symptoms. They found that unlike the reaction to perceived loss of control over the spouses behaviour, perceived loss of control over changes in the caregiver's own life did not predict depression, however the

stability and globality of these changes did. This perhaps relates to Wortman & Dintzer's (1978) proposition that an event must be sufficiently important and aversive for a depressive reaction to occur. It may be that in the face of greater difficulties, for example managing an ongoing challenging behaviour, losses to one's personal life may seem relatively unimportant, although reminders about the cause of these losses may serve to remind one of the changed situation as a whole. As the authors do not relate what kinds of situation the interviewees selected, it is unclear whether the globality and stability ratings do in fact relate to actual changes in the caregiver's life or to the underlying cause of these, that is changes in the care recipient. The study did not look at pessimistic attributional style in relation to positive events, and negative events in general which would have permitted greater testing of the study.

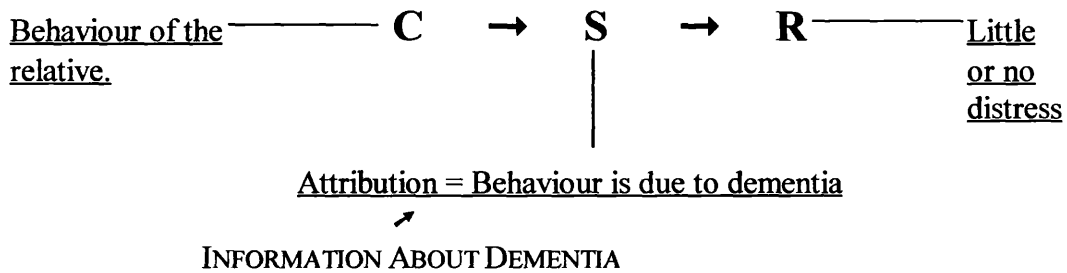
The second study, Morris, Morris & Britton (1989a), utilised the measures from the earlier study to look at the causal attributions of 20 spouse caregivers in relationship to measures of depression and the care recipient's behaviour disturbance. These were measured using Beck Depression Inventory (Beck, Rush, Shaw & Emery, 1979), and the 30 item behaviour checklist from Gilleard (1984) respectively. The study broadly supported the findings of Pagel and colleagues (Coppel et al., 1985; Pagel et al., 1985), except that no correlation was found with the measures of stability or globality when the care recipient's behaviour was partialled out. This led the authors to suggest that the behaviour problems led to the pessimistic attributions which led to depression.

In conclusion these studies suggest that the Reformulated Attribution Theory has some predictive power in distinguishing between depressed and non depressed caregivers, although no relationship was found between a pessimistic attributional style and anxiety. This suggests that meaning, in the form of causal attributions may be important in explaining why only some caregivers become distressed by care giving.

### 1.5 Attributions and Knowledge

If causal attributions do have a role to play in predicting caregiver distress it becomes important to consider how causal attributions are formed and modified. Attribution theory, upon which the reformulated attributional theory is based, predicts that causal attributions have a highly functional value. Kelley (1971) suggests that "...the attributer is not simply a seeker after knowledge; his latent goal is that of effective management of himself and his environment..."(p22), hence 'accurate' attributions are seen to have an adaptive or 'healthy' function (Försterling & Rudolph, 1988). Kelley (1967) describes an attribution as 'accurate' when the effect is attributed to a cause, which is present when the effect is present, and absent when the effect is absent. Therefore, according to Kelley (1967), a caregiver must be able to make accurate attributions about the behaviour changes in their relative's behaviour in order to make an adaptive attribution. It then follows that in order for the caregiver to make an 'accurate' attribution about their relative's behaviour they need an accurate understanding of the disease process. This can be framed in attribution theory terms in the following way (**Figure 1.2**). The

outcome, in this case distress (Reaction-R) is mediated by the individuals attributions (Cause - C), which act as a kind of filter through which the individual interprets what is happening (Stimulus S), in the light of the situation and their knowledge. In theory a functional attribution would minimise distress, as the caregiver would see the care recipient's behaviour as part of the disease process over which neither s/he nor the care recipient has any control, enabling them to make an external, healthy, causal attribution.



**Figure 1.2:** Attributional relationship  
Example of a “healthy” causal attribution

Kelley (1972) argued that knowledge is encoded into causal schemata. This occurs ‘bottom up’, driven by data from the outside world. Causal schemata are “...beliefs or pre-concepts, built up from experience, about how certain kinds of causes interact to produce a specific kind of effect...” (p24 Hewstone, 1989). Kelley ( 1972) describes schemata in terms of a hypothetical matrix of data summarizing the attributor’s

assumptions and beliefs about the effect on various combinations of the causal factors. These schemata then work in a top down, or theory led manner to help the individual interpret and place meaning on the events around them. These schemata could also be termed as the individual's lay model of the disease.

It would therefore seem sensible to predict that educating caregivers about the disease process would lead to modification of their schemata. This would then enable them to more accurately attribute the care recipient's behaviour to the disease process (a stable external specific attribution), rather than to themselves (an internal unstable specific attribution, which could lead to guilt and depression), or to a conscious act on behalf of the individual with dementia (an external unstable attribution, which could lead to anger and resentment). The same may be true of educating caregivers about what their own 'normal' and hence understandable responses to caring may be. Giving caregivers information should improve their psychological well-being, with information being constructed into causal schema to help them make 'accurate' attributions in the future. However, this has not been borne out in clinical trials.

## **1.6 Psycho educational Groups**

After considering the role of attributions in caregiver distress and the theoretical importance of making 'accurate' attributions, it is surprising that educational groups for dementia caregivers have not been a resounding success. Although lack of good quality

evaluations means that a definitive answer has yet to be reached, current research evidence has proven at best to be weakly supportive of the benefits of these interventions.

There are few examples of randomised controlled trials (Knight, Lutzky, & Macofsky-Urban., 1993, Toseland & Rossiter, 1989), and when information giving has been studied it is rarely as a sole intervention. Those clinical trials that have been conducted show varied outcomes. Sutcliffe & Lerner (1988) and Morris, Woods, Davies, Berry, et al. (1992), for example, found that information provision increased knowledge about dementia without reducing caregiver distress whilst Zarit, Anthony, & Boutselis (1987) and Toseland, Rossiter, and Labrecque (1989b), found improved caregiver well being on various measures when information was provided as part of a support group. Meta analyses looking at many outcome studies have found little support for the provision of information about dementia leading to better outcomes than waiting list controls (Knight et al., 1993; Thompson & Thompson, 1998; Toseland & Rossiter, 1989).

Some authors have pointed to statistical difficulties with this kind of research, suggesting that when individuals join a group they are generally not depressed, and hence due to the tendency of regression towards the mean, can only get more depressed (Whitlatch, Zarit, & Von Eye, 1991). Using a method of prediction analysis these critics statistically demonstrated greater improvement following two types of support and information groups than waiting list controls, despite there having been no difference found on

traditional measures (Zarit et al., 1987). It is also important to note that even if someone is assigned to a waiting list they are not placed in an information-free vacuum. It may be that waiting list controls gain equal (or at least sufficient) levels of knowledge about their relative or friend's condition during the period of the group. When one looks at groups where there was a demonstrable difference in information gain between treatment and waiting list controls, there often seems to be a greater improvement in the treatment group than the control group on other measures too (Knight et al., 1993; Toseland & Rossiter, 1989).

It would seem that even taking these methodological difficulties into consideration individuals increase their knowledge base and ability to make 'accurate' adaptive attributions but often remain distressed. Although there is some evidence that learning about dementia may be more helpful than shown by research, further clarification is needed to ensure that these groups are effective. This is vital when considering evidence of caregivers who said that they found learning about dementia depressing (Mathews 1995). This could suggest that accurate attributions are not necessarily adaptive. It may well be that in the case of a degenerating condition like dementia knowing about the disease and its outcome may match more neatly the pessimistic attributional style implicated by Abramson, Seligman & Teasdale (1978) in depression, and hence be unhealthy not healthy.



There is also an alternative explanation for why information groups have not led to great reductions in caregiver distress relating to the ways in which schemata are modified. Langer (1978) proposed that individuals are rarely what Kelley (1971) describes as "...a seeker after knowledge <with a goal> of effective management of himself and his environment..."(p.22). She proposed instead that individuals spends much of the time involved in 'mindless' thought, relying on well-learned and general schema. The individual would have already constructed lay models from their schema to understand their relative's behaviours over the years. Even before they are provided with information to explain their relative's new and often strange behaviours, the caregiver will tend to 'go beyond the information given' (Bruner, 1957) elaborating upon it, perhaps drawing on other information and past experience to complete their understanding. This could be with the accurate attribution that their relative's behaviour is being affected by a disease process, but not necessarily. Individuals have been shown to make what Ross (1977) termed a fundamental attribution error. This error can be defined as "...the tendency for attributers to underestimate the impact of situational factors and to overestimate the role of dispositional factors in controlling behaviour" (p183 Ross, 1977). This means that an individual may be more likely to attribute causality to themselves or their relative. This was demonstrated in the two studies of caregiver's attributions (Coppel et al., 1985; Morris et al., 1989a; Pagel et al., 1985).

Without modification the pre-existing schema will continue to be used. As the likelihood of a schema being activated to interpret ambiguous information increases with the

number of times it has already been used, changing schema may prove particularly difficult in the case of caregivers who can face almost daily ambiguous situations. New information may not be easily integrated, particularly as individuals have a tendency to overlook information which is divergent from their original schema (Wyer, 1981).

There are three main hypotheses about how schema, specifically schema about stereotypes such as dementia, can be modified. Rothbart (1981) suggested that change may occur in a book keeping manner in which each new piece of information changes the individual's model incrementally. Individual pieces of information change the model only slightly, it is the accumulation that makes the change. Rothbart (1981) also suggested a second mechanism, 'conversion' in which a single salient event may bring about schema change. The third type, sub-typing is where information that contradicts the existing schema is concentrated by the individual into a small sample of the population, in other words this group are seen as a sub-category. All three have received experimental support, suggesting that all three occur perhaps at different times. It is probably the former that information giving groups rely on. It could be that an individual's schema are not modified in the short term of an information provision group but instead in a book keeping manner over time as evidence accrues.

Alternatively some caregiver's understandings may 'convert' after a single salient event. It may be that a group does not provide such an event. Weiner (1985) suggested that two factors are implicated in eliciting mindful (or new) attributions; unexpected events

and non attainment of a goal. This could explain why information giving in the context of a support group has been more successful at reducing caregiver distress. These groups are often provided over many weeks and place information within the context of everyday, unexpected problems, with many opportunities for strong contrasts with people's accepted understanding of the disorder. Individuals perhaps need this kind of attributional 'jolt', where tried and tested attributions are called into question, to take on board and assimilate other information in the formation of new attributions. A short term group, that does not challenge Caregiver's understandings within the context of caregivers' own particular situations, may well risk individual's defining what they hear as being true about other people's relatives, but not of their own; in other words sub-typing.

These points suggest that actually knowing about the condition may be more helpful than the research into information groups would suggest. Over time as information is taken in by the caregiver within the context of their own particular situation outcomes may be more positive. This would mean that if one looked at a general sample of caregivers one would predict that those with more knowledge about dementia would be less distressed, as they would have more 'accurate' schema. This study initially intended to test out just that question, however a recent research team has gone some way to providing an answer.

## 1.7 Knowledge and Distress in Caregivers

Graham, Ballard & Sham, (1997) examined the relationship between caregiver's knowledge of dementia and their levels of depression and anxiety. They looked at 109 caregivers whose relatives had been recently referred to a memory clinic. The researchers found that higher levels of knowledge about dementia, correlated with lower levels of depression, but also with higher levels of anxiety. After examining the coping styles of caregivers, Graham and his colleagues concluded that higher levels of knowledge related to a greater feeling of competence amongst caregivers and a decrease in their expectations, which linked to an increased likelihood of making use of more positive coping strategies. The authors suggest that although knowing more about dementia may have made caregivers feel more competent with lower (perhaps more 'accurate') expectations, they may have had an increased anticipation of loss gleaned from knowing more about the condition, resulting in greater anxiety.

Knowing about dementia may result in individuals being able to make more external attributions about dementia and feel less incompetent, recognising failure to modify a behaviour as a result of the disease process not in their incompetence. Conversely the increased feeling of the stability of the problem and discovering that it may become worse over time may have made the caregivers more anxious for the future. To look at this in terms of the earlier hypothesis about how pessimistic causal attributions may differ

for positive and negative events, and hence relate to depression or anxiety, it is possible that here we have an example of caregivers remaining pessimistic (or indeed becoming more pessimistic) in their attributions about negative events, but becoming less pessimistic in their attributions about positive events, leading to a reduction in depression, but an increase in anxiety.

Graham et al. (1997) examined people in the early stage of the disease, having just received the diagnosis, it is not possible to see whether the relationship between knowledge and well being would remain stable over time. The period following diagnosis is often extremely stressful and a time of intense information gathering, but on the other hand it is a point in time when many of the behaviours found difficult by caregivers have not appeared (Stilwell et al., 1984). It may be that as these behaviours increase, and opportunities for positive shared experiences reduce, caregivers may become more depressed and show more pessimistic attributional styles for positive events.

There is one difficulty with this study. All of the caregivers had gained information from the professionals at the memory clinic and had not joined informal support groups such as the Alzheimer's Disease Society. It is not unreasonable to hypothesize that in such formal settings, caregivers who were very distressed may have found it very difficult to ask questions, or to even take in the information given to them. Alternatively they may have even actively avoided being given information. Looking at a wider group of

caregivers who were at varying stages of the disease process and asking about relatives' opinions on being given information might have overcome this difficulty.

Price, Price, Shanahar & Desmond (1986) examined the amount of knowledge about dementia of 148 elderly people of whom about a 1/3 had a relative or friend with Alzheimer's disease. Those who were better educated tended to know more about dementia. Interestingly this was not found in Graham and colleagues' study (1997), where level of education was unrelated to knowledge about dementia. This could be purely a historical or cultural difference, but could suggest some other factor at work, perhaps the often more influential socioeconomic status. Socioeconomic state was not measured in Graham et al.'s study.

In conclusion Graham et al.'s (1997) study provides some evidence that knowing about dementia relates to lower levels of depression, but also to higher levels of anxiety. From this it is possible to hypothesise at what the underlying attributions may be, but the study is not able to tell us whether these hypotheses are correct. Understanding the underlying process could help clinicians to tailor their intervention packages and more effectively work towards improving caregiver's psychological well-being.

## 1.8 The Research Questions

An examination of what may be happening in these complex relationships between information, causal attributions and well-being in caregivers forms the basis of the current study. The main research aims are as follows;

- i.) Primarily the study intends to provide an account of the relationship between Dementia knowledge → Causal Attribution → Psychological well-being. This enables the study to explore whether causal attributions do mediate between dementia knowledge and psychological well-being. This combines the aims of Graham et al's study (1997) with the work of Pagel and his team (Pagel et al., 1985, Coppel et al., 1985) to examine the possible relationship between the two.

The definition of well being will be extended to look at a broader range of symptomatology often found in caregivers. Somatic symptoms and social adaptation will be examined in relation to depression and anxiety.

- ii.) Secondly the research will look at the influence that causal attributions may have on knowing about dementia. As proposed earlier, attributional style in itself could predict whether or not a caregiver would seek information. This is an important relationship to examine as if pessimistic attributional style influences both desire for knowledge and psychological distress, it would then of course follow that an

individual may know less about dementia. This would mean that distress was primarily the result of attributional style and not the lack of information about dementia.

- iii.) Finally, the study hopes to replicate the findings from the two studies, to present more vigorous evidence for the results those studies found. To be more specific, the study aims to look again at the relationship between dementia knowledge and psychological well-being taking into consideration important features that may influence the outcome such as gender, socioeconomic status and time since diagnosis. The relationship between psychological distress and more general attributions (not just about dementia) will also be examined to look at attributions about both positive and negative events.

In summary, the main aim of the current study is to elucidate the relationships between knowledge about dementia, causal attribution and caregiver psychological well-being (incorporating anxiety, depression, somatic and social adaptation).



## **CHAPTER TWO: METHOD**

### **Overview**

A quasi-experimental design was used to examine the relationship between knowledge about dementia, causal attributions and psychological well-being in a community sample of caregivers.

### **2.1 Participants**

Volunteers were recruited from people in contact with formal (Older People's Psychology Services of Essex & Herts Community NHS Trust, Enfield Community Care NHS Trust), and voluntary services (Harlow & Epping Alzheimer's Disease Society). Workers from these organisations asked caregivers who were in contact with their service whether they would agree to be interviewed by the researcher.

The inclusion criteria for caregivers were: (i) Individuals over the age of 18 who (ii) were the principal supporter of friends or relatives with dementia (iii) providing five or more hours of emotional / practical support per week on an informal basis. This support could be based either at their own home or through visits to their care recipient's home or

residential placement. Informal was defined as meaning that the caregiver did not receive payment for their caring beyond the benefits available to caregivers. Only those caring for a relative with dementia were interviewed. Any stage of dementia was considered eligible for the study, although some types of dementia were excluded. Caregivers caring for someone with a dementia related to AIDS, suspected Prion disease or substance misuse were not interviewed.

The required sample size was determined to be at least 65 calculated on the basis of previous research, e.g. Pagel et al. (1985) and Cohen's (1977) power calculation. Due to sampling difficulties, only thirty-seven caregivers were interviewed with an age range of 50 to 84 with the mean age being 69 (SD=9.12). 29.7% (N=11) were male and 70.3% (N=26) were female. Of those interviewed 70.3% (N=26) were caring for their spouse and 16.2% were caring for a parent. The remainder 13.5% (N=5) were caring for a friend or relative not already mentioned.

All participants provided written, informed consent to participate and the study was approved by Essex & Herts Community NHS Trust Ethics Committee and Enfield Community Care NHS Trust Ethics Committee (**Appendix I-III**).

## **2.2 Procedure**

Data were collected during a single 60 - 90 minute interview at the caregiver's home. During this time caregivers were assisted by the researcher in the completion of the questionnaire battery having provided written consent to take part. This visit was considered essential by the researcher, as some older adults have been shown to find it difficult to complete questionnaires unaided perhaps due to lack of experience of using rating scales and sight problems (Hazell, Driver, & Shalan, 1996). This format also allowed the researcher to debrief the caregivers immediately after completing the questionnaires and answer any questions that were raised.

## **2.3 Assessments**

The questionnaire battery included 6 questionnaires. The questionnaires can be found in **Appendix IV-VIII**. These can be grouped by the functions that they perform in seeking answers to the research questions. The questionnaires are described below under the headings of the main elements that they were intended to measure.

***Function One:***

***To gain background information on individuals and their caring situation.***

**Demographic Details**

Information was collected about both the caregiver and their care recipient, as well as broad information about elements which had been found to be important in predicting caregiver distress (Pearlin, Mullan, Semple & Skaff 1990), and which could potentially account for variability in the results. This included items relating to; health, socioeconomic status, past education, other caring commitments, and social support. Questions about these items were brief to keep the assessment procedure to a reasonable time limit which would not overtax the participants.

The questionnaire also included a number of items relating to the exact care provided by the caregiver. This was based upon common tasks identified as often being carried out by caregivers and which were drawn from two recent surveys of caregivers by the National Institute for Social Work Research (Levin et al., 1994) and the Family Expenditure Survey (1997). This should enable comparison of the objective burden with those of the dementia care giving population as a whole.

**Behaviour and Mood Disturbance Scale (BMD)** (Greene, Smith, Gardiner, & Timbury, 1982)

This 34 item questionnaire is a measure of different aspects of the patient's behaviour based on information provided by the caregiver. The measure looks specifically at the care recipient's degree of behaviour and mood disturbance, and is made up of three sub scales ('Apathetic', 'Active' and 'Mood') as well as the total overall score. Caregivers rate statements relating to various behaviours and moods on a five point scale ranging from 'never' to 'always'.

The measure has been shown to have good test retest inter-rater reliability, with reliability coefficients of ( $R^2$ ) 0.90, 0.87, 0.73, for the three sub-scales respectively, and 0.84 for the total score, all reliable at the 0.005 significance level (Greene et al., 1982).

***Function Two:***

*To assess caregiver's level of knowledge about dementia and their attitude in general to receiving information about dementia.*

**Dementia Knowledge Questionnaire (DKQ)** (Price et al., 1986)

This is a short knowledge questionnaire in which the respondent rates for accuracy 20 test items relating to items to dementia. The respondent must state whether they feel the statements are either true, false, or that they don't know. Price et al. (1986) used the

questionnaire to assess dementia knowledge by testing 148 individuals, of whom a third had a relative or friend with dementia. The questionnaire has since been used in a number of studies, but most notably in Graham et al.'s (1997) study.

### **Background Information on Knowledge**

All caregiver's were asked about where they had obtained information from, and asked to rate on a Likert type 7 point scale how helpful they felt gaining information was. They were also asked if they would be interested in more information if it were to be available. Finally they were asked to comment on how information is most usefully given, and indicate what information giving service had been most and least helpful to date.

### ***Function Three:***

*To assess caregiver's attributional style.*

**Attributional Style Questionnaire (ASQ)** (Adapted from Peterson, Semmel, von Bayer, Abramson, et al., 1982)

This self report questionnaire asks the respondent about their attributions to several hypothetical situations (in this shortened version; 3 good and 3 bad). Each event is rated by the respondent on 7 point Likert type scales, to be either; internal or external; stable or changeable; global or specific. Scores can be generated for each of three dimensions (internality, stability and globality) and for good and bad events.

Test-retest reliability of the full scale version of the ASQ has been examined in a number of studies (e.g. Golin, Sweeney, & Schaeffer, 1981 and Peterson & Seligman, 1984). Golin (et al., 1981) found significant test retest coefficients ( $R^2$ ) of; 0.66 for internality, 0.56 for stability, and 0.67 for globality, and for just negative events; 0.47 for internality, 0.61 for stability, and 0.65 for globality. The composite scores reliability was 0.67. These are all significant correlations at the 0.001 significance level. The scale used here is not the complete version, consisting of half the items chosen because they were relevant to older people, again a compromise to keep the questionnaire battery to a manageable size.

The validity of the construct underlying the ASQ was tested by correlating the responses of 169 undergraduates with independent raters (Schulman, Castellon & Seligman, 1981). This found that the raters' ratings of the explanations correlated highly. Correlations across each dimension and composite score were significant at a 0.05 significance level (excepting global positive which suffered from poor inter rater reliability), and mostly at the 0.001 significance level.

Meta analytic studies of the measure (Sweeney et al., 1986; Robins, 1988) looking at over 100 studies of explanatory style have shown a predictive relationship between the measure and depression.

**Attributions about dementia caregiving (Pagel et al., 1985, & Coppel et al., 1985)**

This measure is the collection of questions taken from the study by Coppel and his colleagues (Pagel et al., 1985, Coppel et al., 1985) to assess attributional style in relation to the care recipient's condition and changes in their own life. The measure is comprised of four questions. The first two questions ask about feelings of control, now and in the future over their relative's behaviour and their own life. The third question asks about past beliefs about the cause of the care recipient's condition (Coppel and his colleagues having assumed that everyone would be aware that dementia was the cause of the relative's symptoms), and feelings of self blame. The last question asks about control over personal feelings in private and public.

***Function Four:***

*To assess caregiver's psychological well being.*

**General Health Questionnaire 28 - item (GHQ-28) (Goldberg & Hillier, 1979)**

This is a screening instrument for psychiatric symptomatology for use with the general population. It contains four sub-scales. The somatic scale contains items about people's feelings of health and fatigue, and provides a measure of those bodily sensations which often accompany emotional upsets. The second sub-scale relates to anxiety and to the sleep patterns that this may affect. The third scale measures the extent to which the



respondent is able to cope with the demands of their work and daily life, whilst the final sub scale deals with symptoms of severe depression, including items on suicidal thoughts and intent. The GHQ has been used widely in studies of caregivers (e.g., Brodaty & Hadzi-Pavlovic 1990; Donaldson et al., 1998; Gilleard et al., 1984; Morris, Morris & Bolton, 1988).

**Social Adaptation Self-Evaluation Scale(SASS) (Bosc, Dubini & Polin, 1997)**

This is a recently developed and validated 21 item self report scale for the evaluation of patient social motivation and behaviour in depression. Test retest reliability of the scale has been shown to be good with there being no significant difference between the scores of tests administered once and then a week later (Bosc et al., 1997).

**2.4            Data Analysis**

The data was analysed using a number of different statistical techniques to look for relationships between the variables. There was no need to transform the data prior to analysis. The main research questions were examined by using correlational statistics to look for relationships between the three main variables, dementia knowledge, attributional style and care-giver well-being. The impact of demographic variables was examined using a variety of statistics including, between sample t-tests, between group Anovas, and Pearson Correlations for normally distributed data, and Pearson's chi-

square tests for categorical data. These were used as appropriate. One sample t-tests were used to examine the representativeness of the data, and to compare with data from other studies when appropriate. Judd & Kenny's (1981) method for analysing hypothesised mediating relationships was used to explore the main research question looking at the mediating role of causal attributions between dementia knowledge and Well-being, and also to examine the possible mediating role of causal attributions and dementia knowledge between ratings of the care-recipient's mood and behaviour disturbance and those of caregiver's well being.

## **CHAPTER THREE: RESULTS**

### **Overview**

The results are presented in four sections following the aims of the research questions outlined in the introduction. That is after consideration of the demographic information, to examine for relationships between the three key variables knowledge about dementia, causal attribution and caregiver psychological well-being (incorporating anxiety, depression, somatic and social adaption), in particular to examine whether causal attributions may mediate between knowledge about dementia and caregiver well-being.

The layout of this section is then as follows: The first section (3.1) provides a demographic overview of the sample, including demographic information about both the caregiver and the care recipient. The next section (3.2) looks at each of the three key variables; caregiver distress, dementia knowledge and attributional style. These are considered both descriptively and in relation to the demographic variables. Interactions between these variables are examined (3.3) in order to see if the findings of Graham et al. (1997) and Pagel and his team (Pagel et al., 1985, Coppel et al., 1985) are replicated. In the final section (3.4) the possible role of causal attributions in relation to dementia

knowledge and psychological well-being will be examined. There was no missing data as all respondents answered all questions. Where n values are not quoted they equal 37.

### 3.1 Demographic Description of the Sample

**Table 3.1** outlines the main demographic features of the caregivers. As would be expected most caregivers had retired, with the sample having a mean age of 69 years. The majority of the caregivers were female. Most of the caregivers lived with the person they cared for (70%), and were mainly the spouse of the care recipient. There was no significant difference between the ages of male and female caregivers (means; 69.8 and 68.7 years respectively) but unsurprisingly there was a significant difference in age between the different caregiver-care recipient relationships ( $F(2,34) = 11.6, 34, P < 0.05$ ). Post hoc Bonferroni test indicated that spouse caregivers (mean age = 72.9) were significantly older than son / daughter caregivers (mean age = 56.5, mean difference 15.7,  $P < 0.001$ ). 94.6% of the Caregivers had an ethnic origin of white UK, reflecting the locality. Over 75% of the caregivers had health difficulties of their own, of which 18.9% rated these as severe.

The sample as a whole had a relatively high socioeconomic status (**Table 3.2**), with over 80% of the sample being in socioeconomic groups I-III, and the majority of caregivers owning their own homes. This is representative of the area from which the sample was drawn. Caregivers were asked (as part of the SASS) to what extent they had

**Table 3.1**  
**Demographic data on caregivers**

	<b>Mean</b>	<b>SD</b>	<b>Minimum</b>	<b>Maximum</b>
<b>Age</b>	69	9.1	50	84
<b>No of yrs in full time education</b>	15.8	2.2	11	23
<b>Gender</b>	Male	Female		
	n=11	n=26		
	29.7%	70.3%		
<b>Work Status</b>	Retired	Full time	Part time	
	n=29	n=2	n=6	
	78.4%	5.4%	16.2%	
<b>Proximity to care recipient</b>	Live together	10 minutes or less	10 to 30 minutes	More than 30 minutes
	n=26	n=4	n=2	n=5
	70.3%	10.8%	5.4%	13.5%
<b>Caregiver's rating of own health problems</b>	None	Mild	Moderate	Severe
	n=9	n=11	n=10	n=7
	24.3%	29.7%	27%	18.9%
<b>Relationship of care recipient to caregiver</b>	Spouse	Other	Son/Daughter	
	n=26	n=5	n=6	
	70.3%	13.5%	16.2%	

difficulties in managing their income. Twenty-eight (75.7%) stated that they never had difficulty with their income, whilst of the rest 5 (13.5%) reported either often or all the time having such difficulties. Caregivers were also asked if they felt care giving had reduced their standard of living. Seventeen (45.9%) felt that their standard of living had been reduced since the care recipient became ill, with 7 (18.9%) rating this change as extreme.

**Table 3.2**  
Caregivers' socioeconomic data

<b>Socioeconomic status* before retirement</b>	<b>I. Professional</b>	<b>II. Employers &amp; Managers</b>	<b>III. Intermediate junior / Skilled manual</b>	<b>IV. Semi-skilled manual / personal service</b>	<b>V. Unskilled Manual</b>
<b>Observed</b>	n=6 16.2%	n=5 13.5%	n=19 51.4%	n=4 10.8%	n=3 8.1%
<b>National average*</b>	5%	23%	48%	18%	6%
<b>Housing</b>	<b>Owner occupier</b>	<b>Private rented</b>	<b>Council housing</b>		
	n=33 89.2%	n=1 2.7%	n=3 8.1%		
<b>Goods owned</b>	<b>Central heating</b>	<b>Car</b>	<b>Telephone</b>	<b>Washing Machine</b>	
<b>Observed</b>	36 87%	24 69%	37 100%	37 100%	
<b>National average**</b>	87.3%	69%	93.1%	91%	

\* From the Office of Population Census and surveys (1980)

\*\* From the Family Expenditure Survey (1997)

**Table 3.3**  
**Demographic data on care recipients**

	<b>Mean</b>	<b>SD</b>	<b>Minimum</b>	<b>Maximum</b>
<b>Age</b>	77.24	8.85	59	92
<b>Gender</b>	Male n=24 64.9%	Female n=13 35.1%		
<b>Diagnosis</b>	Alzheimer's Disease n=19 51.4%	Multi-infarct dementia n=7 18.9%	Frontal lobe dementias n=5 13.5%	Exact subtype unkown n=6 16.2%
<b>Who made the diagnosis</b>	Hospital n=27 73%	GP n=4 10.8%	Other n=6 16.2%	
<b>Length of time since diagnosis</b>	up to 1 year n=9 24.3%	1 -2 years n=5 13.5%	2-3 years n=9 24.3%	4 years + n=7 18.9%
<b>Does care recipient take medication because of the dementia</b>	Yes n=25 67.6%	No n=12 32.4%		
<b>Residence of care recipient</b>	Community n=31 83.8%	Residential provision n=6 16.2%		

**Table 3.3** outline's the demographic information about the care recipients who the sample of caregivers were supporting. The care recipients were on average 8.3 years older than their caregivers, and were predominantly male. This matches the accepted belief that there is a pattern of older men being cared for by their wife or daughter. Nearly all of the sample (36/37) were of the ethnic origin white UK.

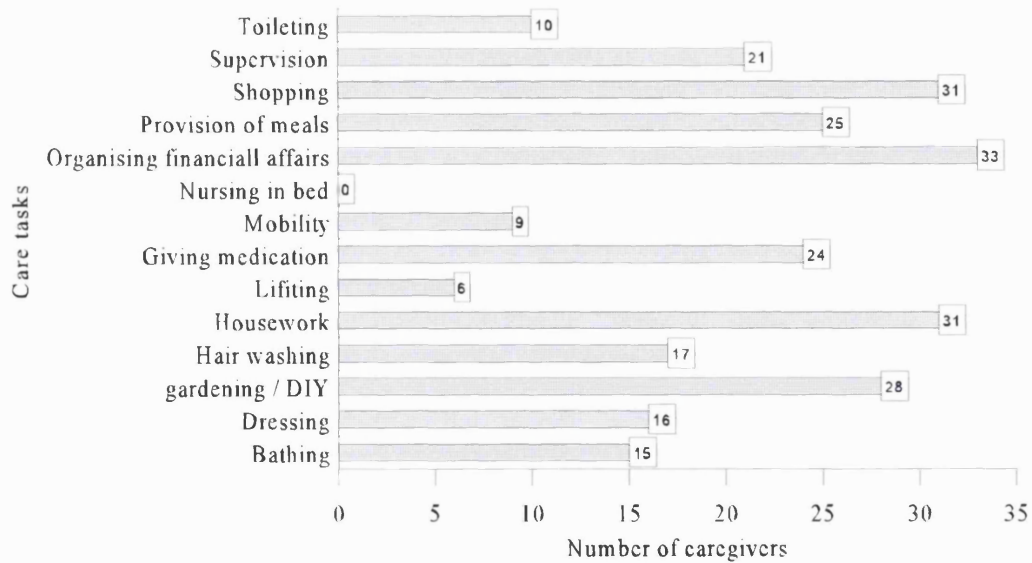
Over half the sample were caring for a relative who had a diagnosis of Alzheimer's disease with the next most common diagnosis being Multi-infarct dementia. This mirrors what is known about prevalence of these disorders. It is notable that 16% of the sample were unaware of, or had not been given, an exact diagnosis for their relative. The majority of diagnoses had been made via a hospital appointment, although a large proportion of the sample (27%) had not been seen by a consultant psychiatrist or psychologist in relation to their dementia. Two thirds of the care recipients had been prescribed medication (acetylcholinesterase inhibitors and/or other types of psychotropic medication) as a result of their dementia. Most of the caregivers had received a diagnosis between 2 and 3 years ago, and the sample showed a fairly even spread across the 4 time periods. The majority of the sample (83.8%) were living in the community.

**Table 3.4** shows the level of behaviour and mood disturbance as measured by the BMD within the group. Levels of behaviour and mood disturbance were relatively high in the group, being on average 13% greater than that in Greene et al.'s (1982) study which validated the measure,  $t=2.68$  (df 36),  $P < 0.01$ .



**Table 3.4**  
Caregivers' ratings of their relative's behaviour

	Mean	SD
<b>Total BMD</b>	59	15.9
<b>BMD: Apathetic Withdrawn sub scale</b>	29.2	9.7
<b>BMD: Active disturbed</b>	22.3	9.2
<b>BMD: Mood disturbance</b>	9.2	4.6



**Figure 3.1** Types of task being carried out by caregiver

The type of tasks that the caregivers were performing for their relative is shown in **Figure 3.1** , as can be seen the most common tasks were organising financial affairs, shopping, housework, and gardening or household repairs. Almost half the sample were carrying out personal care tasks for their relative, for example bathing and dressing, with over a quarter of the sample assisting their relative with toileting, a task that has often been connected with high levels of caregiver distress.

The mean number of tasks carried out by the group (out of a possible total of 14) was 7.2 (Range 1-13, SD 3.7), but there was no difference in the range or number of tasks carried out by the male or female caregivers. There was also no relationship between the number of tasks carried out and the age of the caregiver. Almost three quarters of the caregivers had been providing care to the care recipient for 2 or more years, with almost half having been caring for over 4 years (**Figure 3.2**). There was no correlation between age and length of time providing additional support. There was also no significant difference between the male and female caregivers or between those who did or did not have additional health problems in the amount of time they had been caring. The different diagnostic groups did not significantly differ in length of time they had been caring either.

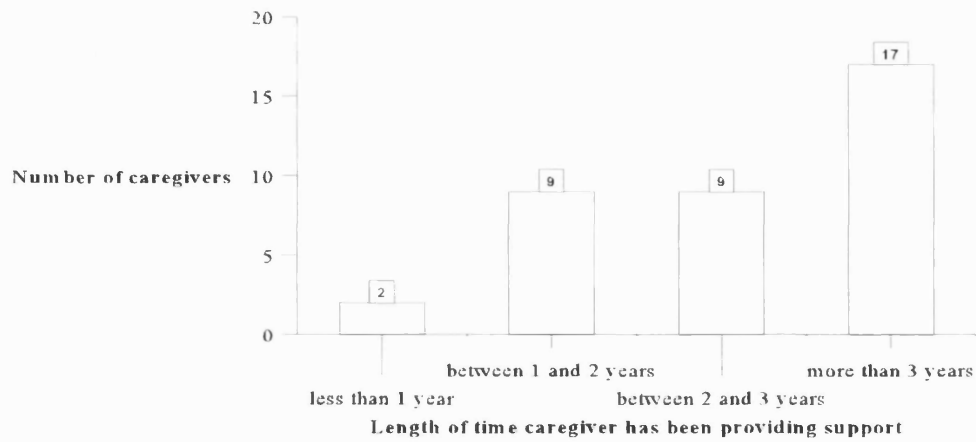


Figure 3.2 Length of time caring

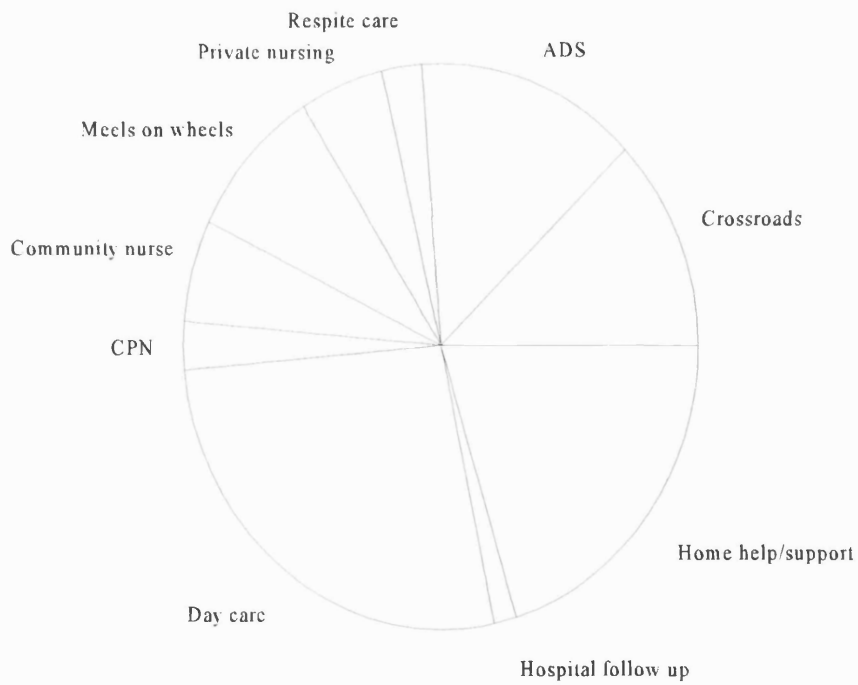


Figure 3.3 Relative contributions of support services to caregivers

The pie chart in **Figure 3.3** shows the relative proportions of assistance given to caregivers from statutory services and voluntary organisations. Day care provided the greatest amount of support, followed by home help, the Alzheimer's Disease Society and Crossroads (a sitting service). The mean amount of help given (excluding caregivers whose care recipient lived in a residential placement), was 7.6 assistance units per month (calculated as 1 unit equalling 1 day's service contact). However the variance was marked with some caregivers receiving no help units, and others receiving as much as 18 units per month. There was no difference in the amount of help received by male and female caregivers, different care recipient diagnoses, or for caregiver's with additional health problems. Nor did the units of help given correlate with the BMD or any of its sub-scales.

Socioeconomic status (**Table 3.5**) did relate to the amount of care received,  $F(4,32)=10.70$ ,  $P<0.001$ ., with a post hoc Bonferroni test indicating that most of the variance was accounted for by socioeconomic group II, Employers and managers, receiving more help than groups III - Intermediate Junior / Skilled Manual (mean difference = -7.21,  $P<0.05$ ); IV - Semi-skilled manual / Personal service (mean difference = -11.00,  $P<0.05$ ); or I - Professional (mean difference = -13.00,  $P<0.05$ ). The post hoc analysis also suggested that Professionals received significantly less help than groups; III - Intermediate Junior / Skilled Manual (mean difference -5.79,  $P<0.05$ ); and V - Unskilled Manual (mean difference = -8.67,  $P<0.05$ ).

**Table 3.5**  
Amount of help received x socioeconomic grouping

	<b>N</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>
<b>I) Professional</b>	6	2	1.6	1 - 5
<b>II) Employers and Managers</b>	5	15	2.5	12 - 18
<b>III) Intermediate Junior / Skilled Manual</b>	19	7.8	4.3	0 - 15
<b>IV) Semi-skilled Manual / Personal Service</b>	4	4	2.2	1 - 6
<b>V) Unskilled Manual</b>	3	10.7	3.5	7 - 14
<b>TOTAL</b>	37	7.7	5.1	0 - 18

Caregivers also rated the help that they had received from family and friends on a scale of 1 (none) to 7 (complete). The mean score for caregivers on this scale was 3.5 (SD=2.2) indicative of 'moderate help'. There was no significant difference between the support reported by male and female caregivers or for those with health problems, nor between the different socioeconomic groups or types of dementia being cared for.

### 3.2 Dementia Knowledge, Caregiver Well being, and Causal Attributions

#### Psychological Well-being (as Measured by the GHQ, SASS)

Psychological well-being was gauged with two different measures within the study. The results for each measure will be examined separately here in relation to the demographic features of the sample.

**Table 3.6**  
**GHQ Scores**  
 Mean of caregivers total score on the GHQ and it's sub-scales

	Mean	SD	Range
<b>Sub-scales:</b>			
<b>GHQA:</b> Somatic symptoms	1.81	1.75	0-5
<b>GHQB:</b> Anxiety and insomnia	2.59	2.17	0-7
<b>GHQC:</b> Social dysfunction	1.62	1.62	0-6
<b>GHQD:</b> Severe depression	0.97	1.62	0-7
<b>TOTAL</b>	7.00	5.64	0-20

The GHQ was scored using the 0,0,1,1 method as a screening tool. As can be seen from **Table 3.6** the mean score of the group was 7, with 56.8% of the sample's scores on the

measure being at or above caseness level (i.e. scoring a total of more than 4; Goldberg & Hillier, 1979). This is significantly higher than in a recent population survey, Buck et al. (1997), where prevalence was estimated to be at 39%, ( $\chi^2 (1) = 4.90, P < 0.05$ ).

There was no statistically significant difference between the obtained score on the GHQ and its sub-scales with the caregiver's gender, socioeconomic status, length of time they had been caring, whether they lived with the person they cared for, or whether or not they had health difficulties of their own. There was also no significant difference dependant on the type of dementia being cared for. Similarly there was no significant correlation found between the measure and the amount of help received (from services or relatives), the number of tasks carried out by the caregiver, or the caregiver's age.

There were some significant correlations between the GHQ and its sub-scales in relation to the caregivers' ratings of the care recipients' mood and behaviour on the BMD (Table 3.7). There was a positive correlation between the obtained total scores on both the GHQ and BMD ( $P < 0.01$ ),  $r = 0.54$  implying that the two total measures share around 29% of the variance. It appears that in particular the ratings of apathetic withdrawn and active disturbed behaviours related not only to high scores on the GHQ as a whole, but also to high scores on each of the four GHQ sub-scales, in particular GHQA - somatic symptoms. Whether or not the caregiver wanted to know more about dementia, or whether or not they rated information as helpful did not appear to significantly relate to the GHQ or its sub-scales, nor to the caregiver's ratings on the SASS.

**Table 3.7**  
**GHQ x BMD**  
Correlation between the total and sub-scale scores on the GHQ and the BMD

<i>Pearson Correlation Coefficients</i>		GHQ				
		<b>GHQ-A Somatic symptoms</b>	<b>GHQ-B: Anxiety &amp; Insomnia</b>	<b>GHQ-C: Social dysfunction</b>	<b>GHQ-D: Severe depression</b>	<b>TOTAL</b>
<b>BMD</b>	<b>BMD-A:</b>	0.59**	0.67**	0.40*	0.60**	0.74**
	<b>Apathetic withdrawn</b>					
	<b>BMD-B:</b>	0.14	0.40*	0.20	0.39*	0.37*
	<b>Active disturbed</b>					
	<b>BMD-C:</b>	0.04	0.31	0.02	0.19	0.19
	<b>Mood disturbance</b>					
	<b>TOTAL</b>	0.25	0.53**	0.41*	0.48**	0.54**

\*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)

The possible range of scores on the Social Adaptation Self-Evaluation Scale (SASS) is 0 to 60 with low scores indicating poorer social functioning. The mean obtained score on the SASS was 41.1 (SD=8.85, Range = 19-57), within what the authors describe as the 'normal range' corresponding to 80% of the population (Bosc et al., 1997). Only 2 of the caregivers' scores fell within the social maladjustment range. The caregiver's ratings on the SASS did not significantly differ between male and female caregivers (means 39.1 and 42 respectively), nor between the different socioeconomic groups, caregiver-care recipient relationships, types of dementia, or with the age of the caregiver.



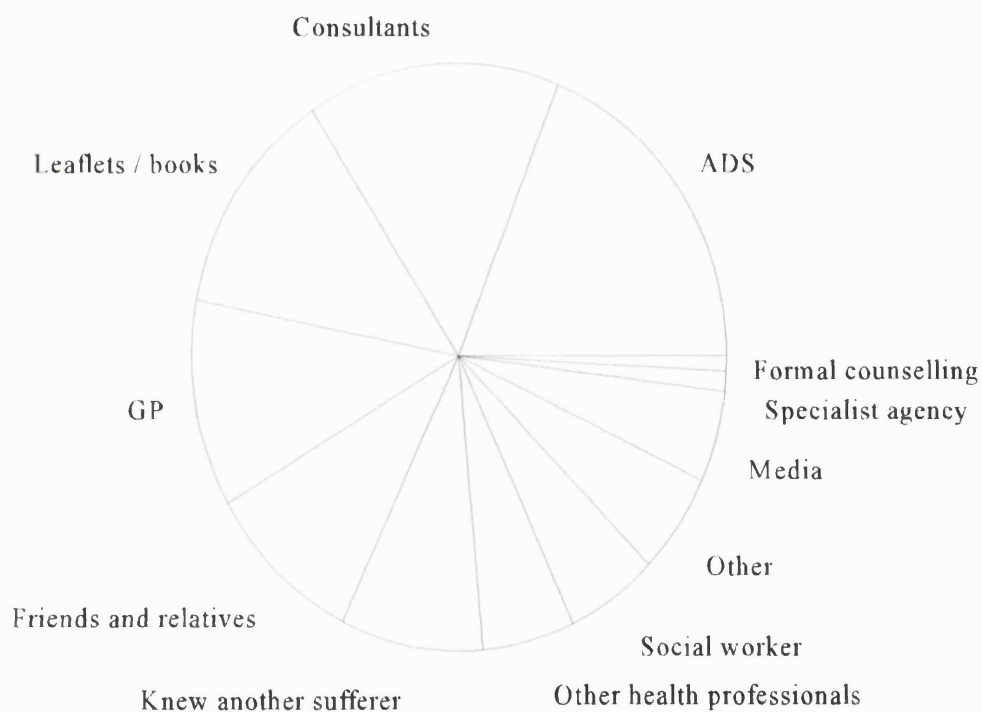
**Table 3.8**  
**SASS x Length of time caring**  
 Mean scores obtained on the SASS by length of time caring

Length of time caring	N	Mean SASS score	SD	Range
Less than 1 year	2	50	1.4	49 - 51
1 to 2 years	9	36.1	6.8	23 - 43
2 to 3 years	9	48.3	6.7	34 - 57
More than 3 years	17	38.9	8.5	19 - 51
<b>Total</b>	<b>37</b>	<b>41.1</b>	<b>8.84</b>	<b>19 - 57</b>

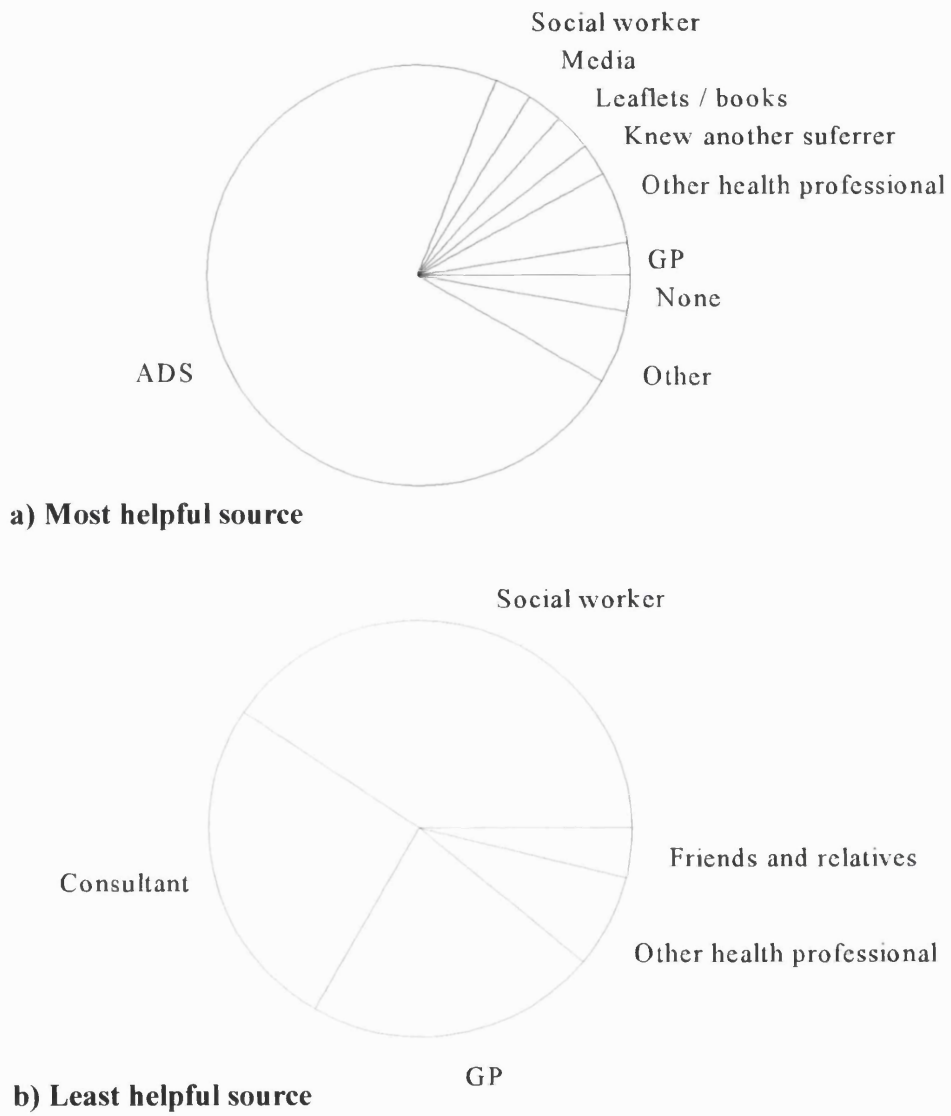
There was also no significant relationship between scores on the SASS and the amount of informal or formal help received, or their ratings of their care recipient on the BMD. Whether or not the caregiver had physical health problems also bore no significant relationship with this measure. There was a relationship between the length of time caring and the obtained score on the SASS  $F(3,33) = 5.45, P < 0.005$  (Table 3.8). Post hoc testing (Bonferroni) revealed that most of the variance was accounted for by caregivers who had been caring for 2 to 3 years being significantly less impaired in social functioning than those who had been caring for 1 to 2 years (Mean difference = 12.2,  $P < 0.05$ ) or those who had been caring for more than 3 years (Mean difference = 9.4,  $P < 0.05$ ). There was also a negative correlation between the caregivers' ratings on the SASS and the number of care tasks they carried out for their relative ( $R = -0.35, P < 0.05$ ), indicating that caregivers who carried out more tasks had more difficulties with social functioning.

### Knowledge of Dementia

Caregivers reported gaining their information about dementia from a variety of sources (Figure 3.4). The most frequently reported source was the Alzheimer's Disease Society (ADS), followed by caregivers obtaining information from literature, hospital appointments, their GP, and from friends or relatives. The mean number of sources of information was 4.9 (SD=1.9).



**Figure 3.4** Sources of information identified by caregivers  
Each section is proportionate to the number of caregivers reporting that source



**Figure 3.5** Most and least helpful sources of information  
Caregivers nominations for the most (a) and the least (b) helpful source of information

When asked who had been most helpful source of information (**Figure 3.5**) 73% of the caregivers identified the ADS as being most helpful. When asked whether anyone had been unhelpful in the information that they provided, of those caregivers that expressed an opinion (73% of the sample), Social Workers were reported to have been least helpful in the information that they provided, followed by hospital doctors and GP's.

Caregivers were asked to rate how helpful having information was in general using a scale of 1 extremely helpful to 7 extremely unhelpful. The mean score of 2.81 (SD 2.21) indicated that they found information helpful, this score differing significantly from the expected rating of information being neither helpful or unhelpful (score = 4),  $t(36) = -3.275$ ,  $P < 0.005$ . Fifty-four percent of the sample felt that they would like more information, although there appeared to be no relationship between finding it helpful to have information and wanting more ( $t(35) = -1.720$ ,  $P = \text{NS}$ ). Of those that expressed an opinion (81.1% of the total caregivers), 46.7% felt that the best way to provide information was by a one to one meeting, whilst 23.3% preferred literature and 20% group formats. The remaining 10% felt that information should not be given.

**Table 3.9** describes the mean total scores obtained by the caregivers on the dementia knowledge questionnaire and its sub-scales. The mean total score obtained by caregivers on the DKQ was 12.89, (std 2.53) range 6 to 17, or 64.5%, with the lowest score being 6 and the highest being 17. The caregivers scored highest on the diagnosis / treatment sub-scale, and lowest on the demographics sub-scale.

**Table 3.9**  
**DKQ Scores**  
Mean of caregivers percentage total score on the DKQ and it's sub-scales

	Mean % correct	SD	Range
<b>DKQ Total</b>	64.5%	12.6	30% - 85%
<b><i>Sub-scales:</i></b>			
<b>Demographics</b>	43.9%	23.9	0% - 75%
<b>Aetiology</b>	66.5%	21.1	20% - 100%
<b>Symptoms</b>	68.6%	20.8	20% - 100%
<b>Diagnosis, treatment</b>	72.5%	14.8	33.3% - 100%

Table 3.10 shows the percentage of caregivers who responded correctly to each question on the DKQ. 15 items were answered correctly by over half of the sample, with 9 items being answered correctly by over three quarters of the sample. Only one item, question 2, was answered correctly by less than a quarter of the sample.

There was no significant difference between the scores obtained by male and female caregivers or by caregivers from the different socioeconomic groups on either the total DKQ score or on the DKQ sub-scales. No relationship was found between the age of the caregiver, the different care giving relationships, the different diagnoses, caregiver's having additional health problems, or with the length of time the caregiver had been in full time education and the obtained DKQ total or sub-scale score. Whether or not a

**Table 3.10****Scoring of individual DKQ items**

Scores represent the proportion of caregivers answering each question correctly

Item (Answer)	Sum	Rank order highest first	% correct
1 Men are much more likely to develop dementia than women. (F)	17	16	45.9%
2 Dementia is the most common mental health problem in the elderly. (F)	6	20	16.2%
3 If one lives long enough all people will eventually develop dementia. (F)	28	8	75.7%
4 Black people do not develop dementia (F)	14	18	37.8%
5 Dementia runs in families / is inherited (F)	19	15	51.4%
6 Dementia is a type of cancer of the brain (F)	26	11	70.3%
7 Dementia can be caused by poor diet (F)	26	11	70.3%
8 Hardening of the arteries is a common cause of dementia. (F)	16	17	43.2%
9 One should be careful around individuals with dementia since one may develop the disease from regular contact with such people.(F)	36	1	97.3%
10 Progressive withdrawal from social activities is common to all people with dementia. (T)	28	8	75.7%
11 Fatigue is a common problem for people with Dementia. (T)	20	13	54.1%
12 People with dementia can no longer learn new skills. (T)	32	4	86.5%
13 People with dementia are very agreeable, co-operative and easy to live with (F)	34	2	91.9%
14 Severe memory loss is always caused by disease and is not a common problem in the elderly (T)	13	19	35.1%
15 Dementia is not curable (T)	27	9	73.0%
16 The younger one is when the first symptoms of the disease occur the more severe the disease will become (T)	19	15	51.4%
17 It is best if families make arrangements for nursing home placement as soon as diagnosis of Dementia is made (F)	31	6	83.8%
18 Eventually the person with Dementia will need 24 hour supervision (T)	33	3	89.2%
19 The Health Service covers all the costs of care of individuals with Dementia (F)	31	6	83.8%
20 Only a psychiatrist can diagnose Dementia (F)	20	13	54.1%

caregiver rated receiving information as being helpful, or whether or not the caregiver desired further information bore no relation to the DKQ scores.

### **Attributional Style**

Attributional style was measured using two different measures, one measuring specific attributions about dementia (based on the methodology of Pagel et al., 1985 and Coppel et al., 1985), and the other looking at causal attributions in general. These will be examined separately and then compared.

The first measure of attributional style looked at caregivers' specific attributions about dementia and being a caregiver. The two items relating to care recipient behaviour were summed to create the 'perceived loss of control over care recipient behaviour' index, as were the two items relating to change in the spouses life to create the 'perceived loss of control over life changes' index. Additionally the scores for internal/external responsibility for the care recipient's behaviour before diagnosis and self blame were summed together to make the 'internal / external' attribution index. Finally the scores for control over personal reactions were combined to form the 'loss of control over personal reactions' index. This followed the scoring method of the original study (Pagel et al., 1985; Coppel et al., 1985).

As can be seen from **Table 3.11** the caregivers showed a tendency towards feeling they had no control over their spouse's behaviour or about the changes in their own life. The

sample's ratings significantly varying from the expected midpoint (7), neither complete or no control, in this direction ( $t(36) = 4.40$ , and  $t(36) = 4.02$ , respectively both with a  $P < 0.001$ ). Conversely the caregivers (on average) felt a degree of control over their own emotions. The sample's ratings again significantly varying from the expected midpoint (7), neither complete or no control ( $t(36) = -3.95$ ,  $P = 0.001$ ). The caregivers made a clearly external attribution about the cause of their relative's condition. This significantly varies from the expected midpoint (8), neither external or internal ( $t(36) = -10.073$ ,  $P < 0.001$ ). Neither sex, age, socioeconomic status, relationship of the caregiver to the patient, amount of help given or provided, caregiver's own illness or length of time caring showed any significant relationship with any of the above measures of the caregiver's specific attributions about dementia. Nor did caregivers who did or did not want further information or the degree to which they had found information helpful significantly relate to any of the indices.

**Table 3.11**  
**Causal Attributions about Dementia**  
Means of ratings made on the indices of causal attributions about dementia

Indices	Mean	SD	Range	Continuum
<b>Perceived loss of control over:</b>				
Spouse behaviour	9.3	3.1	2 - 12	2 (Complete control) - 12 (No control)
Life changes	8.8	2.8	2 - 12	2 (Complete control) - 12 (No control)
Personal Reactions	5.4	2.5	2 - 11	2 (Complete control) - 12 (No control)
<b>Attribution:</b>				
Internal / External	3.9	2.5	2 - 12	2 (External) - 14 (Internal)



The obtained scores on the modified ASQ were also grouped to form a number of composite scores describing the caregiver's attributional style. These groupings reflect the individual's responses to negative and positive events, describing the responses in terms of a continuum along the three attributional style dimensions; internality, stability, and globality. This means that for both positive and negative events composite ratings can be calculated for internality, stability, and globality. In addition to this hopelessness (stable negative + global negative) and hopefulness (stable positive + global positive) scores were calculated. Finally composite scores for all three dimensions across positive and negative events were calculated (Cpositive, Cnegative) with a score for overall causal attributional style, CPCN (Cpositive - Cnegative).

**Table 3.12** outlines the mean score across each of these dimensions. As can be seen by looking at the mean scores the sample as a whole did not make particularly strong external or internal, stable or unstable, global or specific attributions about negative events. However, the sample did make significantly more hopeless attributions in the face of negative events (a one sample t-test from the expected midpoint score of 8 equalling;  $t(36) = 0.036, P < 0.05$ ). The mean score for the composite negative score indicates that overall caregivers tended to make significantly more internal stable attributions as compared to the expected mid point score 12, neither internal nor external,  $T(36) = 8.22, P < 0.001$

**Table 3.12**  
**Causal attributional style**  
**Means of ratings made on the ASQ**

Indices	Mean	SD	Range	Continuum
<b>Negative Events</b>				
Internal negative	4.0	1.6	1 - 7	1 (External) - 7 (Internal)
Stable negative	4.4	1.2	1.3 - 7	1 (Unstable) - 7 (Stable)
Global negative	4.5	1.8	1 - 7	1 (Specific) - 7 (Global)
Hopelessness	8.9	2.6	3.3 - 13.3	2 (Hopeful) - 14 (Hopeless)
Composite negative	13.0	3.7	5.3 - 19.7	3 (Non-pessimistic) - 21 (Pessimistic)
<b>Positive Events</b>				
Internal Positive	3.0	1.3	1 - 5.7	1 (External) - 7 (Internal)
Stable positive	3.9	1.2	1 - 6	1 (Unstable) - 7 (Stable)
Global positive	3.8	1.5	1 - 6.7	1 (Specific) - 7 (Global)
Hopefulness	7.7	2.5	3.3 - 11.7	3 (Hopeless) - 14 (Hopeful)
Composite positive	10.8	3.3	4.3 - 16.3	3 (Pessimistic) - 21 (Non-pessimistic)
<b>Overall Causal Attributional Style (CPCN)</b>	-2.6	4.0	-12 - 6	-18 (Pessimistic) - 18 (Non-pessimistic)

Looking at the ratings for positive events, the caregivers as a group significantly rated the cause of the positive events as more internal when compared to the expected (neither internal or external) midpoint 4 ( $t(36) = 14.83, P < 0.05$ ), although there was no statistically robust style shown on the other two variables (stability and globality). The mean score on the hopefulness scale for positive events did not show a tendency towards or against hopefulness, but when the composite score for all positive events was examined the mean score of 10.81 suggests that as a whole the ratings tended towards

external, unstable specific attributions for positive events. The mean CPCN score indicates that the group's pessimism about negative events significantly outweighed their positivism for positive ones, a one sample t-test revealing that it significantly varied from the expected mid-point score of 0 ( $T(36) = -3.887, P < 0.001$ ).

Again neither sex, age, socioeconomic status, caregiver's health problems, relationship of the caregiver to the patient, amount of help given or provided, or length of time caring showed any significant relationship with any of the above measures of general attributional style. Like the measure of specific attributions about dementia there was also no significant relationship between any of the ASQ scores and wanting to know more about dementia, or having found information about it helpful. Interestingly there were also no significant correlations between the two measures of attributional style.

### **3.3 Interactions Between Three Main Variables**

#### **Dementia Knowledge \* Well being (GHQ, SASS).**

To find out if the data showed similar correlations of dementia knowledge to psychological well-being as found by Graham et al. (1997) the obtained scores of the caregivers on these two measures were correlated. This study however went further to also examine relationships between the sub-scales of the Dementia Knowledge Questionnaire and psychological well-being. As this study commenced before the

publication of Graham and his colleagues (1997) study, the exact measures of psychological well-being used in that study were not used.

Overall there was no significant correlation found between the total GHQ score and total score on the DKQ. However, there were some significant correlations found when the sub-scales were examined. A significant negative correlation ( $R = -0.33$ ,  $P < 0.05$ ) between DKQ total score and the GHQD sub-scale was found. This indicates that in the sample higher knowledge related to lower levels of severe depression and *visa versa*. A negative correlation ( $R = -0.53$ ,  $P < 0.01$ ) was also found between the DKQ Aetiology sub-scale and the GHQD, indicating that knowing more about the aetiology of the disease related to lower levels of severe depression and *visa versa*. A negative correlation ( $R = 0.34$ ,  $P < 0.05$ ) was also found between the DKQ aetiology sub-scale and the GHQB sub-scale, indicating that knowing more about the aetiology of the disease related to lower levels of anxiety and insomnia. Finally there was a negative correlation ( $R = -0.38$ ,  $P < 0.05$ ) between the GHQ total score and the aetiology sub-scale, indicating that knowing more about the aetiology of the condition related to a lower level of overall psychological distress. There were no significant correlations with any of the other DKQ sub-scales, nor with the somatic or social dysfunction sub-scales of the GHQ.

Significant correlations were found between one element of the DKQ with the SASS. A moderate positive correlation was found between the SASS total score and the DKQ aetiology sub-scale total ( $R = 0.36$ ,  $P \leq 0.05$ ), indicating that caregivers within the study

who knew about the aetiology of dementia also tended to report higher levels of social motivation and social behaviour.

### **Causal Attributions \* Well being (GHQ, SASS ).**

To indicate whether the data showed similar correlations of causal attributions about dementia with psychological distress as was found in the study by Pagel and his colleagues (Pagel et al., 1985, Coppel et al., 1985) and Morris et al. (1989) the obtained scores of the caregivers on the measure of attributional style from their study were correlated with the measures of psychological well-being. This study however also looked at whether the caregivers ratings of their more general attributional style towards positive and negative events correlated with well-being. For clarity the analysis will look separately at the ratings on the two different measures of causal attributions.

#### Causal Attributions about dementia and Well being

There were no significant correlations between the GHQ total score and the 4 indices of causal attributions about dementia, however there were two variables that did correlate. Firstly there was a positive correlation ( $R=0.38$ ,  $P<0.05$ ) between the internal / external attribution index and the GHQC (Social Dysfunction), indicating that caregivers who rated themselves as currently having difficulties in the area of social function recalled making more internal attributions about the cause of their relative's condition, whilst those who did not rate themselves as having such dysfunction were more likely to make external attributions about it. The only other correlation found between the two

measures was between the indices of perceived loss of control over own emotions and the GHQ sub-scale measuring anxiety and insomnia ( $R=0.361$ ,  $P<0.01$ ), indicating that those caregivers who rated themselves as having more difficulties with anxiety and insomnia also tended to rate themselves as having less perceived control over their emotions, and visa versa. There was no significant correlation between the caregivers SASS sum ratings with any of the indices relating to causal attributions about dementia.

Judd & Kenny's (1981) method for analysing a mediating relationship was used to consider whether causal attributions about dementia mediate between the mood and behavioural disturbance of the care recipient and caregiver distress. Their method uses a series of three regression models in which a) the mediator is regressed on the independent variable, b) the dependent variable is regressed on the independent variable, and c) the dependent variable is regressed on both the independent variable and on the mediator. In terms of this study this means; a) regressing the causal attributions about dementia indices on BMD scores, b) regressing GHQ and SASS scores on BMD Scores, and c) regressing GHQ and SASS scores on both the BMD and the causal attributions about dementia indices. To demonstrate that there is a mediated relationship it is essential that firstly the BMD scores (the independent variable) must affect the causal attributions about dementia indices (the moderator), secondly that the BMD scores must affect psychological well-being (the dependent variable) and thirdly that the causal attributions about dementia indices must affect psychological well being in the third equation. Then it is essential that the effect of causal attributions about dementia indices

must be less in the third equation than the second and ideally, if perfect mediation holds, the causal attributions about dementia should have no effect when the mediator is controlled for.

A Pearson correlation of the BMD score and attribution about depression indices revealed (Regression a from the equation) only one significant correlation. BMDC (Mood disturbance) correlated positively with the internal external attribution about dementia ( $R= 0.36, P<0.05$ ). However, criterion ( b) of the equation was not satisfied because, as stated earlier, there was no significant correlation found between that sub-scale and GHQ or SASS scores. This means that we cannot reject the null hypothesis that although some indices of the measure of causal attributions about dementia relate to the measures of behaviour and mood disturbance and to psychological well being as measured by the GHQ and the SASS it does not mediate between them.

#### General causal attributional style and Well being

There were several correlations between caregivers' GHQ ratings and their ratings of their general attributional style. Firstly looking at attributions for negative events, the analysis revealed a positive correlation between obtained scores on the GHQA sub-scale (somatic symptoms) and caregivers rating the impact of negative events to be global ( $R=0.48, P<0.001$ ). There was also a significant correlation between making global attributions about negative events and the caregivers' ratings on the GHQB sub-scale (anxiety and insomnia), and their total GHQ score. This suggests that caregivers who

rated themselves as suffering more from symptoms of anxiety and insomnia or as being more generally psychologically distressed also had a tendency to make global attributions about negative events. Finally there was a correlation between caregivers rating themselves as more severely depressed (GHQD) and caregivers making more unstable attributions about positive events ( $R=-0.37, P<0.05$ ). There were no significant correlations found between the caregivers sum ratings on the SASS and any of the ASQ measures of overall causal attributional style. Looking at the causal attributions made by the caregivers about the positive events described in the questionnaire, there was only one significant correlation between these and the measures of caregiver well-being. There were no correlations between the caregivers' causal attributions about positive events and the SASS, and the only correlation with the GHQ was on the scale measuring severe depression. This sub-scale negatively correlated with the tendency to make more stable correlations about these positive events ( $R= -0.37, P<0.05$ ), suggesting that those caregivers who were less likely to rate themselves as depressed were more likely to rate positive events as stable.

Judd & Kenny (1981)'s method for analysing a mediating relationship was again used, this time to consider whether general causal attributional style for negative events mediated between the mood and behavioural disturbance of the care recipient and caregiver distress. A Pearson correlation of the BMD score and causal attributional style (Regression a from the equation ) discovered no significant correlations between the two measures. As criterion (a) of the equation was not satisfied, the null hypothesis that



causal attributions do not mediate between BMD scores and psychological well-being, although being independently related to the measures of psychological well-being cannot be rejected.

### **3.4 Analysis of the role of causal attributions in mediating between caregiver knowledge and well-being**

To test the core main hypothesis that causal attributions (either about dementia or more generally) mediate between knowing about dementia and improved psychological well-being, Judd & Kenny (1981)'s method for analysing a mediating relationship was again used. Criteria b of this equation was tested earlier in the results and did indeed reveal that attributional style did show some impact on psychological well being. However part a of the equation had not been tested. The dementia knowledge sub scales which had met criterion b) (DKQ total and sub-scale b) were compared against the attributional style scores, both from the ASQ and the specific questions relating to causal attributions about dementia.

No significant correlation was found between any of the dementia knowledge total or sub-scale scores and any of the measures of attributional style. Thus no further test for mediation was carried out as criterion a) had not been met, meaning that we cannot reject the null hypothesis that attributional style (specific or general) does not mediate between knowing about dementia and psychological well-being.

## **CHAPTER FOUR: DISCUSSION**

### **Overview**

The discussion is presented in four sections. The first section (4.1) presents a brief summary of the research findings in answer to the research questions posed in the introduction. The next section (4.2) evaluates the research findings in greater depth, considering them within the wider theoretical context. The third section (4.3) considers the limitations of the study, making suggestions for how future research may seek to overcome them. Finally, the last section (4.4) considers both the clinical and scientific implications which can be drawn from the findings.

### **4.1 Summary of the Main Research Findings**

The research aimed to examine the relationship between dementia knowledge, causal attribution and well-being in caregivers. It intended to extend two earlier studies which separately identified the influence of knowing about dementia and causal attributional styles upon caregiver well-being, in addition to exploring the interaction of these two variables. More specifically the research aimed to examine whether causal attributions may actually mediate between knowing about dementia and psychological well-being.

Caregivers who knew more about dementia appeared to be less depressed than those who knew less about the condition. In particular, knowing about the aetiology of dementia significantly correlated with lower scores on the total GHQ and to lower levels of depression, anxiety, and social dysfunction. Considering the relationship between causal attributions about the care giving situation and well-being, the results showed that those caregivers who reported having no control over their own emotions when thinking about their relative's condition were more anxious. Caregivers who rated themselves as having more social dysfunction, as measured by the GHQ, were significantly more likely to make internal attributions about the cause of their relative's condition, blaming themselves.

Those caregivers who tended to make global attributions about negative events rated themselves as being more anxious, and as having more somatic symptoms. Those caregivers who also felt that negative events may change, that is rated them as less stable, reported more symptoms of depression whilst caregivers who rated positive events as being more stable reported fewer symptoms of depression. All of the correlations accounted for less than half of the total variance in caregiver well-being.

The hypothesised mediating role of causal attributions between negative events, in this case the behaviour and mood disturbance of the care recipient, and the well-being of the caregiver was not bourn out by the findings. The main hypothesis that causal attributions

may mediate between dementia knowledge and psychological well-being was not supported.

## **4.2 Discussion of the Findings with reference to Previous Research**

The study not only allowed an exploration of the relationship between dementia knowledge, causal attribution and well-being, but also provided an opportunity to consider the other factors which have been identified by previous research to relate to well-being in caregivers. This section will first look more closely at the main findings in the light of previous research before going on to examine exactly who the research is talking about and to consider the ancillary findings. The results will then be evaluated in the light of more general research into caregiver well-being, with reference to one of the most widely used models of caregiver distress; Pearlin et al.'s (1990) Stress Process Model of Caring.

### **4.2.1 The Main Findings**

#### **Dementia Knowledge and Well-being.**

The research findings about the relationship of dementia knowledge and psychological well-being partly supported those found by Graham et al. (1997). This study, like theirs, found that higher levels of knowledge about dementia correlated with lower levels of depression but the study did not find that increased knowledge correlated with increased

anxiety. Although associations do not provide a causal explanation, these results lend further support to the argument that knowing about dementia is beneficial to caregivers. If this is the case it is important to consider what the underlying mechanism may be.

It was hypothesised that attributional style may mediate between knowing about dementia and caregiver well-being. The findings did not show this to be the case. There was also no support for the idea that knowing about dementia helps the individual to better understand their relative's behaviour. There is a danger of making a type 2 error here, accepting the null hypothesis when it is actually false, as a result of the small sample size. However, if attributional style and having a better understanding of the relative's behaviours does not explain why knowing about dementia relates to lower caregiver distress, what does ? Looking at the Dementia Knowledge Questionnaire sub-scale scores seems to provide some insight into how to answer this question.

The study identified a relationship between one particular subset of questions within the Dementia Knowledge Questionnaire and caregivers' psychological well-being. Those caregivers who knew more about the aetiology of dementia tended to report lower levels of social dysfunction and anxiety, as well as lower levels of symptoms of general psychological distress. As mentioned, it is not possible to establish a causal direction from correlational data. However, it would seem unlikely that being distressed would only affect a caregiver's ability to gain information about just the aetiology of dementia. It would be more likely to affect their ability to gain all types of information about

dementia. It would then seem more plausible that this pattern of results is caused either by an outside factor which influences both, or that in some way knowing about the aetiology of dementia prevents or reduces anxiety, depression and social dysfunction.

The aetiology questions tap into the lay models of the population about disease. One does not have to look very far into history to see quite a different view of the causes of dementia to that espoused today. As recently as the beginning of this century doctors were claiming that dementia resulted from the brain being worn out with age or that it was a consequence of mental health problems (Berrios 1996). Authors such as Fitzpatrick (1984) have pointed to the social Darwinian aspect of such ideas in that they may contain a kernel of truth and so survive in the subculture. For example, the incidence of dementia increases with age, so it is not surprising that individuals relate it to the degeneration that they see in other aspects of an individual's physical self. Indeed there is evidence that doctors continue to rely a good deal on these folk understandings perhaps prescribing medication, such as throat lozenges, they know to be of no proven medical benefit (Fitzpatrick, 1984).

This then begs the question as to why holding inaccurate beliefs about the aetiology of dementia could be distressing for caregivers. One explanation could be that it is the meaning these beliefs may hold for the caregiver that influences caregiver well-being. Searching for meaning is seen as very important to many people with illnesses. Blaxter in his survey of working class middle aged women in Scotland noted how the search for

causal patterns in their health histories was extremely important to them. Blaxter talked about the women making a “...positive strain towards accounting for their present bodily state...by connecting together the relevant health events...” (p.67. Blaxter, 1983). It is not unreasonable to suppose that caregivers may also wonder why they have had this illness imposed upon them.

Fitzpatrick (1984) points out that publicly available ideas about the causes of a particular disease provide only a partial explanation to the individual as to why they, and not others also at risk, have been afflicted. As mentioned individuals have a tendency to go beyond the information given to construct a more complete explanation (Bruner, 1957). It is how the caregivers construct their understanding that may help explain why not knowing about the aetiology of dementia relates to poorer mental health. Taking into consideration Ross's (1977) ideas about attributional bias, an individual's tendency to attribute things not to situational causes but to dispositional ones, it is not unlikely that caregivers without accurate information may complete their understanding by blaming either themselves or someone else. This may be particularly the case in western cultures where there is a tendency towards believing that people can influence their own health outcomes (Helman 1984).

An alternative hypothesis about why knowing about the aetiology of dementia may be important in preventing distress relates to perceived personal threat. Becker (1974) suggested that one of the important features in perceiving a threat of disease is one's

perceived susceptibility to that disease. Those caregivers who have an inaccurate model of dementia may feel more vulnerable to the disease than those who have an accurate model. A caregiver is already likely to have an increased awareness of dementia which may well increase their perception of vulnerability. This is similar to a phenomenon seen in student doctors. Even in the absence of symptoms, student doctors may self-diagnose the disorders they are learning about at the time and even go on to develop the symptoms (Mechanic 1972). Hyper-vigilance of this kind has also been recognised in anxiety disorders where individuals are thought to become over vigilant to changes in themselves which they then interpret catastrophically (Clark, 1986). During the study many of the caregivers made comments about the likelihood of themselves getting dementia citing their memory problems, emotional difficulties, or difficulties concentrating as being indicative of dementia. It is possible that caregivers who may be experiencing difficulties sleeping because the care recipient is restless at night, or who have been finding it difficult to concentrate or remember things due to exhaustion, may then grow concerned that their symptoms actually represent an underlying dementia. A vicious circle may be set up where even the symptoms of depression are misconstrued. Those with inaccurate lay models of the aetiology of the disease would be particularly susceptible to making such a misinterpretation, but it is notable that even clinicians can find it difficult to differentially diagnose depression and dementia.

Both of the above points suggest that it would be helpful to know what individual's existing schemata or lay models of dementia actually are. A number were evident in the



informal comments made by the caregivers. Some talked of the care recipient having insufficiently used their brain and responded, as has often been described with home treatment, in a homeostasis manner (Helman 1978 ) trying to keep the care recipient active to prevent further passivity. Others talked of lack of social interaction and spent their time taking their relative to social events.

A more pragmatic explanation for why not knowing about the aetiology of dementia correlates with higher levels of caregiver distress could be the way in which the questionnaire is constructed. All the answers within the aetiology section are constructed so that someone answering the questionnaire should state that none of the factors listed cause dementia. This could mean then that it is the denial of these factors as being the cause of dementia that is important not knowing the actual cause. Williamson & Schulz (1993) suggests that when facing an extreme stressor a modicum of denial is helpful. Several studies have found that most individuals vastly underestimate their chances of contracting a particular disease, tending to hold 'just world beliefs' that people get these diseases for a reason and excluding themselves from the equation (e.g. Sloan & Gruman 1983). It may be that *not* believing that these factors could have any impact that is the factor keeping some caregivers feeling secure from the disease. It would be interesting to see whether those individuals who have answered the aetiology questions correctly would tend to deny the importance of factors which are influential, in other words continue to deny their vulnerability to the disease. If this were the case it would challenge Kelley's (1967) idea that accurate attributions are healthy

attributions. Here, where it would arguably be accurate for many of the caregivers to see themselves as vulnerable to dementia, denial may be more healthy. Devising a questionnaire with a mixture of true and false answers about aetiology would make it possible to ascertain if this could account for the findings

The idea that caregiver's own ideas and lay models about the aetiology of the condition may be important in explaining why information groups are often less effective than expected. Groups frequently fail to cover the aetiology of the condition, tending to focus instead on managing the care recipient's behaviours increasing coping but leaving the caregiver still distressed (e.g., Morris et al., 1992). The importance of these lay models could also perhaps explain why information groups using a support format (e.g. Toseland et al., 1989a) have been found to be more effective than more didactic teaching sessions (e.g. Morris et al., 1992). Research has shown that individuals may be cautious about talking about their own understanding of a condition in a formal situation. For example, Pill and Stott (1982) found that participants in interviews were often "...unsure of themselves and less articulate when discussing aetiological topics..." (p 46, Pill & Stott, 1982). Informal support groups may enable caregivers to raise their own lay ideas about the condition for discussion. Individuals who as we know are not active seekers after knowledge (Langer, 1978), may need a clear distinction to be made between new ideas and their existing theories, especially to prevent sub-grouping. Having an opportunity to discuss their understanding of dementia could enable incorrect ideas to be directly challenged and modified. Time alone may not be sufficient for this to happen.

The idea that caregivers own lay models about the cause of the disease may influence their well-being is also interesting considering who the caregivers nominated as having been helpful and unhelpful in providing information. Authors such as Helman (1984) have found that patients are more likely to feel supported when they sense that the doctor has understood them. They suggest that as attribution is a sensitive indicator of the patient's perceptions, its recognition is one demonstration of understanding by the listener. Doctors and social workers were the groups whose information giving received most criticism from the caregivers, whilst the Alzheimer's Disease Society was the group most likely to receive praise. It could be that this is because the informality of a support organisation, in addition to the time they can offer caregivers, allows a greater discussion of caregiver's underlying fears.

This is an important issue for services to rectify as research has shown that patients who feel consultations are too didactic may have poorer health outcomes than those who were satisfied with their consultation (Fitzpatrick & Hopkins, 1981). Patients often feel that their doctor is difficult to understand. Even doctors recently trained may be unaware of using specialist jargon (Fitzpatrick, 1984). Clinicians may even refrain from sharing information with clients fearing that they will not understand (McKinlay 1975). Although there was no difference in outcomes for caregivers who had or had not found information helpful this is still an important issue. A one to one consultation was the nominated preferred means of obtaining information by the majority of the sample of caregivers. It is clear that all health professionals should work hard to make use of their

consultations as an opportunity to educate caregivers, and to find out about their lay understandings which could greatly affect how they care.

There was no evidence that socioeconomic status or caregiver's level of education influenced their level of dementia knowledge. Price et al. (1986) and Graham et al. (1997) did find a relationship between level of education and knowledge about dementia. It could be that this effect is not apparent because the caregivers within this study are of a relatively high socioeconomic status. As the two (education and socioeconomic status) are closely linked the group may be too homogenous educationally to demonstrate this effect. This seems to be reflected in the fact that caregivers scored significantly higher on the dementia knowledge questionnaire than those interviewed by Price et al.'s in 1985. It may also be that levels of knowledge about dementia have risen considerably in the general population since the time of Price et al.'s (1985) study, with dementia being more a matter within the public domain. Of course a direct comparison study would be necessary to support or reject this hypothesis.

In summary, it appears that in this sample of caregivers knowing about dementia correlated with well-being, partly supporting the earlier work of Graham et al. (1997). Although it is not possible from this research to assert a causal relationship, it may be that lack of knowledge is one of the factors which results in or fails to prevent caregivers from becoming psychologically distressed. It is hypothesised that one reason for this may be that caregiving increases fear of contracting the disorder. Although no mediating

role was demonstrated between care recipient behaviour and distress, this may be as a result of the small sample size. Alternatively it is proposed that knowing about dementia modifies the caregivers underlying lay models of the aetiology of the disease rather than their understanding of the symptoms. It is mooted that perhaps the reason information groups have been ineffective and that caregivers nominated doctors and social workers as being the least helpful sources of information is at least in part because they failed to access, understand and modify the caregiver's lay models of the aetiology of the disease. The lack of opportunity to discuss the underlying schema that such fears may be based upon could not only hamper the effectiveness of information giving, but could also have a severely detrimental affects on caregiver's satisfaction with services.

### **Casual Attributions and Well-being**

The main findings relating causal attribution to psychological well-being will be considered in connection to the recorded symptoms. As has already been mentioned this study was limited in its ability to detect relationships between causal attributions and well-being which may explain why many of the relationships found by Pagel and his colleagues (Coppel et al., 1985; Pagel et al.,1985) and Morris et al. (1989) were not identified in the study. Again it is not possible to establish a causal chain, and so those mentioned here are speculative.

The study did not find any of the connections between depression and causal attributions about dementia found in the study by Pagel and his colleagues (Coppel et al., 1985;

Pagel et al., 1985), nor the complete pessimistic attributional style described by Abramson et al. (1978) in response to hypothetical events either, although elements were present. Higher levels of depression correlated with caregivers rating negative events as less stable; and rating positive events as specific.

The second finding, that those caregivers who rate positive events as specific, accords with the second part of Abramson and colleagues reformulated learned helplessness theory (Abramson et al., 1978). It is also consistent with the hypothesis that attributions about positive events may be as important in predicting depression as those about negative events, backing the demand that attribution research should consider both (Robins & Hayes, 1995). It also concurs with the hypothesis that people who are already depressed may become pessimistic about positive events too. The other finding, that caregivers were more depressed if they felt that the negative events might change, is perhaps more intriguing as it would seem to counter Abramson's theory and Pagel and his colleague's findings (1995). An explanation for this could relate to the nature of the stressor in dementia care giving. Pagel and his colleagues considered care giving to be a continual stressor, and for some caregivers this may be the case. Stress levels in care giving however often vary over time as the care recipient passes through various stages of the disease (Haley & Pardo, 1989). It is this unpredictable unremitting decline which caregivers seem to find stressful. Caregivers as a group then may be more likely to view something unstable (however negative) as more distressing than something that was stable. This does not seem surprising considering experiments such as that by Glass &

Singer (1972). Their study found that an unpredictable but expected negative event, was far more stressful than an unpleasant event the occurrence of which was predictable. In other words someone who knows something bad will happen, but not what it will be or when it will occur, will be more distressed than if they could predict these things.

This finding may also explain why knowing more about dementia in this study did not, as hypothesised by Graham et al. (1997), correlate with greater anxiety. For caregivers knowing at least what sort of deterioration might happen, is perhaps less stressful than knowing that deterioration will occur whilst not knowing what to expect. This could represent a sample difference between the two studies. Caregivers in the Graham study were just coming to terms with a new stressor whereas in this sample caregivers had for the most part been caring for some time perhaps growing accustomed to the diagnosis.

The study did find some connection between causal attributions and anxiety where Pagel and his colleagues did not. This could be a result of the measure of anxiety used here being more robust. There were two correlations between the measures of attributional style and anxiety. The finding that those caregivers who felt less in control of their own emotions correlated with higher levels of anxiety concurs with findings to date and reinforces the idea that attributions may be important in anxiety as well as depression. The second finding, caregivers who felt unable to control their emotions tending to have higher anxiety ratings, also matches an attributional formulation. Attributionally this can be seen as caregivers making an external stable attribution in regard to their emotions.

Caregivers may fear losing control of their emotions for many reasons but considering the earlier discussion they may misinterpret feeling out of control of their emotions as a sign of dementia.

Global attributions about negative events positively correlated with higher levels of somatic symptoms, whilst self blame positively correlated with higher social dysfunction. These results are more difficult to interpret, mainly due to the lack of clarity about what these measures are actually tapping.

Social dysfunction is one of the main symptoms of depression, and it is recognised that older adults (most of the sample being aged 65 and over) may tend to present somatic symptoms rather than presenting as depressed (Katon, 1982). This could then perhaps relate to Pagel and his colleague's (Coppel et al., 1985; Pagel et al., 1985) finding that people who tended to blame themselves were more depressed. This certainly accords with a pessimistic attributional model of psychological disturbance. Although caregiver's ill health should not have influenced the scoring on the GHQ, which asks them to rate how they have been feeling relative to normal over the last few weeks, it can not be ruled out entirely. This may have been a highly influential factor considering the high proportion of caregivers with ill health.

Looking at the opposite causal direction caregivers may tend to blame themselves more for their relative's condition simply because they are more isolated. Stoller & Pugliesi



(1989) highlight how losing outside contacts can have negative consequences for caregivers leading to role engulfment when the role of caring excludes all others. Skaff & Pearlin's (1992) research suggested that multiple roles provide valuable human contact and feedback. Without outside feedback caregivers can become overly preoccupied and judgmental about their own performance, especially as the reciprocal exchanges between themselves and the care recipient gradually dwindle (Anshensel et al., 1993).

The test of whether causal attributions could mediate between the behaviour and mood disturbance of the relative (i.e. an ongoing stressful situation) and caregiver well-being is rather disappointing. Although causal attributions correlated with dimensions of each, there was no overlap in the actual dimensions so it is not appropriate to suggest a mediating relationship. It is not possible however to state clearly that causal attributions do not mediate between behaviour and mood disturbance and caregiver well-being as again there was an insufficient number of participants to comfortably rule out the possibility of making a type 2 error. There was no evidence found that attributional style may influence who did or did not want to find out about the condition.

In summary, fewer correlations were found between the symptom measures and causal attributions about care giving than in the study by Pagel and his colleagues (Pagel et al., 1985, Coppel et al., 1985), perhaps due to the smaller participant numbers. The results are mildly supportive of Abramson et al.'s (1978) Reformulated Theory of Depression

as although a complete pessimistic attributional style was not identified some of its elements were found.

### **Mediating role of Causal attributions**

The research did not demonstrate a mediating role for causal attributions between dementia knowledge and caregiver well-being. However, again there is a danger of making a type 2 error due to participant numbers. If it is assumed that this finding is accurate, knowing about their relative's condition must affect well-being by some other causal mechanism, volume of knowledge alone seeming an inadequate explanation. Referring back to the earlier discussion, it is possible that knowing about dementia does not change someone's causal attributions about dementia but instead changes how vulnerable they feel to contracting the disease. Here it is only possible to hypothesise, but it is a hypothesis certainly worth testing further in the future.

### **4.2.2 Caregiver Characteristics within the Sample**

As intended, the caregivers interviewed seem to represent a broad sweep of individuals caring for a relative with dementia, the dimensions of which seemed to reflect what is known of caregivers in general. The proportion of male to female caregivers (29.7% : 70.3%) is close to that found by Stone et al.'s survey of caregivers (1987, 33%: 67%). However the group were slightly older than caregivers in general (General Household Survey 1995). The high proportion of spouse caregivers interviewed may explain this.

Most of the caregivers had a health problem(75.7%). This is proportionately high as of the total older adults population in Great Britain 66% have a long standing illness (General Household Survey 1996). This seems to back up the work of authors such as Katon et al.(1982) who have highlighted the negative physiological impact of caregiving.

The caregiver group represented a fairly financially affluent portion of society as based upon their socioeconomic status at prior employment. This matches the socioeconomic make up of the study area suggesting no obvious selection bias. This affluence also seems to be reflected by the goods owned by the group. The caregiver group in the study had either an equal or higher proportion of goods ownership on all categories compared to the general population in 1997 as measured by the Family Expenditure Survey 1996/7. The caregivers in this sample also had a higher proportion of home ownership (89.2%) than the general population of people over the age of 65 in Great Britain (62%: General Household Survey 1996).

It is important to note that past socioeconomic status does not necessarily indicate current socioeconomic state. Question 45 from the SASS; “Do you have difficulties in managing your resources and income” revealed that just under a quarter of the caregivers had experienced such difficulties at least sometimes, and almost a quarter of the sample felt that their standard of living had been reduced by caring. This would also suggest that this group are not as affluent as they at first seem. The group’s high proportion of home ownership may actually represent greater difficulties rather than ease. For

example, the English House Condition Survey (1996) found that of those owner occupiers who were over 85, many of them lived in housing that needed essential modernisation.

Although very few of the care recipients lived in permanent residential accommodation it was notable that of those caregivers supporting relatives in residential accommodation, most were still very involved in the care of their relative. This concurs with Rosenthal & Dawson's (1992) assertion that care does not cease when a relative is admitted to long term residential accommodation.

The group cannot be said to ethnically represent caregivers in Great Britain, where it is estimated that approximately 6% of the population over the age of 65 are from ethnic minority groups (Social Trends 1995). The representation of caregivers from the ethnic minorities 2.7% matches the local populace, suggesting that there was no obvious selection bias in this respect.

The care recipients (63.9%) were mainly male, matching the pattern of care expected when looking at spouse caregivers. Similarly the proportion of the different diagnoses was roughly equivalent to the relative prevalence of the different conditions in the population as a whole, although there was a large grey figure represented by the group who were unaware of their exact diagnosis. Care recipients had received their diagnosis over a fairly broad span of time and represent caregivers from all parts of the caring

process. As noted in the results a large proportion were not in contact with the local NHS dementia services, and so had not had an opportunity necessarily to speak to a health care professional knowledgeable about the condition. This again represents more truly the situation of caregivers in the community, than say the Graham et al. (1997) study which recruited from a memory clinic.

As mentioned in the results, the level of behaviour and mood disturbance as measured by the BMD within the group was high, being on average 13 % greater than that in Green et al.'s (1982) study validating the measure. As would then be expected the caregivers were particularly distressed with 56.8% of the sample scoring at or above caseness, significantly higher than in a recent study (Buck et al.,1997). This is high when considering the population prevalence of difficulties like anxiety and depression have been estimated to be 13.7% and 17.8% in an urban sample of older people (Lindesay et al., 1989). As this was not a truly random sample this study does not intend to suggest prevalence of caregiver distress in the population, but it does allow us to say that this was a particularly distressed group of caregivers. Conversely the levels of social dysfunction in the group fell within the 'normal' range. The sample did not appear to be particularly socially maladjusted, which is interesting when considering the part that such maladjustment plays in depression (Leader & Klein 1996). This could be a result of the group's involvement in the Alzheimer's Disease Society. Many of the caregivers said that this had actually led to an increase in their social circle and contacts, a testament to the helpfulness of this organisation in reducing the social isolation of caregivers.

In summary, the study's aim of looking at a broader group of caregivers than Graham et al.'s (1997) study was met. The group cannot however be said to be representative of all dementia caregivers in Great Britain. The care recipients were predominantly male and although representative of the prosperous commuter belt around London, have a higher socioeconomic status than caregivers in general. They do not have the ethnic diversity of many parts of Great Britain. After considering the demographic details of the caregivers there appeared to be no obvious sampling bias, the caregivers matching the local area.

#### **4.2.3 Other Factors in Caregiver Distress**

In addition to the main hypotheses it was also possible to consider whether this research supports earlier findings relating to caregiver well-being.

Supporting the findings of several other authors (e.g. Aneshensel et al., 1995; Abster & Cummings, 1994; Donaldson et al., 1998; Gilleard et al., 1984; Morris et al., 1988; Pruchno & Resch, 1989; Terri et al., 1992) a relationship was found between the behaviour and mood disturbance of the relative, and higher levels of caregiver distress. This was particularly so for the apathetic withdrawn and active disturbed behaviours. These related not only to high scores on the GHQ as a whole, but also to high scores on its sub-scales, in particular the sub-scale measuring somatic symptoms. This suggests that the higher the mood and behaviour disturbance of the care recipient the more

psychologically distressed is their caregiver. Like other studies the behaviour and mood disturbance of the relative, although correlating strongly with scores on the GHQ, did not account for all of the variance, suggesting that there are other important factors implicated in caregiver well-being. Although there was some relationship between the length of time caring and caregiver distress the ongoing incremental increase in caregiver distress over time found by Grad & Sainsbury (1963) was not replicated. The results suggested a pattern of alternating increasing and decreasing distress. A longitudinal study would be necessary to verify this but it would comply with Aneshensel et al.'s (1993) contention that stress levels vary over time as various key events occur. This finding highlights the importance of looking at caregivers across the lifespan of the caring relationship when predicting prevalence of psychological well-being. The research did not find a relationship between the amount of formal or informal help given to caregivers and the care recipient's score on the BMD, indicating that there was no obvious relationship between need and the provision of care.

There was no significant relationship between the caregiver's ratings of the amount of formal or informal help received and caregiver distress. This may reflect the fact that the help recorded formally was mainly instrumental, which has been shown to offer little protection to caregivers' mental health. Support from relatives can also be stressful in itself (Chenoweth & Spencer 1986). This can perhaps be seen in the fact that two of the caregivers cited their relatives as having been least helpful in providing information. Cicirelli (1983, 1986) found that interpersonal strain between ageing parents and adult

children can result in the children having negative feelings about providing support. Semple (1992) states that caring may in itself activate latent family strains, resulting in emotional distress for the whole family and even lead to a situation where relatives 'get their own back' for past ills. Anshensel's (et al., 1995) longitudinal studies of care giving found that stress certainly proliferated in the face of such family tensions.

The study did not bear out the frequently found research finding that female caregivers are more distressed than male caregivers (e.g. Coen et al., 1997; Townsend et al., 1989; Donaldson et al., 1998 ). There was no significant difference found between male and female caregivers scores on either the SASS or the GHQ and it's sub-scales. Miller & Cafasso (1992), Verbrugge (1985), and Abel (1990) have proposed that female caregivers are not actually any more distressed than their male counterparts. They suggest that this has become an accepted truth through methodological error and the tendency for researchers not to report findings of no difference. Other authors have suggested that female caregivers tend to be more distressed because in general more is expected of women resulting in a greater actual burden of care being placed upon them (e.g. Charlesworth, Wilkin, & Durie, 1984; House, Umberson, & Landis, 1988; Miller & Cafasso, 1992; Morris, Woods, Davies & Morris, 1991). If this is the case then it is unsurprising that no difference was found between men and women in this study as there was no significant difference in the range or number of tasks carried out by them or the amount of formal or informal help they received.



There was also no significant support for Meshefedjian et al.'s (1998) finding that caregivers from lower socioeconomic groups find caring more distressing. Some of the studies from the United States, where people with low incomes are more able to access publicly supported programmes, also fail to find the hypothesised relationship between socioeconomic status and caregiver distress (Zarit & Edwards 1996). This study found an almost inverse relationship of socioeconomic status to the amount of formal help received by caregivers, with the top socioeconomic group, group I: professionals receiving the least help. The actual pattern of formal help received was quite complex with both the bottom socioeconomic group (V: Unskilled Manual) and the second to top receiving most (II: Employers and Managers). It is unclear why this might be, other than perhaps group II could be most able to access help in the complex health and benefits system, whilst group V may be most entitled to help. This is, of course, pure speculation but may explain why the expected patterns of higher levels of distress with lower socioeconomic status were not found, strengthening the view that it is service purchasing/accessing power that is more important than socioeconomic status per se.

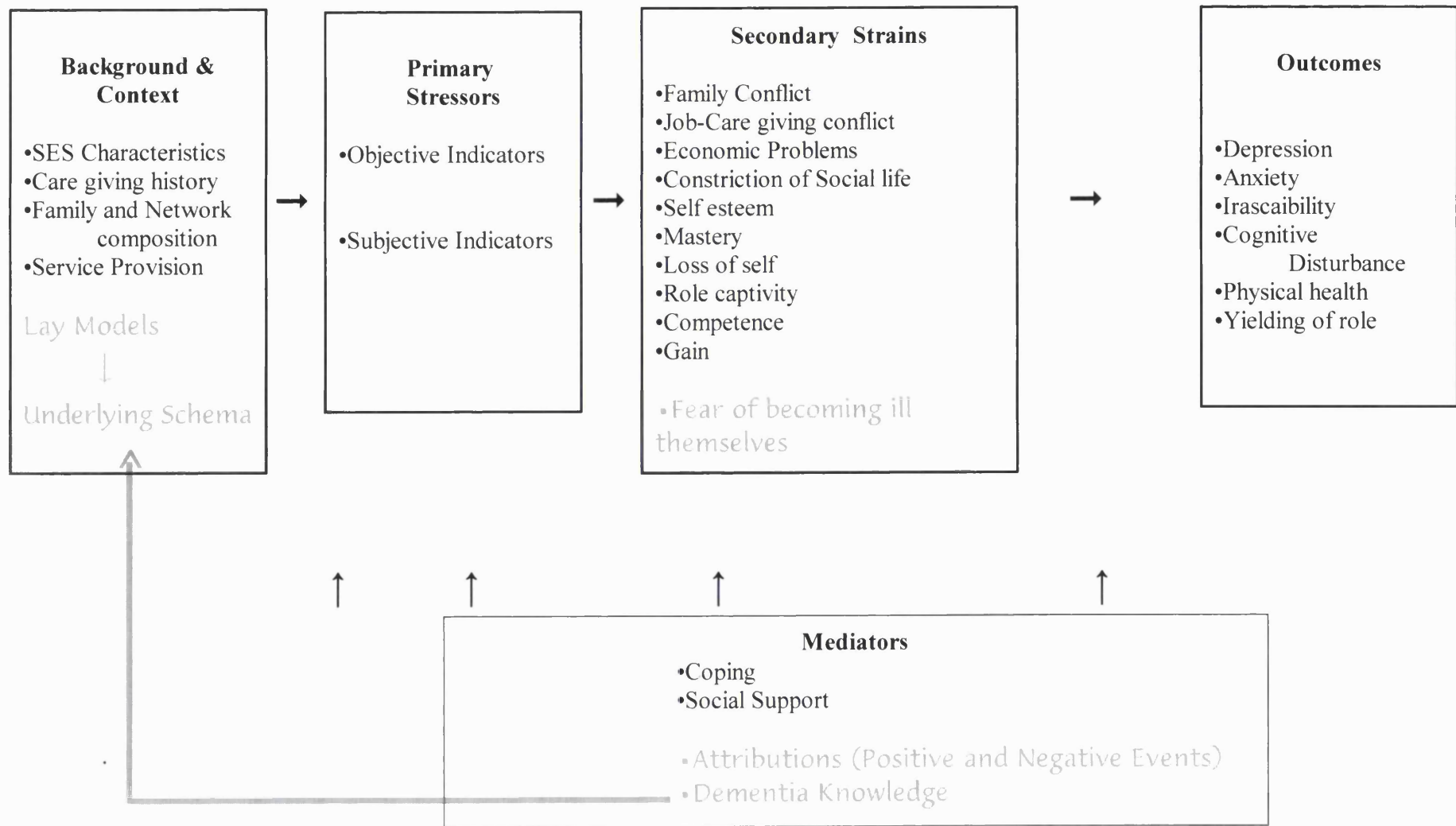
In conclusion, the findings from the study in part replicated some of the other findings about the relationships of a number of factors to caregiver distress. Others, that were not replicated, highlight the need for consideration of potentially confounding factors such as socioeconomic status.

#### **4.2.4 How the findings fit with existing models of caregiver stress:**

##### **Pearlin's Stress Process Model of Caring**

The literature identifying risk and protective factors which may mediate between the task of caring and caregiver distress is vast and constantly growing, with a plethora of often contradictory research findings making it difficult to see how findings relate to the literature as a whole. Pearlin and his colleagues (1990) have offered a conceptual framework which attempts to organise thinking and establish coherence around some of the findings. Their Stress Process Model of Caring (**Figure 4.1**) combines elements which have been found to be relevant to caregiver distress and aims to provide an account of the stress process by which caring may or may not lead to distress. The model does not see caregiver distress as an event or as a unitary phenomenon but instead as a "... mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers' health and behaviour..." (p591 Pearlin et al.,1990). This matches with the findings of the present study.

As mentioned this study supports many of the factors already contained within the model. It also suggests ways in which the model could be extended. This study has demonstrated that both attributional style and dementia knowledge correlate with lower levels of caregiver distress. A number of authors had already begun to think about the role of appraisal and feedback within the model (e.g., Charlesworth & Adams, 1997).



**Figure 1.3 :** The Stress Process Model of Caring  
After Pearlin et al. (1990) with additions based on research findings

These elements seem to fit neatly into the mediators domain, although perhaps the term modifier would be more appropriate. They are both factors that appear to intervene between the primary stressors and distress. These attributions are not only about both the difficulties of the care giving situation but may also be attributes about the positive events in the caregiver's life, this study having demonstrated that attributions about positive events relate to depression in caregivers.

There also seems to be some evidence that caregiver's lay understandings are important in terms of their health outcomes. These models would be included in the background and context domain of the model, as the caregiver would have constructed understandings of disease and their relative before the onset of the disorder. It may well be that dementia knowledge may act directly on these lay understandings or via an individual's schemata to modify them. This may work, as discussed earlier, in a balance fashion by which a message gets through when there is a sufficient weight of argument or may be rushed through at a time when primary stressors challenge their existing schemata's utility. Lay understandings may also relate to a secondary stressor not identified in the original model, 'fear of contracting the illness'.

### **4.3 Methodological Difficulties**

#### **Representativeness of the Sample**

This study did not use a truly random sample of caregivers due to the difficulties of

recruiting such samples. Recruiting proved difficult even without attempting such randomisation . Dementia caregivers are an elusive group. Although many caregivers are in touch with services, many others care in isolation, forming what Caird & Cargill (1987) referred to as a 'silent epidemic'. This was clearly demonstrated in a recent study where health workers in Camberwell (Cooper & Fearn 1998) aimed to set up a dementia register, and identified only one in five of the expected cases via services. The cases identified were estimated to be on average no more severely disabled and dependent than those who were unknown. Thus for any study getting hold of this silent majority is difficult, if essential.

Most of those referred to this study came via the Alzheimer's Disease Society and local day centres, and it is not unrealistic to suggest that those referring to the study may have selected those they felt would be most able to respond to the questions and who would also be willing to do so. It may well be that those who did not want to be interviewed had a particular attributional style or have found information so unhelpful they wished no further involvement with services.

Ideally a fully random sample would have been drawn from electoral registers and offered initial interviews to assess their eligibility to take part in the study, this was not however possible within the bounds of the study. On the positive side this was intended to be an exploratory study to look at correlations between the measures rather than group differences. The group also represented a broad sample in terms of their

demographic details. The study did not include a control group as it intended to look specifically at whether the concepts were relevant to caregivers. The important comparison was between caregivers who were more or less distressed.

### **Representativeness of the care recipient's condition**

In an attempt to gain greater numbers and due to the difficulty, and hence unreliability of diagnosis (Alzheimer's Disease Society 1999), no single specific diagnosis of dementia was included in the study. It may well be that those caring for individuals with different dementia's may have had very different care giving experiences and knowledge. The study attempted to control for this, and indeed statistically these factors did not play a significant role in the obtained results.

### **Representativeness of the Geographical Area Studied**

As has already been noted the area within which the study was carried out (West Essex and East Hertfordshire) has a more affluent socioeconomic status than much of the UK. This may have had an important limitation on the comparison with Graham et al.'s study (1997). Their study found that there was a significant relationship between education and dementia knowledge. As education is often linked to socioeconomic status this sample bias may have excluded a particular range of the results.

Services for people with dementia vary vastly across the UK, perhaps particularly in the area of diagnosis and treatment of dementia. In particular two factors have grown in

importance and influence; firstly the use of memory clinics for diagnosis of dementia and secondly the use of the so called 'anti-dementia' drugs. Within the area studied the memory clinic rarely convened, being funded by research monies. Conversely the research in the area means that many individuals receive the so-called 'anti-dementia' drugs, whilst in neighbouring areas they do not.

These two factors may greatly affect the outlook for caregivers in this area as opposed to those in other parts of the country. The remit of a memory clinic includes the provision of advice and information and as mentioned in the earlier critique of Graham et al.'s (1997) study, caregivers who have been through this process may know much more about dementia. The prescription of anti-dementia drugs may also have an impact on attributions about dementia. These drugs would certainly not have been available to the caregivers in Pagel and his colleague's study (Pagel et al., 1985,; and Coppel et al., 1985). The prescription of these drugs may have greatly influenced the caregiver's ratings of the stability of their relative's difficulties. Caregivers supporting a relative prescribed one of these drugs may have experienced an improvement in their relative's condition. For example, improvement in functioning has been found in clinical trials in around a quarter of those prescribed Exelon, one of the acetylcholinesterase drugs (Walker, 1998). It is notable that a large proportion of the sample's relatives took these types of medication. These factors indicate that caution should be shown when generalising these findings to areas with different service provision.

### **Difficulties with the research design**

Ideally, of course, any study that wished to look at causal mechanisms would be longitudinal. This was not possible in this instance due to the amount of time available for the research.

Other difficulties with the design centre around the way in which the questionnaires were presented. The interview format unfortunately meant close involvement in completion of the questionnaires by the researcher who was not blind to the research question. The order in which the questionnaires were completed intended to reduce as far as possible prior knowledge of the research questions influencing the outcome. This meant that questions about caregivers' psychological well being were asked after those about their attributional style, but before the assessment of their knowledge about dementia. Caregivers made their actual rating independently. This method meant that it was not possible to look at inter-rater reliability.

### **Difficulties with the measures**

Several of the questionnaires proved slightly problematic for this group. Firstly the GHQ, asks caregivers to rate how they have been feeling over the last couple of weeks. As has already been mentioned many of the caregivers had been caring for years not weeks. It is fair then to assume that those who were distressed may have been so for a number of weeks. The scoring on the GHQ would mean that these individuals would not score as distressed.



The caregivers found the two attribution measures particularly difficult to complete, finding it hard to score their attributions on the continuum given. The power of the questionnaire may also have been significantly reduced by cutting it in half as a necessity of both reducing the length of the questionnaire battery, and to only include items relevant to older people. Peterson, Villanova & Raps (1985) identified lack of sufficient events as being one of the factors implicated in the failure to find significant results. This questionnaire may well need further modification for this group and would benefit from having more events for caregivers to rate. This factor may well have contributed to the lack of significant results for the pessimistic attributional style as a whole.

The DKQ is also problematic. Perhaps the most important difficulty is that the measure adheres to a purely medical model of dementia. For many years the medical model, in which the "...bizarre and troublesome behaviours of dementia sufferers was attributed to the disease process in the brain while their real life predicament was not taken into account..." (p542, Kitwood, 1993), dominated dementia care resulting in a 'caretaking' model of care in which the person with dementia had "...almost totally disappeared..." (p541, Kitwood, 1993). This model has now been challenged by the growing evidence that individuals with dementia are far more aware of their environment than was once thought (Feil, 1982; Miesen, 1992; ) and that a caretaking approach could compound the losses of the disease itself ( Kitwood, 1988, 1989, 1990; Miesen, 1993). Tom Kitwood (1990) has described aspects of a 'malignant social interaction', which although not malicious in nature, damages the care recipient resulting in negative symptoms of

frustration and distress. He and many others have advocated a more person centred approach which recognises fully the person hood of the individual with dementia and emphasises the ability of carers to make a difference by the way in which they interact with the care recipient. The DKQ omits and even conflicts with this perspective emphasising lack of control and may even have influence caregivers' helpless attributions about dementia.

Many of the items in the DKQ are also more ambiguous than the questionnaire suggests and are less relevant for certain types of dementia than for others. For example, although in general it is true to say that dementia is not inherited (Question 5), in a small number of cases it is (Alzheimer's Association 1998). However, as has been stated no significant difference was found between the different diagnostic groups. Ideally this questionnaire would be adapted to overcome these difficulties, in particular to include items related to a more person centred perspective. The measure was used here without adaption to enable comparison with the existing research literature.

Finally, correlating self-report measures within this study could have lead to type 1 errors in the analysis. Using an independent rater for some of the measures, such as a professional who knew the caregiver and recipient, would have overcome this difficulty.

### **Difficulties with statistical Power**

Difficulties with statistical power when looking at casual attributions has been the subject

of much debate. Robins (1988) found, that of the 87 studies he examined, only 8 of the analyses had a probability of 0.80 or better of detecting a small-medium true population effect. He suggests that this is probably the reason many studies fail to find an effect. Peterson, Villanova and Raps (1985) examined 61 studies and concluded that small sample sizes are one of the factors which distinguishes studies which do not find that a pessimistic attributional style has an effect on well-being, from those that do. Robins found that, at lower levels of power, correlations tend to be found more between the measures of well-being and the stable and global attributions of depression. This seems to mirror the findings of this study, and that of Morris et al (1989). The study originally intended to obtain a larger sample which would have overcome this difficulty. This does not nullify the results found, but suggests that from this study it is not possible to say that a pessimistic attributional style in general does not relate to attributional style or mediate between dementia knowledge and well-being.

It must also be noted that the correlations within the study only account for a small amount of the variance. This is as would be expected due to the myriad of factors which interrelate to cause caregiver distress, as represented by Pearlin et al.'s (1991) model.

#### **4.4 Clinical and Research Implications of the Current Study**

As with most research, this study has raised almost as many questions as it had sought to answer. Although the role of causal attributions is still unclear the study has

suggested that attributions of some sort are important in caregiver well-being and that knowledge may be important in modifying them. From these findings it is possible to make some suggestions about how to improve clinical practice as well as to set forth directions for future research.

This study highlights the value of educating caregivers about dementia, particularly about its aetiology. Groups that omit to talk about how the disease is caused may fail to address the issue most concerning caregivers. The caregivers in this study were not wholly satisfied with the information that they had received from formal services, and yet clearly felt that this was the source which should provide them with information. Most caregivers said that individual sessions would be the best way to hear information, which seems to indicate that caregivers want the opportunity to meet one to one, and that a group format should be seen as a supplement to having an opportunity to discuss their situation in private. This seems to fit well with best practice at some memory clinics, where testing is backed by an opportunity for the caregiver and care recipient to talk about their concerns.

It would also seem important that any discussions with caregivers are not purely didactic. Accessing caregivers' understanding of dementia may well be essential in supporting caregivers and reducing their levels of depression and anxiety. The modification of meaning forms a large part of most psychological interventions for anxiety and depression (Power & Brewin 1997). It is then perhaps unsurprising that failing to access

underlying beliefs would severely limit the effectiveness of any intervention to reduce caregiver distress. Not only must a caregiver be able to repeat information that they have learned about dementia, this information must be integrated into their understanding of their situation so that they can utilise this information without having to be an 'active attributer'.

Failure to access and modify a caregiver's understanding would seem likely to result in caregivers continuing to use their existing understanding. This could be problematic not only for their own well-being, but could also cause difficulties for the care recipient. For instance, a caregiver's compliance with the care recipient's treatment plan may be influenced by how well this plan fits with or contradicts their understanding (Stimson, 1974). Caregivers by necessity make many decisions for their relative and so it is not unreasonable to assume that they may make this decision too, especially as nearly all those care recipients who were on medication had this medication managed by their caregiver. A caregiver's lay model of dementia could also affect whether they utilise coping and management strategies taught to them and even whether they seek help in the first place. Caregivers may undertake inappropriate, and perhaps stressful interventions if their underlying models are not accurate. One caregiver in the sample continually 'tested' their partner's memory hoping this would help 'build it up' causing great distress to both of them.

To be more specific it would seem that it is essential that clinicians specifically access

caregivers understanding of the aetiology of the disease, as this may be worrying them. Many caregivers talked of their struggle to find out from their General Practitioner about their relative's condition with a considerable number of caregivers suggesting that they had not been given even basic information. Even if these caregivers had actually forgotten the information, this suggests that for many the information they were asking for had not been made available in a way that they could recall it easily again later. The practical importance of providing written, as well as verbal, information has been repeatedly demonstrated as little is remembered of information provided verbally (Ley and Morris, 1984).

The challenge may however be greater than just asking clinicians to provide accurate information. In 1995 an Alzheimer's Disease Society's survey revealed large deficiencies in General Practitioners' knowledge and understanding of dementia and this could still be the case. Fitzpatrick (1984) argues that doctors retain many lay assumptions and ideas about illness acquired before training and that these assumptions play an important role in clinical practice. It may be essential that training should aim to access and modify these underlying assumptions. Research into medical professionals' lay beliefs about dementia may act as a good starting point. Certainly studies which have considered attitudes to working with older people have shown that many clinicians find working with this group difficult and many hold assumptions which could be unhelpful (Gatz & Pearson, 1988;). It would also be interesting to know whether General Practitioners' attitude to the disorder may be influenced by the fact that they may have historically felt

unable to have a treatment role. If this were the case it would seem unfortunate that many General Practitioners do not prescribe anti-dementia medication. Robinson & Henry (1977) suggested that the rise in the number of self-help groups may in part be a result of caregivers perceived failure of existing services in many respects including the provision of information. It seems that there has already been some improvement in information giving, as it is notable that this group were relatively well informed about dementia, at least as measured by the DKQ, when compared with caregivers in Price et al.'s study in 1986.

In this sample, many caregivers were keen to find out about their condition from health professionals, despite being disappointed with the information they received. Teaching about the disorder and about how best to put that information across to caregivers could well help improve consultations. Fitzpatrick (1984) points out that; "...one of the main functions of the doctor is to provide a name for problems and an explanation of the name...(and)... it is important to be aware of the meanings that patients come to assign to the diagnoses that they receive..." (p 27). He suggests that if clinicians fail to do this the individual may suffer secondary handicaps as a result of their beliefs.

With reference to this particular study it would be helpful in the future to interview more caregivers preferably chosen using a completely random sampling method. In such a study it would also seem important that attributions about the more positive aspects of caregiving are also considered, these having been demonstrated to relate to depression

in caregivers. Several authors have already identified some of the positive aspects of caring which may well help moderate the burden of care giving (e.g. Farran, 1997; Farran, Keane-Hageert, Salloway, Kupferer, et al., 1991; Noonan & Tennstedt, 1997). For example, Farran (1997) talks of the existential growth that caregiving can bring, whilst Williamson & Schulz (1990) have suggested that caregivers who believe that providing support and assistance reciprocates for help they have received from their partner before they became ill often have lower levels of distress.

In conclusion, it would seem essential that information giving remains a focus for services. It is important for workers providing information about dementia to provide information about the aetiology of the condition and to attempt to access and modify the caregiver's meaning and understanding of dementia and to ensure that it is accurate. Little is known about the models of dementia caregivers may have constructed and so more explorative work is necessary to complete our understanding. It may be helpful to look at the lay models of dementia in the community at large, as it could be that it is only by changing the understanding of the disease at this level that may encourage those caregivers who care for the 'silent epidemic' to come forward in greater numbers.

There is no easy solution to alleviating caregiver distress. However, it is important that solutions are sought especially considering the present emphasis on community care. Being distressed over a relative's suffering may seem to be a very normal reaction and yet failure to address depression and anxiety can lead to further distress not only for the



caregiver but for the care recipient too. As has already been mentioned there is increasing evidence that individuals with dementia are probably more aware of their environment and surroundings than was once thought ( Miesen, 1992; Williams & Garner, 1998), and can become distressed themselves when living with a highly distressed caregiver (Homer & Gilleard, 1994). Depression in caregivers has also been linked with violence within care giving relationships (Paveza et al., 1992). Caregiver distress is a major determinant of community service use and institutionalization (Chenoweth & Spencer, 1986), community placement being far more likely to succeed where there are informal caregivers. Supporting caregivers may also help to improve the quality of care by making use of their in-depth knowledge of the individual. Miesen (1992) insisted that an understanding of the individual with dementia's personality and past history is essential to understanding symptoms such as fear, restlessness, sadness, aggression, inactivity, and 'claiming' behaviour within the context of the losses they are currently undergoing. Caregivers have privileged insight into the personality and past of the care recipient with latecomers, even trained care workers, being unlikely to gain an equal understanding (Sixsmith, Stilwell, & Copeland, 1993). All these factors highlight the need to continue to work to find better ways of supporting caregivers. Clarifying the role of causal attributions and lay theories further and then integrating this into practice to increase effectiveness could help the dementia caregivers of the future meet the challenge of caring.

---

## REFERENCES

- Abel, E. K. (1990). Informal care for the disabled elderly: A Critique of recent literature. *Research on Ageing*, **12**, 139-157.
- Abramson, L. Y., Seligman, M. E. P., Teasdale., J. D. (1978). Learned helplessness in humans: critique and reformulation. *Journal of Abnormal Psychology*, **87**, 49-74.
- Absher, J. R. & Cummings, J. L. (1994). Cognitive and non-cognitive aspects of dementia syndromes: An overview. In A. Burns & R. Levy (Eds), *Dementia*. London: Chapman & Hall Medical.
- Age Concern, (1998). *Older People in the United Kingdom: September 1998*. London: Age Concern.
- Alzheimer's Association (1998) <http://www.alz.org/taking/rtstress.htm>.
- Alzheimer's Disease Society (1999) <http://www.alzheimers.org.uk/dementia2.htm>.
- Aneshensel, C. S., Pearlin, L. I., and Schuler, R. H. (1993). Stress, Role Captivity, and the Cessation of Caregiving. *Journal of Health and social Behaviour*, **34**, 54-70.
- Baars, B. (1986). *The Cognitive Revolution in Psychology*. New York: Guildford.
- Beck, A. T. & Beamesderfer, A. (1974). Assessment of depression: The depression inventory. In P. Pinchot & R. Oliver-Martin (eds), *Psychological measurements in Psychopharmacology Modern Problem of Pharmacopsychology*, **7**, PP. 151-177. Basel, Switzerland: Karger.
- Beck, A., Rush, A. J., Shaw, B. F. & Emery, G. (1979). *Cognitive Therapy of Depression*. New York: Guildford Press.
- Becker, M. (1974). The Health belief Model and personal health behaviour. *Health Education Monographs*, **2**, 328-335.
- Berrios, G. E. (1996). *The History of Mental Symptoms: Descriptive psychopathology since the 19<sup>th</sup> Century*. Cambridge: Cambridge University Press.
- Blaxter, M. (1983). The causes of disease: women talking. *Social Science and Medicine*, **17**, 59-69.

- 
- Bolton, D. & Hill, J. (1997). On the causal role of meaning. In M. Power, C. R. Brewin (Eds), *The Transformation of Meaning in Psychological Therapies - Integrating Theory and Practice*, pp. 15-32. Chichester: Wiley.
- Bosc, M., Dubini, A., and Polin, V. (1997). Development and validation of a social functioning scale, the social adaption self-evaluation scale. *European Neuropsychopharmacology: Supplement*, 7, S57-S58
- Brodaty, H. & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. *Australian & New Zealand Journal of Psychiatry*, 24, 351-361.
- Bruner, J. S. (1957). Going beyond the information given. In H. Gurber, G. Terrell & M. Wertheimer (Eds), *Contemporary Approaches to Cognition*. Cambridge, Massachusetts: Harvard University Press.
- Buck, D., Gregson, B.A., Bamford, C. H., McNamee, P., Farrow, G. N., Bond, J. & Wright, K. (1997). Psychological distress among informal supporters of frail older people at home and in institutions. *International Journal of Geriatric Psychiatry*, 12, 737-744.
- Caird, F. I. & Cargill, D. (1987). Chronic brain failure: the silent epidemic. *Australian and New Zealand Medical Journal*, 100, 13-16.
- Cantor, M. H., (1983). Strain among Caregivers: A study of experiences in the United states. *Gerontologist*, 23, 597-604.
- Charlesworth, G. & Adams, L. (1997). Pearlin rules OK ? Issues in care giving and Dementia. *PSIGE Newsletter*, 62, 9-13.
- Charlesworth, A., Wilkin, D., & Durie, A. (1984). *Carers and Services: A Comparison of Men and Women Caring for Dependent Elderly People*. Manchester: Equal Opportunities Commission.
- Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist*, 26, 269-272.
- Cicirelli, V. (1983). Adult children's attachment and helping behaviour to elderly parents: A path model. *Journal of Marriage and the Family*, 45, 815-926.
- Cicirelli, V. (1986). The helping relationship and family neglect in later life. In K. Pillemer & R. Wolf (Eds), *Elder Abuse: Conflict in the Family*, pp49-66. The Hague: Martins Nijhoff.
-

- Clark, D. M. (1986). A cognitive approach to panic. *Behaviour Research and Therapy*, **24**, 461-470.
- Cochran, S. D. & Hammen, C.L. (1985). Perceptions of stressful life events and depression: A test of attributional models. *Journal of Personality and Social Psychology*, **48**, 1562-1571.
- Coen, R. F., Swanwick, G. R. J., O'Boyle, C. A. & Coakley, D. (1997). Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, **12**, 331-336.
- Cohen, J. (1977). *Statistical Power Analysis for the Behavioural Sciences* (Rev. Ed.). New York: Academic Press.
- Cooper, B. & Fearn, R. (1998). Dementia Care Needs in an Area Population: case Register Data and Morbidity Survey estimates. *International Journal of Geriatric Psychiatry*, **13**, 550-555.
- Coppel, D. B., Burton, C., Becker, J., & Fiore, J. (1985). Relationships of cognitions associated with coping reactions to depression in spousal caregivers of Alzheimer's disease patients. *Cognitive Therapy and Research*, **9**, 253-266.
- Cummings, J. L., and Benson, D. F. (1986). Dementia of the Alzheimer type: an inventory of diagnostic classical features. *Journal of the American Geriatric Society*, **34**, 12-19.
- Derogatis, L. R., Rickels, K. P., & Rock, A. F. (1976). The SCL-90 and the MMPI: A Step in the validation of a new self-report scale. *British Journal of Psychiatry*, **128**, 280-289.
- Donaldson, C., Tarrrier, N. & Burns, A. (1998). Determinants of carer stress in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, **13**, 248-256.
- Duijnste, M. (1992). Caring for a demented family member at home: objective observation and subjective evaluation of the burden. In B. M. C. Miesen & G. M. M. Jones (Eds), *Caregiving in Dementia- Research and Applications*, London: Routledge,.
- Dura, J., Haywood-Niler, E. & Kiecolt-Glaser, J. K. (1990). Alzheimer's and Parkinson's diseases and dementia caregivers: Effects of chronic stress. *Gerontologist*, **30**, 332-338.

- 
- Eagles, J. M., Craig, A., Rawlinson, F., Restall, D. B., Beattie, A. G. & Besson, J. O. A. (1987). The psychological well-being of supporters of the demented elderly. *British Journal of Psychiatry*, **150**, 293-298.
- Eaves, G. & Rush, A. J. (1984). Cognitive patterns in symptomatic and remitted unipolar major depressives. *Journal of Abnormal Psychology*, **93**, 31-40.
- Farran, C.J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress / Adaption and Existentialism. *The Gerontologist*, **37**, 250-256.
- Farran, C. J., Keane-Hageert, E., Salloway, S., Kupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family carers. *The Gerontologist*, **31**, 483-489.
- Feil, N. (1982). *Validation: The Feil Method*. Winslow Press: Bicester.
- Fitzpatrick, R. M. (1984) Lay concepts in illness. In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler & J. Thomson (Eds), *The Experience of Illness*, pp 11-30. London: Tavistock.
- Fitzpatrick, R. M. & Hopkins, A. (1981). Patients' satisfaction with communication in neurological outpatient clinics. *Journal of Psychosomatic Research*, **25**, 329-334.
- Försterling, F. and Rudolph, U. (1988). Situations, attributions, and the evaluation of reactions. *Journal of Personality and Social Psychology*, **54**, 225-232.
- Gardner, H. (1985). *The Mind's New Science: A History of the Cognitive Revolution*. New York: Basic Books.
- Gatz, M. P. & Pearson, C. G. (1988). Ageism revised and the provision of psychological services. *American Psychologist*, **43**, 184-188.
- Gilhooly, M. L. M. (1984). The social dimensions of senile dementia. In I. Hanley & J. Hodge (Eds), *Psychological Approaches to the Care of the Elderly*, London: Croom Helm.
- Gilleard, C.J. (1984). *Living with Dementia: Community care of the Elderly and Mentally Infirm*. London: Croom Hill.
-

- 
- Gilleard, C. J., Belford, H., Gilleard, E., Whittick, J. E. & Gledhill, K. (1984). Emotional Distress amongst the Supporters of the Elderly Mentally infirm. *British Journal of Psychiatry*, **145**, 172-177.
- Glass, D. C., and Singer, J. E. (1972). *Urban Stress-Experiments on Noise and Social Stressors*. USA: Academic Press.
- Goldberg, D. P. and Hillier, V. F (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine*, **9**, 139-145.
- Golin, S., Sweeney, P. D., & Schaeffer, D. E. (1981). The causality of causal attributions in depression: A cross-lagged panel correlational analysis. *Journal of Abnormal Psychology*, **90**, 14-22.
- Golodetz, A., Evans, R., Heinrtiz, G. & Gibson, C. (1969). The care of chronic illness: the responsor role. *Medical Care*, **7**, 385-394.
- Grad, J. & Sainsbury, P. (1965) An evaluation of the effects of caring for the aged at home. In *Psychiatric Disorders in the Aged: WPA Symposium*. Manchester: Geigy.
- Graham, C., Ballard, C., & Sham, P. (1997). Carer's knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry*, **12**, 931-936.
- Greene, J.G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. *Age and Ageing*, **11**, 121-126.
- Haley, W.E. & Pardo, K.M. (1989). Relationship of severity of dementia to care giving stressors. *Psychology and Ageing*, **4**, 389-392.
- Hamilton, M. (1967). Development of a rating scale for primary depressive illness. *British Journal of Social and Clinical Psychology*, **6**, 278-296.
- Hazell, J., Driver, H., & Shalan, D. (1996). Obtaining service criticism from older adults. *PSIGE Newsletter*, **57**, 28-29.
- Helman, C. G. (1978). Feed a cold, starve a fever: Folk models of infection in an English suburban community and their relationship to medical treatment. *Cultural Medical Psychiatry*, **2**, 107-137.
- Helman, C. G. (1984). *Culture, Health and Illness*. Bristol: Wright.
-

- 
- Hewstone, M. (1989). *Causal Attribution: From cognitive process to collective beliefs*. Massachusetts: Blackwell.
- Hoffart, A. & Martinsen, E. W. (1990). Agoraphobia, depression, mental health locus of control, and attributional styles. *Cognitive Therapy and Research*, *14*, 343-351.
- Homer, A. C. and Gilleard, C. J. (1994). The effect of inpatient care on elderly patients and their carers. *Age and Ageing*, *23*, 274-276.
- Hooker, K., Frazier, L. D. & Monahan, D. J. (1994). Personality and coping among carers of spouses with dementia. *The Gerontologist*, *34*, 386-392.
- House, J., Umberson, D., & Landis, K. (1988). Structures and processes of social support. *Annual Review of Sociology*, *14*, 115-126.
- Johnson, C. L., (1983). Dyadic family relations and social support. *Gerontologist*, *23*, 377-283.
- Jones, E. E., Kanneuse, D. E., Kelley, H. H., Nispert, R. E., Valins, S. & Weiner, B. (1972). *Attribution: Perceiving the Causes of Behaviour*. New Jersey: New Learning Press.
- Judd, C. M., & Kenny, D. A. (1981). *Process analysis: Estimating the effects of social interventions*. New York: Cambridge University Press.
- Katon, W. (1982). Depression: Somatic symptoms and mental disorders in primary care. *Comprehensive Psychiatry*, *23*, 274-287.
- Katon, W., Kleinman, A. & Rosen, G. (1982). Depression and somatization: A review. *American Journal of Medicine*, *72*, 127-135.
- Kelley, H. H. (1967). Attribution theory in social psychology . In D, Levine (Ed), *Nebraska Symposium on Motivation* (Vol 15). Lincoln: University of Nebraska Press.
- Kelley, H. H. (1971). *Attribution in Social Interaction*. Morristown, New Jersey: General Learning Press.
- Kelley, H. H. (1972). Attribution in social interaction. In E. E. Jones, D. E. Kanouse, H. H. Kelley, R. E. Nisbett, S. Valins, & B. Weiner (Eds), *Attributions: Perceiving the causes of behaviour*. Morristown, New Jersey: General Learning Press.
-

- 
- Kiecolt-Glaser, J. K., Dura, J. R., Speicheer, C. E., Trask, O. J. & Glasser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic Medicine*, **53**, 345-362.
- Kitwood, T (1988). The technical, the personal and the framing of dementia. *Social Behaviour*, **3**, 161-180.
- Kitwood, T. (1989). Brain, mind and dementia: With particular reference to Alzheimer's Disease. *Ageing and Society*, **9**, 1-15.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's Disease. *Ageing and Society*, **10**, 177-196.
- Kitwood, T. (1993). Editorial: Person and Process in Dementia. *International Journal of Geriatric Psychiatry*, **8**, 541-545.
- Knight, B. G., Lutzky, S. M. & Macofsky-Urban, F. (1993). A Meta-Analytic Review of Interventions for Caregiver Distress: Recommendations for Future Research. *The Gerontologist*, **33**,240-248.
- Kramer, B. J. (1997). Gain in the caregiving experience- Where are we ? What next ? *The Gerontologist*, **37**, 218-232.
- Langer, , E. J. (1978). Rethinking the role of thought in social interaction. In J. H. Harvey, W. J. Ickes, & R. F. Kidd (Eds), *New Directions in Attributions Research* (Vol 2). Hillsdale, New Jersey: Erlbaum.
- Lazarus, R. S. & Folkman, S. (1984). *Stress Appraisal and Coping*. New York: Springer Publishing Company.
- Leader, J. B., & Klein, D. N. (1996). Social adjustment in Dysthymia, Double depression and Episodic Major Depression. *Journal of Affective Disorders*, **37**, 91-101.
- Levin, E., Moriarty, J. & Gorbach, P. (1994). *Better for the Break*, National Institute for Social Work Research Unit. London: HMSO.
- Ley, P. and Morris, L. A. (1984). Psychological aspect of written information for patients. In S. Rachman (Ed), *Contributions to Medical Psychology*, Vol 3. Oxford: Pergamon Press.
- Light, E. & Lebowitz, B. D. (1989) *Alzheimer's Disease treatment and Family Stress: Directions for Research*. Rockville: National Institute of Mental Health.
-



- Lindesay, J., Briggs, K., & Murphy, E. (1989). The Guys / Age Concern Survey: Prevalence rates of cognitive impairment, depression and anxiety in an urban elderly community. *British Journal of Psychiatry*, **155**, 317-329.
- Livingston, G. & Hinchliffe, A. C. (1993). The Epidemiology of Psychiatric Disorders in the Elderly. *International Review of Psychiatry*, **5**, 317-326.
- Mathews, V. (1995). A study of the effects of a carer training programme. *PSIEGE*, **53**, 13-15.
- McKinlay, J. B. (1975). Who is really ignorant: Physician or patient ? *Journal of Health and Social Behaviour*, **16**, 3-11.
- Mechanic, D. (1972). Social Psychologic factors Affecting the Presentation of Bodily Complaints. *New England Journal of Medicine*, **286**, 1132-1139.
- Meshefedjian, G., McCusker, J., Bellavance, F. & Baumgarten (1998). Factors associated with symptoms of depression among informal carers of demented elders in the community. *The Gerontologist*, **38**, 247-253.
- Metalsky, G. I., Halberstadt, L. J. & Abramson, L. Y. (1987). Vulnerability to depressive mood reactions: toward a more powerful test of the diathesis stress and causal mediation components of the reformulated theory of depression. *Journal of Personality and Social Psychology*, **52**, 386-393.
- Miesen, B. M. (1992). Awareness in dementia patients and family care giving. In G. Jones & B. Miesen (Eds), *Caregiving in Dementia: Research and Applications*. London: Routledge,
- Miesen, B. M. (1993). Alzheimer's Disease, the phenomenon of parent fixation, and bowly's attachment theory. *International Journal of geriatric Psychiatry*, **8**, 147-153.
- Miller, B. & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact?. *The Gerontologist*, **32**, 498-507.
- Mineka, S., Pury, C. L. & Luten, A. G. (1995). Explanatory style in anxiety and depression. In G. McClellan Buchanan & M. E. P. Seligman (Eds), *Explanatory Style*, pp. 135-158. New Jersey: Lawrence Erlbaum Associates.
- Morris, L.W., Morris, R.G & Britton, P.G. (1988). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, **61**, 231-236.

- 
- Morris, L. W., Morris, R. G. & Britton, P. G. (1989a). Cognitive style and perceived control in spouse carers of dementia sufferers. *British Journal of Medical Psychology*, **62**, 173-179.
- Morris, L.W., Morris, R.G, and Britton, P.G. (1989b). Social support networks and formal support as factors influencing the psychological adjustment of spouse caregivers of dementia sufferers. *International Journal of Geriatric Psychiatry*, **4**, 47-51.
- Morris, R.G., Woods, R.T., Davies, K.S., Berry, J., and Morris, L.W. (1992). The use of a coping strategy focussed support group for carers of dementia sufferers, *Counselling Psychology Quarterly*, **5**, 337-348.
- Morris, R.G., Woods, R.T., Davies, K.S. and Morris, L.W. (1991). Gender differences in carers of Dementia sufferers, *British Journal of Psychiatry*, **158** (Suppl.10), 69-74.
- Nezu, A. M., Nezu, C. M. & Nezu, V. A. (1986). Depression, general distress, and causal attributions among university students. *Journal of Abnormal Psychology*, **95**, 184-186.
- Noonan, A.E., & Tennstedt, S.L. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist*, **37**, 785-794.
- Pagel, M. D., Becker, J., and Coppel, D. B. (1985). Loss of control, self-blame, and depression: an investigation of spouse caregivers of Alzheimer's disease patients. *Journal of Abnormal Psychology*, **94**, 169-182.
- Paveza, G. J., Cohen, D., Eisdorfer, C., Freels, S., Semla, T., Ashford, J. W., Gorelick, P., Hirschman, R., Luchins, D., Levy, P. (1992). Severe family violence and Alzheimer's disease: prevalence and risk factors. *The Gerontologist*, **32**, 493-497.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., Skaff, M. M. (1990). Caregiving and the stress process; overview of concepts and their measures. *The Gerontologist*, **30**, 583-594.
- Peterson, C., & Seligman, M.E.P. (1984). Causal explanations as a risk factor for depression: theory and evidence. *Psychological Review*, **91**, 347-374.
- Peterson, C., Seligman, M. E. P., von Baeyer, C., Abramson, L. Y., Metalsky, G. I. & Seligman, M. E. P. (1982). The Attributional Style Questionnaire. *Cognitive Therapy and Research*, **6**, 287-299.
-

- Peterson, C., Villanova, P., Raps, C. S. (1985). Depression and attributions: Factors responsible for inconsistent results in the published literature. *Journal of Abnormal Psychology*, **94**, 165-168.
- Pill, R. & Stott, N. C. H. (1982). Concepts of illness causation and responsibility: some preliminary data from a sample of working-class women: new data and fresh insights. *Social Science and Medicine*, **16**, 43-52.
- Pomara, N., Deptula, D., Gallow, M. P., LeWitt, P. A. & Stanley, M. (1989). CSF GABA in caregiver-spouses of Alzheimer's patients. *American Journal of Psychiatry*, **146**, 787-788.
- Power, M. & Brewin, C. R. (1997). *The Transformation of Meaning in Psychological Therapies in Psychological Therapies: Integrating Therapies*. Chichester: Wiley.
- Price, J., Price, J., Shanahar, P & Desmond, S. (1986). Elderly persons' perception and knowledge of Alzheimer's disease. *Psychological Reports*, **58**, 419-424.
- Pruchno, R. A., Burant, C. J., & Peters, N. D. (1997). Typologies of caregiving families: Family congruence and individual well-being. *Gerontologist*, **37**, 157-167.
- Pruchno, R. A. & Resch, N. L. (1989). Aberrant behaviours and Alzheimer's disease: mental health effects in spouse caregivers. *Journal of Gerontology: Social Sciences*, **44**, S177-S182.
- Rabins, P. V., Mace, H. L. & Lucas, M. J. (1982). The impact of dementia on the family. *Journal of the American Medical Association*, **248**, 333-335.
- Rehm, L. P. (1977). *A Self Control Model of Depression*. New York: Academic Press.
- Robins, C. J. (1988). Attributions and depression: Why is the literature so inconsistent. *Journal of Personality and Social Psychology*, **54**, 880-889.
- Robins, C. J. & Block, P. (1989). Cognitive theories of depression viewed from a diathesis stress perspective: Evaluations of the models of Beck and Abramson, Seligman and Teasdale. *Cognitive Therapy and Research*, **13**, 297-313.
- Robins, C. J. & Hayes, A. M. (1995). The role of causal attributions in the predictions of depression. In G. McClellan Buchanan & M. E. P. Seligman (Eds), *Explanatory Style*, pp. 71-98. New Jersey: Lawrence Erlbaum Associates.

- 
- Robinson, D. & Henry, S. (1977). *Self-help and health: Mutual aid for Modern problems*. London: Martin Robinson.
- Rosenthal, C. J. & Dawson, P. (1992). Wives of institutionalised elderly men. *Journal of Ageing and Health*, **3**, 315-334.
- Ross, L. (1977). The intuitive psychologist and his shortcomings: Distortions in the attribution process. In L. Berkowitz (Ed), *Advances in Experimental Social Psychology* (Vol 10). New York: Academic Press.
- Rothbart, M. (1981). Memory processes and social beliefs. In D. L. Hamilton (Ed), *Cognitive Process in Stereotyping and Intergroup Behaviour*. Hillsdale, New Jersey: Erlbaum.
- Schulman, S. J., Castellon, C. & Seligman, M. E. P. (1989). Assessing explanatory style: The content analysis of verbatim explanations and the Attributional Style Questionnaire. *Behaviour Research and Therapy*, **27**, 505-512.
- Seligman, M. E. P. (1974). Depression and learned helplessness. In R. J. Friedman & M. M. Katz (Eds), *The Psychology of Depression: Contemporary Theory and Research*. New York: Wiley.
- Seligman, M. E. P., Peterson, C., Kaslow, N. J., Tannenbaum, R. L., Alloy, L. B. & Abramson, L. Y. (1984). Attributional style and depressive symptoms in children. *Journal of Abnormal Psychology*, **93**, 235-238.
- Semple, S. J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *The Gerontologist*, **32**, 648-655.
- Shanas, E. (1979). The family as social support in old age. *Gerontologist*, **19**, 169-173.
- Sixsmith, A., Stilwell, J., & Copeland, J. (1993). 'Rementia': Challenging the limits of dementia care. *International Journal of Geriatric Psychiatry*, **8**, 993-1000.
- Skaff, M.M. & Pearlin, L. I. (1992). Caregiving: Role Engulfment and the Loss of Self. *The Gerontologist*, **32**, 656-664.
- Sloan, R. & Gruman, J. (1983). Beliefs about cancer, heart disease and their victims. *Psychological Reports*, **52**, 415-424.
- Stillwell, J. A., Hassall, C. & Rose, S. (1984). Changing demands made by senile dementia on the National Health Service. *Journal of Epidemiology and Community Health*, **38**, 131-133.
-

- 
- Stimson, G. (1974). Obeying doctor's orders: a view from the other side. *Social Science and Medicine*, **8**, 97-104.
- Stoller, E. P. & Pugliesi, K. L. (1992). The transition to the care giving role: A panel study of helpers of elderly people. *Research on Ageing*, **11**, 312-330.
- Sutcliffe, C. & Lerner, S. (1988). Counselling carers of the elderly at home: A preliminary study. *British Journal of Clinical Psychology*, **2**, 177-8.
- Sweeney, P. D., Anderson, K., Bailey, S. (1986). Attributional style in depression: A meta-analytic review. *Journal of Personality and Social Psychology*, **50**, 974-991.
- Sweeney, P. D., Shaeffer, D. & Golin, S. (1982). Attributions about self and others in depression. *Personality and Social Psychology Bulletin*, **8**, 37-42.
- Teri, L., Truax, P., Logsdon, R., Zarit, S., Uomoto, J. & Vitaliano, P. P. (1992). Assessment of behavioural problems in dementia: The revised memory and behaviour problems in dementia: the revised memory and behaviour problems checklist. *Psychology and Aging*, **7**, 622-631.
- Thompson, C. & Thompson, G. (1998). Support for carers of people with Alzheimer's type dementia. *The Cochrane Library*, **1**. Oxford: Update Software.
- Toseland, R.W. & Rossiter, C.M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist*, **29**, 438-448.
- Toseland, R. W., Rossiter, C. M. & Labrecque, M. S. (1989)a .The effectiveness of peer-led and professionally led groups to support family. *The Gerontologist*, **29**, 465-471.
- Toseland, R. W., Rossiter, C. M., and Labrecque, M. S. (1989)b. The effectiveness of three group intervention strategies to support family caregivers. *American Journal of Orthopsychiatry*, **59**, 420-429.
- Townsend, A., Noelker, L., Deimling, G. & Bass, D. (1989). Longitudinal impact of interhousehold care giving on adult children's mental health. *Psychology and Ageing*, **4**, 393-401.
- Verbrugge, L. (1985). Gender and health: An update on hypotheses and evidence. *Journal of Health and Social Behaviour*, **26**, 156-182.
-

- Vitaliano, P. P., Scanlan, J. M., Krenz, C., Schwartz, R. S. & Marcovina, S. M. (1996). Psychological distress, care giving, and metabolic variables. *Journal of Gerontology*, **51B**, P290-P299.
- Walker, Z. (1998). Exelon: Introducing a new treatment for Alzheimer's disease. *Geriatric Medicine*, **28**, 1-4.
- Weiner, B. (1985). An attributional theory of motivation and emotion. *Psychological Review*, **92**, 548-573.
- Whitlatch, C. J., Zarit, S. H., & von Eye, A. (1991). Efficacy of interventions with caregivers: a re-analysis. *The Gerontologist*, **31**, 9-14.
- Williams, D. D. R. & Garner, J. (1998). People with dementia can remember: Implications for care. *British Journal of Psychiatry*, **172**, 379-380.
- Williams, J. M. G. (1992). *The Psychological Treatment of Depression 2<sup>nd</sup> Edition*. London: Routledge.
- Williamson, G. M., & Schulz, R. (1993). Coping with Specific Stressors in Alzheimer's Disease Caregiving. *The Gerontologist*, **33**, 747-755.
- Wortman, C. B. & Dintzer, L. (1978). Is an attributional analysis of the learned helplessness phenomenon viable ? A critique of the Abramson-Seligman-Teasdale reformulation. *Journal of Abnormal Psychology*, **87**, 75-90.
- Wyer, R. S. (1981). An information-processing perspective on social attribution. In J. H. Harvey, W. J. Ickes & R. F. Kidds (Eds), *New Directions in Attribution research* (Vol 3). Hillsdale, New Jersey: Erlbaum.
- Zarit, S. H., Anthony, C. R., & Boutselis, M. (1987). Interventions with caregivers of dementia patients: comparison of two approaches. *Psychology & Ageing*, **2**, 225-232.
- Zarit, S. H. & Edwards, A. B. (1996). Family caregiving: research and clinical intervention. In R. T. Woods (Ed), *Handbook of the Clinical Psychology of Ageing*, pp 333-368. Chichester : Wiley.

**APPENDICES**

<b>Appendix I</b>	Consent Form
<b>Appendix II</b>	Information Sheet Given to Participants
<b>Appendix III</b>	Ethics Committee Forms
<b>Appendix IV</b>	Demographic details
<b>Appendix V</b>	ASQ (Adapted Version)
<b>Appendix VII</b>	Attributions about dementia care giving.

**Appendix I** Consent Form

**Research Project Looking at Factors which Affect Caring for  
Someone who has Dementia**

**I agree to take part in this research project.**

**I understand that:**

- Any information I give will be kept confidential.**
- I can withdraw at any point.**
- I do not have to answer a question, unless I wish to do so.**

**Signed:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Print:** \_\_\_\_\_

**Witnessed:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Print:** \_\_\_\_\_



**Appendix II Information Sheet Given to Participants**

**Research Project Looking at Factors which Affect Caring for  
Someone who has Dementia**

Currently there is a research project being carried out in Essex and Hertfordshire looking at factors which influence the experience of caring for someone with a dementia. To do this the Researcher (Fiona Roberts) needs to interview people who are caring for a friend or relative who has Alzheimer's disease or some other form of dementia. Fiona is working in liaison with the Alzheimer's Disease Society, Herts & Essex NHS Trust, and the Petersfield Centre - Romford. If you are caring for someone with these difficulties, you may be able to help.

❖ **What will happen if you wish to take part.**

Fiona will arrange to meet with you to ask some questions about you and the person you care for. This should take no longer than two hours, and can be organised at your convenience. Agreeing to take part will not affect the services you receive.

Your answers to the questions will be kept confidential, and you can withdraw your help at any point.

❖ **What if you don't want to take part.**

You do not have to participate. If you do not take part it will not affect any services you receive.

❖ **What happens to the information.**

All the responses will be made anonymous and collated. They will provide important information to help services understand the best way to support Carers, the research may even get published, and so help others around the country. All those who take part will be sent a summary of the findings.

---

**If you have any questions or would like to take part, please leave a message with your name and a contact address or phone number.**

**To contact Fiona either,**

**phone           01582 461899**

**or write to    The Sub-department of Clinical Health Psychology,  
University College London, Gower Street, London, WC1E 6BT**

**or via your local Alzheimer's Disease Society Representative**

**WEST ESSEX  
LOCAL RESEARCH ETHICS COMMITTEE**

Parndon Hall, The Princess Alexandra Hospital NHS Trust, Hamstel Road, Harlow, Essex CM20 1QX

Tel: 01279 827082  
Fax: 01279 429371

JT/dt

25 February 1998

**CONFIDENTIAL**

Ms F Roberts  
Clinical Psychology Department  
Mental Health Unit  
Princess Alexandra Hospital

Dear Ms Roberts

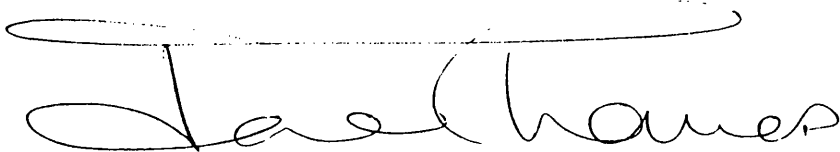
**1192 CAUSAL ATTRIBUTIONS, KNOWLEDGE OF DEMENTIA AND  
PSYCHOLOGICAL WELL-BEING IN CAREGIVERS OF PEOPLE  
WITH DEMENTIA**

The West Essex Local Research Ethics Committee met on 19 February 1998 and considered your application.

I write to inform you that approval was given for this project.

Please note that I may be contacting you from time to time for information on the progress of the project. I would also be grateful if you would notify me when the project is completed, or if it is terminated for any reason prior to completion, and if there are any material changes to the protocol for the project perhaps you will advise me accordingly. May I take this opportunity to wish you every success with the project.

Yours sincerely



**Jane Thomas**  
Secretary to the West Essex Local Research Ethics Committee

The Clock House East Street Barking IG11 8EY  
Telephone 0181 591 9595 Fax 0181 532 6201  
Minicom 0181 532 6230 DX 121410 Barking 4

*FROM THE OFFICE OF THE  
BARKING AND HAVERING  
LOCAL RESEARCH ETHICS COMMITTEE*

9 December 1998

Barking and Havering  
Health Authority

Fiona Roberts  
Clinical Psychologist in Training  
3 Cranford Court  
Shakespeare Road  
Harpenden  
HERTS AL5 5NY

direct dial 0181-532-6221 /ME

our ref BH- LREC/020998/8.6  
please quote on all correspondence

Dear Ms Roberts

Barking and Havering Local Research Ethics Committee  
Meeting 02.09.98 - agenda item 8.6 - NEW APPLICATION - Agreed  
Meeting 11.11.98 - agenda item 4.8 - matters outstanding

study no:

study title: causal attributions, knowledge of dementia and psychological well-being caregivers of people with dementia

Thank you for your letter of 24 October and 29 September, which were submitted to the LREC meeting on 11 November, and accepted.

When writing in future about this matter, please always quote our reference number and the study title. Thank you for your help.

Yours sincerely



Maureen English (Mrs)  
Consumer Services Officer  
(LREC administration)

*Chairman:* Peter Dixon  
*Chief Executive:* Christine Outram

17 February 1999

Fiona Roberts  
Psychology Department  
Mental Health Unit  
Chase Farm Hospital

Dear Ms Roberts

**621 - Causal Attributions, Knowledge of Dementia and Psychological well-being in Caregivers of People with Dementia**

I write to inform you that the above study has been approved Chair's Action having been taken.

The committee look forward to receiving a copy of your interim report in six months time or at the end of the study if this is sooner.

Yours sincerely



Mrs L H Lipson  
Chair, LREC

document7



**Can the patient:**

- |   |  |
|---|--|
| 1[ <sub>01</sub> ]Cut toe nails                             | 4[ <sub>01</sub> ]Get up the stairs              |
| 2[ <sub>01</sub> ]Feed themselves                           | 5[ <sub>01</sub> ]Wash hair                      |
| 3[ <sub>01</sub> ]Bath self                                 | 6[ <sub>01</sub> ]Go to the toilet independently |
| 7[ <sub>01</sub> ]Walk to the end of the road unaccompanied |  |

**Accommodation:**

- |  |   |
|--|---|
| [ <sub>01</sub> ]Always lived together                             | [ <sub>01</sub> ]Carer lives <=10mins         |
| [ <sub>02</sub> ]Patient next door to the Carer.                   | [ <sub>02</sub> ]Carer lives >10mins, <30mins |
| [ <sub>03</sub> ]Carer has moved in with Patient                   | [ <sub>03</sub> ]Carer lives >30mins          |
| [ <sub>04</sub> ]Patient has moved in with Carer.                  |   |
| [ <sub>05</sub> ]Patient lives in a care home / hospice / hospital |   |
| [ <sub>06</sub> ]Live completely independently from each other     |   |

**Type of accommodation:**

- |                                      |  |
|--------------------------------------|--|
| [ <sub>01</sub> ]Owner occupier      | [ <sub>04</sub> ]Council Tenant                                      |
| [ <sub>02</sub> ]Private Rented      | [ <sub>05</sub> ]Sheltered accommodation / hospice / hospital / home |
| [ <sub>03</sub> ]Housing Association | [ <sub>06</sub> ]Other _____   |

**Electric goods owned:**

- |                                   |                                    |             |
|-----------------------------------|------------------------------------|-------------|
| 1[ <sub>01</sub> ]Telephone       | 5[ <sub>01</sub> ]Fridge / Freezer |             |
| 2[ <sub>01</sub> ]Video recorder  | 6[ <sub>01</sub> ]Car              |             |
| 3[ <sub>01</sub> ]Dishwasher      | 7[ <sub>01</sub> ]Washing Machine  |             |
| 4[ <sub>01</sub> ]Central Heating | 8[ <sub>01</sub> ]Microwave        | Total [ ]/8 |

**About the Carer:**

**Sex of Carer:** [<sub>01</sub>]Male [<sub>02</sub>]Female      **Age of Carer:** [ ] [ ] whole yrs

**Ethnicity (Client defined):**

[ <sub>10</sub> ]White	[ <sub>16</sub> ]Bangladeshi
[ <sub>11</sub> ]Caribbean	[ <sub>17</sub> ]Chinese
[ <sub>12</sub> ]Black African	[ <sub>18</sub> ]Asian
[ <sub>13</sub> ]Black other	[ <sub>19</sub> ]Ireland
[ <sub>14</sub> ]Indian	[ <sub>20</sub> ]Other
[ <sub>15</sub> ]Pakistan	

**Relationship of Carer to Patient:**

- |                                 |                          |                                 |
|---------------------------------|--------------------------|---------------------------------|
| [ <sub>01</sub> ]Spouse         | [ <sub>03</sub> ]Sibling | [ <sub>05</sub> ]Son / Daughter |
| [ <sub>02</sub> ]Other relative | [ <sub>04</sub> ]Other   |                                 |

**Number of other dependents on Carer:** [ ] [ ]

**Marital Status of Carer:**

- |                                      |                                       |                                   |
|--------------------------------------|---------------------------------------|-----------------------------------|
| [ <sub>01</sub> ]Married/Co-Habiting | [ <sub>03</sub> ]Single               | [ <sub>05</sub> ]Married to Carer |
| [ <sub>02</sub> ]Widowed             | [ <sub>04</sub> ]Divorced / Separated |                                   |

**Age Carer left full time education** [ ] whole years

**SES:**

- |                               |                                 |
|-------------------------------|---------------------------------|
| [ <sub>01</sub> ]Professional | [ <sub>04</sub> ]Skilled Manual |
|-------------------------------|---------------------------------|

[<sub>02</sub>] Employers & Managers [<sub>05</sub>] Semi-Skilled Manual / Personal Service  
 [<sub>03</sub>] Intermediate Junior (non-manual) [<sub>06</sub>] Unskilled Manual

**Carer's rating of their impairment by any physical/emotional/psychological difficulties:**

[<sub>01</sub>] Mild [<sub>02</sub>] Moderate [<sub>03</sub>] Severe

**Chronicity of the worst of these conditions:**

[<sub>01</sub>] less than 1yr [<sub>02</sub>] 1yr - 5yrs [<sub>03</sub>] more than 5yrs

**Type of accommodation (If Different to patient):**

[<sub>01</sub>] Owner occupier [<sub>04</sub>] Council Tenant  
 [<sub>02</sub>] Private Rented [<sub>05</sub>] Sheltered accommodation / hospice  
 [<sub>03</sub>] Housing Association

**How long ago did Carer first notice difficulties:**

[<sub>01</sub>] 0-3 months [<sub>04</sub>] 1-2 years [<sub>07</sub>] more than 4 years  
 [<sub>02</sub>] 3-6 months [<sub>05</sub>] 2-3 years  
 [<sub>03</sub>] 6 months-1 year [<sub>06</sub>] 3-4 years

**Length of time since Carer first began to provide assistance:**

[<sub>01</sub>] 0-3 Months [<sub>03</sub>] 6 months-1 year [<sub>05</sub>] 2-3 years  
 [<sub>02</sub>] 3-6 Months [<sub>04</sub>] 1-2 years [<sub>06</sub>] more than 3 years

**Amount of assistance given by Carer:** CAREASTD [ ] hours per day

**Type of help given by Carer:**

[<sub>01</sub>] Nursing in bed [<sub>01</sub>] Toileting [<sub>01</sub>] Hair Washing  
 [<sub>01</sub>] Bathing [<sub>01</sub>] Dressing [<sub>01</sub>] Lifting  
 [<sub>01</sub>] Giving medication [<sub>01</sub>] Supervision [<sub>01</sub>] Provision of meals  
 [<sub>01</sub>] Shopping [<sub>01</sub>] Mobility [<sub>01</sub>] Housework  
 [<sub>01</sub>] Gardening / DIY [<sub>01</sub>] Organising financial affairs/ paying bills/ organising household repairs

**Where has the Carer obtained information about this condition from:**

[<sub>01</sub>] Formal counselling<sub>10</sub> [<sub>01</sub>] GP<sub>16</sub>  
 [<sub>01</sub>] Hospital Doctor / Consultant<sub>11</sub> [<sub>01</sub>] Other Health Professional<sub>17</sub>  
 [<sub>01</sub>] Social Worker<sub>12</sub> [<sub>01</sub>] Voluntary Groups / Support Groups<sub>18</sub>  
 [<sub>01</sub>] Leaflets, Presentations, Books<sub>13</sub> [<sub>01</sub>] Media (TV, radio, Newspapers)<sub>19</sub>  
 [<sub>01</sub>] Friends, relatives<sub>14</sub> [<sub>01</sub>] Specialist agency<sub>20</sub>  
 [<sub>01</sub>] Knew someone with it<sub>15</sub> [<sub>01</sub>] Other \_\_\_\_\_<sub>21</sub>

**If more than one which was the most useful:** [ ] (Code)

**Which was the least helpful / unhelpful ?:** [ ] (Code)

**How helpful do you think it has been in general to know X's condition ?**

Extremely [<sub>01</sub>]-----[<sub>02</sub>]-----[<sub>03</sub>]-----[<sub>04</sub>]-----[<sub>05</sub>]-----[<sub>06</sub>]-----[<sub>07</sub>] Extremely  
 Helpful Neither Helpful nor unhelpful Unhelpful

Would you like more information ?:                    [ 01 ] Yes    [ 02 ] No

How would this most usefully be given ?:

How much emotional or practical help is given by /Friends/Relatives to the Carer:

[ 01 ]-----[ 02 ]-----[ 03 ]-----[ 04 ]-----[ 05 ]-----[ 06 ]-----[ 07 ]

None

Moderate

Complete

Electric goods owned (If different to the Patient):

1[ 01 ]Telephone	4[ 01 ]Central Heating	
2[ 01 ]Video recorder	5[ 01 ]Fridge / Freezer	
3[ 01 ]Dishwasher	6[ 01 ]Car	<b>Total</b>
7[ 01 ]Washing Machine/8	8[ 01 ]Microwave	



Appendix V ASQ (Adapted Version)

**ASQ- Abridged**

*Please complete all sections.*

**Imagine that: *You meet a friend who compliments you on your appearance.***  
**Write down one major cause of this happening.**

**Is the cause of your friend's compliment due to something about you or something about other people or circumstances ?**

Totally due to other people or circumstances.	1	2	3	4	5	6	7	Totally due to me.
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In the future when you are with your friend, will this cause again be present ?**

Will never be present again.	1	2	3	4	5	6	7	Will always be present.
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects interacting with friends or does it also influence other areas of your life ?**

Influences just this particular situation.	1	2	3	4	5	6	7	Influences all situations in my life.
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Imagine that: *You become very rich.***

**Write down one major cause of this happening**

**Is the cause of your becoming very rich due to something about you or something about other people or circumstances ?**

Totally due to other people or circumstances.	1	2	3	4	5	6	7	Totally due to me.
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In your financial future, will this cause again be present ?**

Will never be present again.	1	2	3	4	5	6	7	Will always be present.
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects obtaining money or does it also influence other areas of your life ?**

<b>Influences just this particular situation.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Influences all situations in my life.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Imagine that: *A friend comes to you with a problem and you don't try to help them.***

**Write down one major cause of this happening.**

**Is the cause of your not helping due to something about you or something about other people or circumstances ?**

<b>Totally due to other people or circumstances.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Totally due to me.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In the future when a friend comes to you with a problem, will this cause again be present?**

<b>Will never be present again.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Will always be present.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects what happens when a friend comes to you with a problem or does it also influence other areas of your life ?**

<b>Influences j this particular situation.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Influences all situations in my life.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Imagine that: *You meet a friend who is hostile towards you.***

**Write down one major cause of this happening.**

**Is the cause of your friend being hostile due to something about you or something about other people or circumstances ?**

<b>Totally due to other people or circumstances.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Totally due to me.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In the future when you are interacting with friends, will this cause again be present?**

<b>Will never be present again.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Will always be present.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects interacting with friends or does it also influence other areas of your life ?**

<b>Influences just this particular situation.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Influences all situations in my life.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Imagine that: *Your child / relative has been treating you more lovingly.***

**Write down one major cause of this happening.**

**Is the cause of X treating you more lovingly due to something about you or something about other people or circumstances ?**

<b>Totally due to other people or circumstances.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Totally due to me.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In your future interactions with X will this cause again be present?**

<b>Will never be present again.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Will always be present.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects how X treats you or does it also influence other areas of your life ?**

<b>Influences just this particular situation.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Influences all situations in my life.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Imagine that: *You can't get all the work done that others expect of you.***

**Write down one major cause of this happening.**

**Is the cause of your not getting the work done due to something about you or something about other people or circumstances ?**

<b>Totally due to other people or circumstances.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Totally due to me.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**In the future when you are doing some work expected by others, will this cause again be present?**

ASQNS17

<b>Will never be present again.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Will always be present.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

**Is the cause something that just affects doing work or does it also influence other areas of your life ?**

<b>Influences just this particular situation.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>Influences all situations in my life.</b>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

*For official use only*

<b>±</b>	<b><u>Internal</u></b>	<b><u>Stable</u></b>	<b><u>Global</u></b>	<b>:</b>	<b><u>Internal</u></b>	<b><u>Stable</u></b>	<b><u>Global</u></b>
	<b>1</b>	<b>2</b>	<b>3</b>		<b>7</b>	<b>8</b>	<b>9</b>
	<b>4</b>	<b>5</b>	<b>6</b>		<b>10</b>	<b>11</b>	<b>12</b>
	<b>13</b>	<b>14</b>	<b>15</b>		<b>16</b>	<b>17</b>	<b>18</b>

**Hopelessness  
Coneg  
Copus-Coneg (CPCN):**

**Hopefulness  
Copus**

**Appendix VII** Attributions about dementia care giving.

C/A/B Q

***Perceived Control***

**Can you describe a something about the person that you care for which is unpredictable and upsetting to you:**

**How much control do you feel you have over (example of unpredictable spouse's behaviour) in terms of being able to influence or modify it within a certain range ?(Please Tick One)**

COMPLETE	1	2	3	4	5	6	NO
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL

**How much control do you feel you will have in the future over (example of unpredictable spouse's behaviour) in terms of being able to influence or modify it within a certain range ?(Please Tick One)**

COMPLETE	1	2	3	4	5	6	NO
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL

**Since you have been caring for X can you describe something about your life which has upset you since it changed:**

**How much control do you feel you have over this particular (example of upsetting life change event) in terms of being able to influence the outcome ? (Please Tick One)**

COMPLETE	1	2	3	4	5	6	NO
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL

**How much control do you feel you will have in the future over (life event) in terms of being able to influence the outcome ? (Please Tick One)**

COMPLETE	1	2	3	4	5	6	NO
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL

***Causal Attribution***

**These questions are about when X's symptoms first showed (before you got a diagnosis).**

**Did you think that (X's symptom) were due to something primarily about you or primarily about X or some combination of the two ? (Please Tick One)**

TOTALLY DUE TO	1	2	3	4	5	6	7	TOTALLY
ANOTHER PERSON	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	DUE TO ME.
OR CIRCUMSTANCE.								

To what extent did you feel yourself responsible for what was happening to X(*Please Tick One*)

DID NOT BLAME	1	2	3	4	5	6	7	TOTALLY
MYSELF AT ALL.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	BLAMED
								MYSELF.

***Control Over Personal Reactions***

These questions are about how you can control personal feelings overwhelming and paralysing you.

How much control would you say you have over your reactions when you're with other people in public and X behaves unpredictably ? (*Please Tick One*)

COMPLETE	1	2	3	4	5	6	No
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL
							(overwhelmed and paralysed)

How much control would you say you have over your reactions when you are alone and thinking about X's disease ? (*Please Tick One*)

COMPLETE	1	2	3	4	5	6	No
CONTROL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	CONTROL
							(overwhelmed and paralysed)

***Ratings:***

<i>Perceived Loss of control over Spouse Behaviour</i>	<i>IE+FC=</i>	[	]
<i>Perceived Loss of Control over Life-Change Events</i>	<i>IE+FC=</i>	[	]
<i>Causal Attribution</i>	<i>IE+SB=</i>	[	]
<i>Loss of Control over personal Reactions</i>	<i>COPR1+COPR2=</i>	[	]