Alzheimer's Disease Care-giving:
Psychological Outcome, Coping Style, and Causal Attributions.

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I also wish to thank my mum for getting me going, and my wife and children for keeping me going. In the end, I got there.
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Alzheimer's Disease Care-giving:
Psychological Outcome, Coping Style, and Causal Attributions.

Wayne Burgoine

Abstract

Literature Review

With Alzheimer's disease on the increase, family members are increasingly interacting with nursing home care services. This relationship with nursing staff is felt to be crucial to the overall care-giving experience, and the review sets out to examine how different family carer variables may affect this. Attribution theory is utilised to present a conceptual model, then examined for its potential usefulness.

Research Report

Objectives: To examine the psychological outcome, coping style, and causal attributions, for both family and nurse carers of people with Alzheimer's disease (of 'Late Onset').

Method: The study recruited 57 participants, 27 family and 30 nurse carers. Each completed a demographics questionnaire, the Hospital Anxiety and Depression Scale (HADS), the Brief COPE inventory, and the Causal Dimensions Scale-Revised (CDS-II).

Results: Positive correlations were found between anxiety, depression, and dysfunctional coping style for both groups of carers. Comparisons revealed that family carers suffered significantly greater levels of anxiety and depression, with nearly two-thirds (63%) of the family carers reporting some psychological morbidity. In comparing coping styles, family carers were significantly more likely to utilise acceptance, whereas nurse carers utilise more positive reframing and humour. In terms of attributions, family carers reported significantly lower levels of external control compared to nurses, and empathically family carers were significantly better at describing the feelings of nurses than vice-a-versa.

Conclusions: Identifying associations can potentially improve the identification of poor coping and outcome in carers, and the implications of this are discussed for both family-inclusive assessment and nurse job satisfaction. Family and nurse carer differences are discussed in terms of improving the interactions, interventions, communication, and the overall care environment.

Critical Appraisal

The appraisal details a personal account of the research origins, some management issues, and an exploration of subsequent learning outcomes.
Section 1

Self Contained Literature Review

“Alzheimer’s Disease Care-giving:
The Family Carer’s Experience and their Relationship with Nurse Carers”
Abstract (Section 1)

Introduction
It is recognised that Alzheimer’s disease is on the increase, resulting in more family members finding themselves in a caring role. As the disease progresses and resources are stretched, families can find themselves increasingly interacting with formal services. These relationships are felt to be crucial for improving the quality of care and communication within the family-nurse-patient triad.

Review Aims
The aim of this literature review was to explore the factors that can affect a family caregiver’s relationship with nursing staff, by utilising existing knowledge of coping and psychological outcomes, then attribution theory.

The Context of the Nurse-Family Relationship
Structured around those family carer background and contextual factors, the review explores how these variables have an effect on coping, outcomes, and the relationships with formal care. There are increasing views within the literature that these relationships may benefit from a deeper analysis of carer beliefs and cognitions, to discover how carers make sense of their experiences.

Theoretical Model of Care-giving
Family and nursing care within Alzheimer’s disease is explored using attribution theory and a conceptual model of care-giving is presented. These theoretical concepts are examined within the available literature and considered for their usefulness in understanding the meaning that underpins family care, to potentially aid their relationships with nursing care.

Conclusion
The review is summarised and ideas are offered for future research.
1. Introduction

The purpose of this review was to examine the family experience of caring for someone with Alzheimer's disease and explore potential factors that can influence their relationships with formal services, in particular nursing care. The structure will follow a journey through frequently researched areas of coping and outcome, using the background and contextual elements of the care-giving experience, then introduce an attributional-based theoretical model that may aid understanding in this area. First the review will introduce the clinical area of Alzheimer's disease by summarising its definition, epidemiology, and aetiology; then care-giving by summarising the initial impact that this disease has on family and nurse carers and their interactions.

1.1. Alzheimer's disease

1.1.1. Definition of Alzheimer's disease

Since the first diagnosis of this type of dementia by Alois Alzheimer in 1907, Alzheimer's disease has become the commonest diagnosis of dementia, accounting for between one-half and two-thirds of all cases (Longley & Warner, 2002). Characterised by a development of multiple cognitive deficits, a clinical diagnosis is usually made if symptoms match the diagnostic criteria as detailed in the Diagnostic and Statistical Manual (DSM-IV-TR, APA, 2000), including memory impairment, and two or more other cognitive disturbances (i.e. in language, motor skills, or executive functioning). In addition, Alzheimer's disease is highlighted by a progressive nature to the decline in these abilities. The natural history of the disease usually follows a decline as shown in Figure 1 below.
Alzheimer's disease can be differentiated between early-onset (under age 65) and late onset (over age 65). Late-onset tends to be more comparable than early-onset, with many similarities in symptoms and presentation, however early-onset can produce a wide ranging clinical picture, with quite different cognitive and physical impairments, as well as a wide range of psychiatric and behavioural features (Dearden, 2004). For the purposes of this review any subsequent reference to Alzheimer's disease will relate to that which is of late onset.

1.1.2. Epidemiology and Aetiology of Alzheimer's Disease

Population estimates in the UK suggest that the number of people aged fifty and over will increase from 19.8 million (in 2002) to around 27 million by 2031, with those aged eighty
and above nearly doubling to 5 million (National Statistics, 2005a). Alzheimer’s disease currently affects over 750,000 people in the UK, namely one in every 20 people over the age of 65 and one in every 5 people over the age of 80 (Alzheimer’s Society, 2005a). The combination of these statistics implies a continual increase of numbers affected by the disease in the UK for the foreseeable future.

UK population trends and dementia prevalence rates are reported to be similar to that of North America (Bowie & Takriti, 2004), so it is likely that there will be a mirroring of a US study that predicts Alzheimer’s disease to quadruple over the next 50 years (Brookmeyer, Gray, & Kawas, 1998). Couple these figures with the burden that Alzheimer’s disease imposes on society and it can be expected that there will be huge implications for the resources of the family and social networks of those affected, and more widely, UK health providers such as the National Health Service.

The aetiology of Alzheimer’s disease still remains unclear although researchers believe that many aspects inclusive of age, genetic background, and lifestyle, have their own risk factors that may work together to lead to the onset of the disease (Alzheimer’s Society, 2005b). Other than the exploration of genetic risk factors like those found with Down’s Syndrome (Lott & Head, 2001), researchers have also attempted to discover potential variables that may increase the risk of Alzheimer’s disease, such as traumatic brain injury (Lye & Shores, 2000) and depression (Dal Forno, Palermo, Donohue, Karagiozis, Zonderman, & Kawas, 2005), or variables that may provide a protective function such as caffeine (Maia & de Mendonça, 2002). Recent advances in medical treatments provide the possibility of being able to slow the progress of the disease, but ultimately cognitive processes decline and lead to death, usually resulting in years of adjustment and caregiving responsibilities for those family and social systems around them.
1.2. Alzheimer’s Disease Care-giving

The person with Alzheimer’s disease is usually cared for by either a member of their own family or nursing staff within a nursing home environment. It is generally the case that families will keep their relative at home until their own resources have been exhausted (Almberg, Grafstom, & Krichbaum, 2000).

1.2.1. Family Carers

Family care-giving refers to the process of one or more family members giving aid or assistance to other family members beyond that required as part of normal everyday life (Walker, Pratt & Eddy, 1995). In 2001 the UK census highlighted that in England and Wales there were around 5.2 million carers, which accounts for one in ten of the population. With 2.8 million of these carers over the age of 50 (National Statistics, 2005b) it is likely that a large amount of informal caring is due to older age health problems such as Alzheimer’s disease.

In terms of caring for a family member with Alzheimer’s disease, the cost has been associated with a variety of physical, emotional, financial, and social burdens (Connell, Janevic, & Gallant, 2001). Compared to general care-giving, dementia care requires more hours per week, causing likely employment complications, strain, mental and physical health problems, reduced leisure time, and family conflict (Ory, Yee, Tennstedt, & Schultz, 1999). These burdens are expressed differently within each unique family network, and they will produce varying experiences depending upon the interacting components of the relative with Alzheimer’s disease, the primary care-giver, the rest of the family, and the environment within which they live.
Recognition of carers within UK government policy has been growing over the past twenty years. Since The Griffiths Report (1988) a greater awareness of the needs of carers has continued to be integrated into subsequent strategies and guidelines, including The Carers Act (SSI, 1996a, 1996b), Caring for Carers: A National Strategy for Carers (DOH, 1999), and Forget Me Not: Mental health Services for Older People (Audit Commission, 2000). Most recently, the National Service Framework for Older People (DOH, 2001a) integrated the needs of carers into all of its standards and service models, including person-centred assessment, intervention, and support strategies.

1.2.2. Nurse Carers

UK nursing homes are now divided almost equally between the public and private sector, with recent trends showing reductions in public sector beds (by 39% to 189,000) and increases in private sector beds (by 839% to 193,000) in the twenty years leading up to 2000 (Kerrison & Pollock, 2001). Nursing home management, particularly in the private sector, has the difficult 'balancing act' task of making financial gains for the company, providing good quality care for residents, and maintaining an effectively functioning work environment for its staff.

Nursing home staff have reported associations between stress and satisfaction (Hinshaw & Atwood, 1993), particularly when caring for cognitively impaired clients (Novak & Chappell, 1996). Levels of stress have been found to increase with greater demands of staff time and skills (Baillon, Scothern, Neville, & Boyle, 1996) and higher levels of aggression from clients (Rodney, 2000), but be alleviated by regular clinical supervision (Hallberg, Welander, & Axelsson, 1994) and managerial support (Bennett, 2001). If stress is not dealt with staff can become burnt out (Freudenberger, 1974), which is associated with poorer
effectiveness to perform their job (Motowidlo, Packard, & Manning, 1986), increased negative attitudes towards themselves and clients (Maslach & Jackson, 1981), and increased behavioural disturbances in dementia clients (Bahareethan & Shah, 2000).

Nursing home residents are protected by national regulatory bodies such as the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection (from the Care Standards Act 2000), and national minimum standards for care homes for the elderly (DOH, 2001b). With these government policy pressures to improve quality of care, alongside increasing numbers of private nursing homes required to make profits, nurse resources could get stretched further. It is likely that nursing staff will find it difficult to involve a resident’s relatives, with family needs often going unnoticed in systems of nurse care where the emphasis is often on the practical and ‘hands on’ notions of care-giving (Kellett, 1999a).

### 1.2.3. Relationships between Family and Nurse Carers.

When caring for someone with Alzheimer’s disease interactions between families and nursing staff, sometimes occur within the home, often occur as part of respite care, and usually always occur when there is a transition to a nursing home.

Whilst the care-recipient is at home, family carers have reported respite care to be an important requirement (Caserta, Lund, Wright, & Redburn, 1987), giving the opportunity for temporary relief. The reality appears less simple, with some family carers reporting increased stress due to issues around organisation, anxieties about the care provided, and difficulties following respite care (Worcester & Hedrick, 1997). Differences in care-giver experiences can also be associated with the type of service used, with less stress found for
in-hospital respite care where a complete break is achieved (McNally, Ben-Schlomo, & Newman, 1999).

Transition of a relative to a nursing home can create a mixture of feelings in the family carer including experiencing a loss of control; being disempowered; feeling guilt, sadness and relief simultaneously; possessing a sense of failure; and having to make a forced and negative choice (Kellett, 1999b). This transition time can be encapsulated by emotional turmoil (Dellasega & Mastrian, 1995), which can continue long after admission to the nursing home (Ryan & Scullion, 2000).

Many families express the desire to continue to care for their loved ones following admission to nursing homes (Sharp, 1990). However, the family carer may be left with an ambiguous role in which poorly defined responsibilities for providing care can lead to problematic relationships with nursing staff (Gaugler, Anderson, Zarit, & Pearlin, 2004), and poor perceptions of care that can lead to increased strain and burnout (Almberg et al., 2000).

With nine out of ten family carers continuing to care for their relatives beyond simply visiting (Kane & Penrod, 1995), nursing homes and their staff may need to be more proactive at including families within individual care packages. Despite a recognition within published research that family carers can be ‘essentially invisible’ within nursing care environments (Kellett, 1999a), research has been scarce in finding ways to improve this. There are significant gaps in knowledge as to the detail behind the family-nurse relationship, which is an essential area of investigation for improving care provision and communication between the family-nurse-patient triad.
1.3. Summary

With an increasing prevalence of Alzheimer’s disease predicted at least over the next thirty years, more families are likely to find themselves in a care-giving position. Supporting the needs of these carers through health policy guidelines alone may be inadequate, as there can often be a mismatch between the services on offer and those devised (Brodaty, Thomson, Thompson, & Fine, 2005). The interaction between informal and formal care is most prominent around the time when families are struggling to cope and nursing care is sought, and without an in-depth exploration of these relationships the meanings behind them can be lost (Lyons & Zarit, 1999).

Recently, the ‘care of the carer’ approach (Nolan, Grant, & Keady, 1996) has dominated the literature base and researchers have begun to collate this evidence into useful reviews of particular areas (e.g. Dilworth-Anderson, Williams, & Gibson, 2002), often in the form of contextual variables such as race, age, and gender. Following this structure to explore coping and outcome is common, yet poorly recognised in researching family-nurse carer relationships. To improve the way that services are provided and increase the likelihood that they are appropriately matched to the needs of family carers, more knowledge is needed in discovering the contextually-specific needs of those carers, such as for those living within different geographical areas, different ethnic backgrounds, and different care-giver cohorts (Train, Livingston, & Manela, 2001).
2. **Review Aims and Search Method**

In examining the area of Alzheimer's disease care-giving, this review aimed to collate the evidence about psychological coping and outcome, using contextual variables, then explore the relationship that each may have on a family carer's relationship with nursing staff.

The literature search incorporated three strategies. Firstly, finding relevant journal articles using a number of different computerised databases including; MEDLINE, PsychINFO, EMBASE, CINAHL, and the British Nursing Index. Secondly, utilising internet based electronic journal libraries including Swetswise Information Services, Wiley Interscience, and Elsevier Science Direct. And thirdly, by following up articles cited in those journals collected from the first two methods. The journal databases and libraries employed the use of the following search terms: 'Alzheimer's disease', 'Dementia', 'Care-giving', 'Carer', 'Family', 'Nurse', 'Coping', 'Relationship', 'Interaction'.

With such a large number of studies available, a number of processes were adopted to filter the research into a useful selection appropriate to the context of the present study. Firstly the basic elements surrounding the clinical area needed to be present, namely that the participants had Alzheimer's disease of late onset, sample sizes (and if available the effect size and power) were of a satisfactory level according to Cohen (1988), and if possible they were recruited from a UK sample. Secondly there needed to be some compatibility with the present study, namely the research investigated psychological outcome, coping, or attributions that were evaluated using evidence-based methods and standardised measures.
3. The Family Care-giving Experience and Relationships with Nurses

3.1. Making Sense of the Family Care-giving Experience

In order for clinicians and services to begin to make sense of the experiences that families encounter whilst caring for a relative with Alzheimer’s disease, researchers have attempted to develop an all encompassing model, such as the one conceptualised by Pearlin et al., which will be adapted for this study and is shown in Figure 2 below.

Figure 2. Conceptual model of Alzheimer’s care-givers’ stress.

Despite the many factors that this model attempts to encase, its authors described it as something to be built upon (Pearlin et al., 1990), providing a useful template with which to formulate other elements of the care-giving experience. Within the care-giving literature there has been a tendency to concentrate on biomedical issues of care (Mackenzie, 2004), so this review will be extending its focus into a carer’s background and contextual factors (as suggested by Pearlin et al., 1990).
3.2. Family Carer Background and Contextual Factors

For this section the format will be based on the conceptual model by Pearlin et al. (1990) exploring family care-giver stress, in particular the Background and Context variables, which are detailed in Figure 3 below. Each will be described in terms of the impact that each variable has on a family carer’s psychological outcome and coping, and then explore possible effects on relationships with nursing staff.

Figure 3. Family background and context components of the literature review.

3.2.1. Gender of Carer

The role of primary care-giver is consistently found to be taken on by women (Stone et al., 1987). Research into the effects of gender on the care-giving experience point toward women experiencing greater negative consequences (Donaldson et al., 1998), with more depressive symptoms, anxiety, general psychiatric symptoms, and lower life satisfaction compared to their male counterparts (Yee & Schultz, 2000). In a meta-analysis of 14
studies of gender differences in care-giving, Miller and Cafasso (1992), found that female
care-givers were more likely to carry out personal care and household tasks, and more
likely to report greater burden. With expectations that women will assume this care-giving
role (Montgomery, 1992), men are less exposed to the stresses and strains of care-giving,
however qualitative research into care-giving males revealed problematic issues revolving
around social isolation (Siriopoulos, Brown & Wright, 1999) and lack of comfort with
formal services (Harris, 1993).

Differences between the genders may vary greatly according to the type of relationship the
carer has for the care-recipient (i.e. spouse or child), with different generations producing
varying ideas and beliefs about caring within their cohort. Gender differences may also be
a reflection of different coping styles that tend to be favoured by one sex or the other
(Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997), which may have an effect on the
decision-making processes and subsequent outcomes.

In their relationships to nursing staff, female family carers are more likely to take on the
role of ‘Supercare-giver’ (Corocan, 1992), not reliant on support and assistance from
others, and sensitive to the provision of nursing care when it is provided. Unless roles and
responsibilities are classified early on, any ambiguities in the care provision may lead to
conflicts and criticisms (Gaugler et al., 2004). Men on the other hand can find themselves
mismatched by support and services, which is available to them in a care-giving world that
society orientates towards women (Connell et al., 2001). Good nursing relationships may
prove essential in balancing the care responsibilities with female relatives, whilst ensuring
that male relatives feel that they can play a useful role in some aspect of the care required.
3.2.2. Carer Health

Research into the effects of a care-giver’s age on outcome appears to be scarce and has not been adequately studied (Pezzini, 2003). It could be inferred that with increased age comes reduced overall health levels, which will have an affect on the ability to provide care. In this area, research has found that a care-giver’s health can be a reliable predictor of depression (Zanetti, Frisoni, Bianchetti, Tamanza, Cigoli, & Trabucchi, 1997), suggesting an overall vulnerability to the psychological consequences of care-giving.

The effects of care-giving may vary across ages, reflecting different cohort factors, including lifestyles, responsibilities, and expectations. Practically, older carers may find the increasing dependence tiresome, while younger carers, possibly with their own younger families to care for, may not have the time to take on extra duties. Some research has found that older female carers experience greater burden while younger female carers report more complaints, loneliness and resentment in their roles as care-givers (Heru, Ryan, & Iqbal, 2004). With differing effects as age increases, sometimes more burdensome (Kriegsman, Pennix, & van Eijk, 1994) and sometimes more protective (Pezzini, Bianchetti, Bellelli, & Trabucchi, 2003), further investigation is required to clarify the most effective support and intervention strategies for various carer ages and cohorts.

Effects of age on the nurse-family relationship can work in a number ways, as both the family and nurses (although usually above sixteen) can be of any age. Research has found that older family carers tend to be more passive in their interactions, not expecting support from staff and adopting coping mechanisms centred mainly on stoicism (Reed & Morgan, 1999). Nurses may benefit from a more proactive approach in order to improve and increase the involvement of an elderly family carer. Younger family carers tend to be juggling multiple roles, as was found with care-giving daughters (Brodaty et al., 1990), so
nurses need an awareness that stresses in this group may be from other sources but may still impact on their relationships with staff and the care-recipient.

In order to improve the evidence base for nurse-family relationships, other age groups and relationships (other than elderly spouses) need further research to elaborate on how different types of carers should be supported, rather than hoping that spouse-specific dementia interventions will generalise.

3.2.3. Carer Ethnicity

At present it is estimated that there are around 14 thousand people in the UK from ethnic minorities who suffer from a form of dementia (Alzheimer's Society, 2005c). With the increasing number of carers needed to support these people, more attention was needed to include ethnic and cultural variables when researching the study of care-giver stress (Connell & Gibson, 1997), including cultural values, beliefs, traditions, symbols, language, and social organisation that is meaningful to the group members (Aranda & Knight, 1997).

There is currently a wealth of published literature focusing on comparing the care-giving experience of Alzheimer's disease from different ethnic backgrounds, and this has been usefully brought together in a number of comprehensive meta-reviews (Connell & Gibson, 1997; Janevic & Connell, 2001; Dilworth-Anderson et al., 2002). Differences between black (African-American) and white (American Caucasian) care-givers are the most common example of comparative studies (as they are usually from North America), and they have begun to demonstrate the complexities that these contextual factors can have on family carers.

This body of knowledge has found that in terms of the care-giving relationship, white U.S. carers are predominantly spouses, whilst black carers in the U.S. are more likely to be adult children, friends or other family members (Cox, 1995; Haley, 1995; Hinrichsen & Ramez,
White care-givers were found to be significantly more depressed when compared with black carers, and black and white non-care-givers (Farran, Miller, Kaufman, & Davis, 1997; Haley, West, Wadley, Ford, White, et al., 1995; Lawton, Rajagopal, Brody, & Kleban, 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995). Black carers tended to use more positive reappraisal than white carers when dealing with care-giving difficulties (Haley, Roth, Coleton, Ford, West, et al., 1996; Knight & McCallum, 1998; Wood & Parham, 1990). Finally, black carers were likely to receive more informal support from family and friends compared to white carers (Cox, 1996; Wood & Parham, 1990). Overall, these studies highlight the need for an awareness of the cultural differences within the care-giving environment.

Generalising these results to a UK sample should be completed with caution as the research has utilised American population comparisons (e.g. Haley et al, 1996), small sample sizes (e.g. Weitzman, Chee, & Levkoff, 1999) that reduce the statistical power of the results (Cohen, 1988), and have sometimes included predominantly one particular gender, usually female (e.g. Cox, 1996).

Future research into this area should consider not just the constitution of the sample, but where they are recruited, such as utilising local Alzheimer Association centres (Cox, 1999) rather than through research centres (Knight & McCallum, 1998) to improve the likelihood of a more clinically representative sample.

Forming effective family-nurse relationships may need to tackle a number of ethnic barriers, from basic communication incompatibility due to differences in verbal and non-verbal language, to differing societal beliefs such as some cultures attributing cognitive impairment to punishment for past sins or just part of the normal aging process (Alzheimer’s Association, 2005). Further research knowledge into the effects of culture on these relationships is particularly scarce in the UK, however it is crucial if services are to
reach all dementia carers and reduce the likelihood of inadvertently designing services that are inappropriate to those carers with culturally and linguistically diverse backgrounds (Brodaty et al., 2005).

### 3.2.4. Relationship to Care-Recipient

This care-giver-related variable is concerned with relationship-level coping (Coyne & Fiske, 1992), and considers each partner’s efforts to cope with their own and with their partner’s distress in terms of the structure and quality of their previous and existing relationship. As the disease progresses the carer has to take on additional roles to compensate for the care-recipient’s loss of abilities. In the context of a marriage, a greater burden is placed on the healthy partner to cope with the stresses of the illness on behalf of both partners, without the spousal support they once received from the care-recipient. (Majerovitz, 1995).

It is usual that the adult children and spouses of people with a dementia are the more likely to assume the role of the care-giver (Ory et al., 2000). In particular, spouse care-givers have been found to suffer from higher levels of depression and stress, and lower levels of life satisfaction, compared to other family care-givers (Schultz, O’Brien, Bookwala, & Fleissner, 1995). This may arise from a spouse’s sense of duty within the marriage (“for better or worse”), or the reality of having to live within the same home and trying to maintain a functional day-to-day life. Either way spouses appear to provide the most comprehensive kind of care and spend the most hours per week doing so (Neal, Ingersoll-Dayton, & Starrels, 1997). In cases where it is the adult-children that take upon the care-giver role, the responsibility often comes to lie on the adult daughter (Cantor, 1983), who will then have to interweave an additional care-giving role amongst existing roles. Research certainly suggests that adult-child carers may be less likely to cope, as they are
four times more likely to institutionalise the care-recipient compared to spouses (Scott, Edwards, Davis, Cornman, & Macera, 1997).

What is clear from research in this area is that regardless of the cohort effects that are likely to have a huge impact on expectations and responsibilities for care-giving, nurses need to be aware of the past relationship. Whether there have been adaptations to care through respite, or permanent changes through nursing home placement, an effective family-nurse relationship needs to be mindful of the pre-morbid partnership that existed prior to the disease onset, as this often remains unchanged (Gilhooly, Sweeting, Whitting, & McKee, 1994).

3.2.5. Family and Network Composition

The impact of Alzheimer's disease reaches far beyond that of the primary care-giver, not only to immediate family, but also extended family, friendships, neighbours, and in some cases work colleagues. The strain of care-giving often branches out to many other members of the person's family and network, with aspects of this stress presenting itself through conflicts (Pratt, Schmall, & Wright, 1987), disagreements (Pearlin, Turner, & Semple, 1989), and readjustments in family roles (Bengtson & Kuypers, 1986).

The family system within modern society is diverse and complex, placing each care-giver within a unique network of relationships, with differing roles, differing geographical locality (Gwyther, 1998), and differing distributions of responsibilities for care. As the carer and cared for rarely exist in isolation, inclusion of more members from a network such as through the use of family counselling (Qualls, 1988), family teaching (Seltzer, Ivry, Litchfield, 1987), or in providing self-help material, improves the potential of family coping, adjustment and involvement in local community services.
Relationships with nursing carers and services are likely to differ between individuals, with family structures varying considerably. It has been suggested that home caring is often shared among family members, rather than left to one individual carer (Johnson, 1983), meaning that handing over responsibilities to nursing staff may be different for each member of a care-recipient’s family network. Family-Nurse relationships may therefore vary in quantity and quality for different members of a care-recipient’s family, demonstrating the need to have clear and consistent communication with all members of each family system. These relationships may also benefit from greater exploration into the care-recipient’s family and social system, to incorporate other ‘hidden carers’ such as grandchildren, extended family members, and friends.

3.2.6. Occupational, Educational and Economic Attainments

Research into the occupational, educational, and economic attainments of care-givers for relatives with Alzheimer’s disease is scarce. In terms of education, there is evidence to suggest that carers of a higher educational level are more likely to view themselves as healthier and tend to utilise more problem-focused coping strategies (DiBartolo & Soeken, 2003). Also assuming a link between education and wealth, those carers from higher socio-economic groups appear more likely to seek medical attention earlier (Pollitt, 1996). Occupational factors are influential in terms of the practicalities of managing the care, which comes with the progressive worsening of the care-recipient’s cognitive and behavioural abilities. As the relative becomes more dependent, the carer can find themselves increasingly involved in care duties. Any existing employment activities by the carer will be in competition with the demands of the relative, and this could be an important time as to when a carer decides how much care they are going to provide.
Research in the UK suggests that a quarter of carers reported that they had to give up paid work to provide care for a family member (Train et al., 2001).

With the increasing ratio of private nursing homes within the UK (Kerrison & Pollock, 2001), there is likely to be an increasing similarity with US research, which identifies greater service usage with access to a funding source such as Medicare (Hinrichsen & Ramirez, 1992). Relationships with nursing care staff may prove difficult to establish as time constraints and additional accessibility costs may restrict a family carer’s ability to access the care-recipient’s placement, especially in rural areas (Ho, Weitzman, Cui, Levkoff, 2000). Nurses may need to be mindful of these accessibility issues, by ensuring visits are well planned and co-ordinated, being proactive in enabling contact, and working around each family member’s financial resources and occupational commitments.

3.2.7. Geographical Issues

A care-giver’s geographical location and mobility factors can have a huge impact on their ability to access services and support. Pedlar & Biegel (1999) found that carers were less likely to utilise services if they were seen as ‘inconvenient’. Research into the barriers that care-givers’ encounter when attempting to access services include transportation difficulties (Keefover, Rankin, Keyl, Wells, Martin, & Shaw, 1996), reduced access to professionals with expert knowledge of Alzheimer’s disease (Morgan, Semchuk, Stewart, & D’Arcy, 2002), and lower overall supply of health services available (Chumbler, Cody, Booth, & Beck, 2001). Accessibility may also be hampered by a care-giver’s worries about meeting ‘strangers’, possible financial costs, and the quality of the service on offer (Winslow, 2003).
Carers who do not access services have been found to suffer greater depression and burden (Bass, Looman, & Ehlrich, 1992), whilst utilisation can promote a carer’s sense of belonging, feeling supported by others who understand their problems, and feeling less lonely (Winslow, 2003). Obtaining aid, support, or permanent care from nursing staff may often be due to ‘last resort’ or a ‘failing to cope’ reasoning (Ryan, 2000), so any breakdowns in the family-nurse relationship may prove extremely negative for family members and lead to further feelings of isolation and rejection.

3.3. Summary

It is clear that a carer’s background and contextual framework can have huge implications not just for the way in which they respond and interact with the care-giving experience, but for their feelings and beliefs about services and support that may be available to them. Despite scarce knowledge in some areas, the complexity of the relationship between the person with dementia, their family carers and professional carers cannot be underestimated (Clarke, 1999).

All of these contextually-based factors are socially driven, increasing the likelihood that individual need may be over-shadowed by expectations, social norms, cultural values, and religious beliefs. Research into coping and outcome has its roots in the biomedical approach (Adams, 1998), attempting to measure illness through symptom-based questionnaires and interviews, so as to reduce stress and improve coping. This approach highlights the current societally-based need to treat symptoms rather than adopting a more useful ‘rehabilitative’ method of reducing the impact of these symptoms for sufferers (Hall, 1990). This can be achieved through gaining a greater understanding of the cognitions and beliefs that carers may hold for their experiences, which can potentially
validate their actions and emotions, as well as provide a more in-depth knowledge of the underlying meaning of care-giving.

In order to investigate these ideas further, psychological theories and frameworks can be utilised to explore the meaning behind care-giving, in order to better inform the family-nurse relationship. One such approach that has attempted to encapsulate these ideas is that of Attribution theory, which attempts to analyse how people attribute causes to their experiences. Although still relatively under-researched for dementia care-giving, this approach has gained support for its usefulness in highlighting influential cognitive factors (Jones & Hastings, 2003), and in developing a greater knowledge for carer understanding (Fopma-Loy, 1997) and subsequent interventions (Kushlick, Trower, & Dagnun, 1997).

4. Attribution Theory and the Family Care-giving Experience

4.1. Attributions

In developing the cognitions and beliefs that we hold, we all have an innate need to explain what is happening in our world, both to ourselves and to other people, attributing cause to the events around us. These causal investigations can have an effect on our sense of influence that we have upon our environment and its influence on us. In turn these investigations can have an effect upon how much we believe events and behaviours are the result of our own actions or others, and how much these causes can change or vary in the future. It is through the theories of this attributing process that this review will now follow.
4.2. Causal Attribution Theory

Attribution theory is based on the principle that individuals seek to know why particular events have occurred (Weiner, 1985) and is concerned with how people account for the events they experience and the actions they observe (Brewin, 1988). In essence it looks at how people make sense of their world.

The first psychological theory of attribution was proposed by Heider in 1958, which utilised a ‘common-sense’ approach to psychological investigation to formulate the process by which an untrained observer (or ‘naïve psychologist) makes sense of the actions of others (Hewstone, 1989). This theory (Heider, 1958) proposed that the observer’s main role was to find the underlying causes to those things happening in their world. In particular, Heider suggested that ordinary explanations for events and actions could be broken down via one of two ways, either by attributing the cause to something to do with the person who performed it or by attributing it to something external, making the fundamental internal – external distinction.

Heider’s principles of ordinary explanation were formalised into subsequent theories of attribution such as Correspondent Inference Theory (Jones & Davis, 1965) and Kelley’s Covariation –Configuration Theory (Kelley, 1967). Together these theories emphasise a concern with common-sense explanations to address the kinds of information that people use to determine causality, the kinds of causes that they distinguish, and the rules they use for making causal attributions (Hewstone, 1989).

The use of attribution theory for the analysis of events and actions in a person’s world has been criticised for being overwhelmingly individualistic and cognitive (Augoustinos &
Walker, 1995), leading subsequent researchers to seek out the effects of group and societal influences on attributions (Hewstone, 1989). Although under-represented by attribution theory, attributions are clearly linked to social and cultural representations (Augoutinos & Walker, 1995), emphasising the impact of a person’s background, societal integration, and cultural beliefs.

Subsequent developments of Heider’s (1958) original attribution ideas were extended by Weiner into theories of motivation (1972), achievement motivation (1974), and motivation and emotion (1986). Usefully Weiner developed his theories and models around a three-dimensional analysis of causal attributions. These three causal dimensions included firstly, locus of causality, which refers to whether the cause is something about the person or something external to the person; secondly stability, which refers to whether the cause is constant or variable over time; and thirdly controllability, which refers to whether the cause is under the control or not under the control of the person or others (in Weiner, 1974). Support for the existence of these dimensions was demonstrated empirically in factor-analytic (Meyer, 1980) and multidimensional scaling (Passer, 1978) studies, however there has been some criticism as to how much the controllability dimension contributes to the model (Abramson, Seligman, & Teasdale, 1978).

These dimensional characteristics were used by Weiner (1974) to show how individuals explain their success or failure on achievement tasks. This approach has been used extensively to reveal the importance of causal perceptions of achievement behaviours within a variety of environments such as education (Rogers, 1982) and health (Watts, 1982). Utilising these causal attribution principles, the review will now follow a branch from these early ideas, which looked into the use of attributions for help-giving behaviours, and apply this to Alzheimer’s disease care-giving.
4.3. Causal Attribution Model of Care-giving

Weiner (1980) presents an ‘Attribution-Emotion-Action’ model that he believes can be usefully applied across a variety of help-giving situations to examine the attributions of judgements of helping behaviour. The model that is shown diagrammatically in figure 4. below (link to bracketed numbers), presumes that the perceiver of an event will, after an initial reflexive behaviour and affective reaction (1, 2), seek to find an initial cause (3). These initial causal analyses give rise to help (4) and affective reactions (5). However these causes will be examined in terms of underlying properties in terms of the causal dimensions (6). The causal dimensions then relate to help (7) and affective reactions (8), although help was also found to be strongly affected by the affective reactions themselves (9). This model attempts to capture the judgements of aid and helping behaviour, stressing the relationship between attribution, affect, and action (3,6,8,9; shown by the thicker arrow in figure 4).

Figure 4. Weiner’s (1980) Attribution-Emotion-Action model.
Initially, the model gained some empirical support (Meyer & Mulherin, 1980; Reisenzein, 1986), however the ecological validity of the findings have been questioned as to their applicability in realistic settings (Sharrock, Day, Qazi, & Brewin, 1990).

Weiner's help-giving attributional model (1980) has been examined within a variety of applied help-giving settings, including mental health (Sharrock et al., 1990) and learning disability (Dagnan, Trower, & Smith, 1998; Stanley & Standen, 2000). Findings appear to provide mixed results, with the main determinants of help-giving interchanging between Controllability (Stanley & Standen, 2000; McGuinness & Dagnan, 2001), Stability (Sharrock et al., 1990), and Globality dimensions (McGuinness & Dagnan, 2001), or not related to attributions at all (Jones & Hastings, 2003).

Researchers usually gather carer attributions by either conducting qualitative interviews (e.g. Leeds Attributional Coding System, used by Tarrier, 2002) or using quantitative measures of hypothetical situations (e.g. Attributional Style Questionnaire, used by Sharrock et al., 1990). There are conflicting arguments about the use of hypothetical situations (using vignettes) to elicit attributions, as they have the advantage of allowing the production of standardised and comparable material (Hewstone, 1989). However a disadvantage is that participants may report care-giving experiences and therefore attributions that have been projected upon them by their work setting (Fopma-Loy, 1997).

Overall, a common theme across all studies investigating help-giving suggests that cognitive factors play an influential role (Jones & Hastings, 2003), with attribution analysis being important for understanding underlying processes, and able to play a positive role for developing carer interventions (Kushlick, Trower, & Dagnan, 1997).
4.4. Applying the Model to Alzheimer's Disease Care-giving

Currently there is only a small body of literature available that explores attributions within those family members caring for a relative with Alzheimer's disease. When attributions are explored in this area, the focus tends to be directed towards the person with the disease or illness (Paton, Johnson, Katona, & Livingston, 2004). Only rarely (e.g. Tarrier, Barrowclough, Ward, Donaldson, Burns, & Gregg, 2002) are family carers asked about their attributions for their own feelings in terms of the care-recipient's behaviours.

A study by Tarrier, Barraclough, Ward, Donaldson, Burns, and Gregg (2002) interviewed 100 carers living in the community, focusing on household issues, illness history and current problems, irritability, and the care-giving relationship. As well as rating levels of expressed emotion, they also used independent raters to code responses into attributional categories, namely internal-external, personal-universal, controllable-uncontrollable, and stable-unstable. They found that carers rated patient causality as predominantly internal, universal (to Alzheimer's disease), and uncontrollable. More interestingly attributions were explored in relation to the carer, and the results found them to be overwhelmingly external, uncontrollable, and specific (to certain areas of their life). This study's methodology leads itself to possible biases as incorrect coding is always possible when the participant is not coding their own attributions, as has been found with the fundamental attribution error (Hewstone, 1989) whereby a rater would have a tendency to see actions as dispositional rather than situational. However, in terms of carer beliefs about patient behaviour, the results were consistent with schizophrenic illness care-giving (Barraclough et al., 1994), namely that personal (or internal) and controllable attributions were associated with increased carer strain, distress, and poorer coping styles (Tarrier et al., 2002).
As existing literature for family carers is scarce, there may be some merit in at least briefly examining the larger body of research that exists for nurse carers. This knowledge has mainly been gathered within adult mental health or learning disability settings. Findings have suggested that helping behaviours are seen as less successful when problem behaviours are perceived as stable (Sharrock et al., 1990), more controllable by the care-recipient (Leggett & Silvester, 2003), or both (Reid & Millard, 1997). In addition, nurses have reported regularly engaging in attributional activity to understand the behaviours of residents (Fopma-Loy, 1997). In terms of agitated behaviours, carers perceived them as uncontrollable and those that attributed stable causes were more likely to expect further incidents of agitation in the future (Fopma-Loy, 1993).

Although only a small body of literature exists for investigating the attributions within family care-giving for Alzheimer’s disease, it is useful to attempt to collate these findings into Weiner’s model (Figure 4) in order to provide a conceptual model of this family care-giving. Considering the criticisms of this model and the importance that they play in the care-giving experience (stated earlier), family carer background and context variables are integrated into each stage as they are influential at every stage, and provide greater depth of meaning. See Figure 5 below.
One of the crucial elements of this model in terms of this literature review is the final component, whereby all of the knowledge, causal analysis and emotions for the events within this care-giving experience, lead to judgements about their course of action for providing care and whether this will come from themselves or others, e.g. nursing care. Ultimately these decisions will have an impact on whether family carers utilise services and support, and any subsequent relationships that evolve from this.

4.5. Attributions and the Family-Nurse Relationship

The conceptual model shown above (Figure 5) can act as a practical guide for attempting to understand the meaning behind family care-giving, and it may provide some useful knowledge to formal services as to the causes behind family carer reactions and interactions. At present the use of attribution theory has been limited to carer and care-recipient interaction, both for family and nurse carers, and some useful knowledge has
emerged from this. However, there is clearly a significant gap in the literature for examining the usefulness of attribution theory for relationships between carers, as these play an increasingly significant role as the Alzheimer's disease progresses and worsens.

5. Conclusion

Increasing numbers of people affected by Alzheimer's disease have meant that more resources from families and society have had to be allocated towards providing care. Only within the last twenty years have health services begun to recognie the importance of raising the awareness of this care-giving role to improve the way that carers are supported. In the UK, the last five years have seen an enormous jump in this recognition, with the national service frameworks for older people (DOH, 2002), thoroughly incorporating carers into many aspects of care provision. This awareness of carers' needs not only encompasses the practicalities for providing care, but stresses the importance of the carer's health, both physically and psychologically. Clinical Psychology has been able to inject its theoretical knowledge and ideas within this area, to guide and support the way that psychological health is monitored and improved.

Understanding the psychological consequences of caring for someone with Alzheimer's disease is paramount if health services are to continue to improve the quantity and quality of resources available to families. Psychologists have provided useful frameworks within which researchers have been able to improve the knowledge behind the causes of care-giver stress, so as to work towards effective interventions that may help reduce it. The background and context of each carer has been highlighted in this review as an important factor that can give clues as to who will utilise certain coping styles, access help and support, and be prone to poorer outcomes.
Much of the research studying care-giving in Alzheimer's disease has been carried out in North America. Some caution is needed in generalising the results to UK populations, particularly when examining contextual factors. The complexities of studying the interactions between different contextual factors constrains researchers in finding simplistic meaning in the results found, instead knowledge is being pieced together using a variety of different perspectives, to attempt to collectively create a clearer picture of the care-giving experience.

With a wealth of knowledge for the coping, stresses and outcomes relating to various care-giving factors, researchers have begun to start utilising various theoretical models. These models have started to delve beyond these surface level stressors and strains, to explore deep-rooted beliefs and meaning. Instead of just describing what is happening, research is focusing its interest on why care-giving may be perceived so differently. One particular avenue of exploration is concerned with how a carer attributes causes to the feelings and behaviours of themselves and others, namely attribution theory. A conceptual framework is presented to describe a contextually rich, attribution-based perspective to the care-giving experience, to provide a potentially useful direction for improving family-nurse relationships. More research is clearly needed to expand upon these ideas, to validate the strengths of attribution theory and address its weaknesses, and re-establish its usefulness after nearly fifty years since its conception.

Despite the fact that nurse and family carers can find themselves increasingly interacting as the disease progresses, there is very little research that has explored this relationship. Family carers are often studied when the care-recipient is transferred from their care, but little knowledge is known about their feelings for nursing staff prior to and following this transition. Studying carers before a permanent nursing home placement may help provide health services with information regarding the use and non-use of services. Examining
their interactions with professionals since diagnosis may have an impact on the utilisation of support, and what beliefs they may hold for both themselves and healthcare workers throughout their care-giving experience. In addition nurses are often asked about their views and beliefs about their patients, but are rarely asked about their relationships with the care-recipients' families, despite their regular interactions with them. Improving family-nurse relations has the potential of maximising communication, maintaining consistent care interventions, and ensuring that all members of the care-giving system feel valued, involved, and supported.
6. References


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Section 2

Research Report

(OPTION 1 – Full Report)

Alzheimer’s Disease Care-giving:

Psychological Outcome, Coping Style, Causal Attributions, and Empathy.
**Abstract (Section 2)**

**Objectives:** To examine the psychological outcome, coping style, and causal attributions, for both family and nurse carers of people with Alzheimer's disease (of 'Late Onset').

**Design:** A cross-sectional design was employed to explore self-reported experiences within Alzheimer's disease care-giving for both family and nurse carers, then compare and contrast any differences found between these two groups.

**Method:** The study recruited 57 participants in total, 27 family carers and 30 nurse carers. Each participant completed a demographics questionnaire, the Hospital Anxiety and Depression Scale (HADS), the Brief COPE inventory, and the revised version of the Causal Dimensions Scale (CDS-II). The focus of the attribution scale centred on aggression directed towards carers, with family and nurse participants being asked to rate their own feelings, then re-rate the scale empathically to reflect a member of the other carer group.

**Results:** Positive correlations were found between anxiety, depression, and dysfunctional coping style for both groups of carers. Comparisons revealed that family carers suffered significantly greater levels of anxiety and depression, with nearly two-thirds (63%) reporting some psychological morbidity. In comparing coping styles, family carers were significantly more likely to utilise acceptance, whereas nurse carers utilised more positive reframing and humour. In terms of attributions, family carers reported significantly lower levels of external control compared to nurses, and empathically family carers were significantly better at describing the feelings of nurse carers than vice-a-versa.

**Conclusions:** Identifying associations between measures of care-giving experiences can potentially improve the identification of poorer coping and outcome in carers, and the implications of this are discussed for both family-inclusive assessment and nursing staff job satisfaction. Many differences exist between the outcomes, coping styles and attributions formed by family and nurse carers, and these are discussed in terms of improving the interactions, interventions, communication, and the overall care environment.
1. Introduction

1.1. Outline of this Study

The present study sets out to explore the care-giving experiences of both family and nurse carers for those people with Alzheimer’s disease (‘Late Onset’, age 65 and over). Carer outcomes, in terms of psychological morbidity and coping styles, are investigated to identify potential associations and differences between the two carer groups. In addition, an attribution theory approach is utilised to explore how carers make sense of their experiences, in particular, when they are confronted with aggression from the care-recipient. There will also be an exploration of the empathy that family and nurse carers have for each other in the context of care-recipient aggression.

1.2. Review of the Literature

Alzheimer’s disease accounts for around 55 percent of all cases of dementia, and currently affects three quarters of a million people in the UK (Alzheimer’s Association, 2005a). The incidence of the disease increases with age, affecting one in twenty people over the age of sixty-five, with this rate doubling every five years between the ages of 65 and 95 (Longley & Warner, 2002). With population projections predicting an increasingly aging society at least over the next thirty to forty years (National Statistics, 2005), the number of those people affected by Alzheimer’s disease are set to quadruple over this time span (Brookmeyer, Gray & Kawas, 1998), placing greater demands on the caring resources of families, health services and society as a whole.

The responsibility of caring for a person with Alzheimer’s disease usually starts with informal networks of support such as family or friends but, as the demands exceed resources, formal care is often sought. The cost of care-giving on a family member
encompasses a range of physical, emotional, financial, and social burdens (Connell, Janevic & Gallant, 2001). Compared to non-dementia care, dementia care has been found to require more hours a week; cause likely employment complications; strain; mental and physical health problems; reduced leisure time; and family conflict (Ory et al., 1999). Despite common core features of Alzheimer’s disease that are usually identified for diagnosis (APA, 2000), the effects are likely to differ greatly across individual presentations and interact with considerable complexity for varying types of family and social networks.

The important role that family members play in the care provision of relatives with Alzheimer’s disease has only been formally acknowledged within UK health policy over the past twenty years. Recognition has developed from a general awareness of the contribution that family carers make (Griffiths, 1988), to recent integration of family carer needs into national standards and guidelines for all aspects of older adult health care (DOH, 2001). This raised awareness has increasingly led to more research, studying various care-giving experiences and the impact that these have on a family carer’s physical and mental health.

Research to date has found that caring for a family member with Alzheimer’s disease is associated with increased psychological morbidity, including anxiety and stress (Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999); depression (Schultz & Williamson, 1991); increased burden (Burns & Rabins, 2000) that can be exacerbated by poor problem-solving skills (Heru, Ryan, & Iqbal, 2004); and dysfunctional coping strategies (such as avoidance and denial) that appear to be stable over time (Powers, Gallagher-Thompson, & Kraemer, 2002). Unfortunately research into the effects of care-giving do not always provide consistent findings. A recent study found only slightly elevated anxiety and depression levels in carers, although strong correlations did exist between the two (Garand, Dew,
Eazor, DeKosky, & Reynolds, 2005). Understanding of the associations that may exist between different care-giving variables has the potential to aid clinicians in identifying the risk of poor coping and outcomes.

There are a number of limitations to the results of many existing coping and outcome research studies, with one key issue centring around problems with the sample. Studies tend to be biased towards a female gender (e.g. Powers et al., 2002), have small sample sizes (e.g. Heru et al., 2004) that reduce statistical power (Cohen, 1988), and have questionable external validity due to factors such as recruiting through research centres (Knight & McCallum, 1998). Many of these issues may be the result of researchers finding the recruiting process troublesome with elderly participants (Kelsey, O’Brien, Grisso, & Hoffman, 1989), particularly when attempted in rural areas (DiBartolo & McCrone, 2003). Future research needs to begin to address some of these sampling issues or at least identify the impact that they may have on the validity and generalisability of any findings.

In terms of coping, a distinction has made between emotion-focused and problem-focused styles (Lazarus & Folkman, 1984). Emotion-focused coping is aimed at reducing or managing the emotional distress that is associated with the situation (Carver, Scheier, & Weintraub, 1989), and has been found to heighten stress, particularly in female carers (Lutsky & Knight, 1994). Problem-focused coping is aimed at problem solving or doing something to alter the source of the stress (Carver et al., 1989), and tends to induce a more positive focus (Borden, 1991). Nursing staff are able to utilise clinical supervision and support that can reduce stress (Hallberg, Welander, & Axelsson, 1994), and due to a practically focused ‘hands on’ approach (Kellett, 1999a) are likely to utilise more problem-focused coping strategies, which are associated with better outcomes for dementia care-giving (Borden, 1991).
Assessing a carer’s ability to cope has historically proved troublesome to researchers, as there are still few reliable and valid instruments available to measure this construct (Endler, Parker, & Summerfeldt, 1998). Problems often surround the use of inapplicable or inappropriate coping items (Stone, Greenberg, Kennedy-Moore, & Newman, 1991), and the measures themselves can often seem long and daunting, particularly to older adults. This has led researchers to design and develop shorter and more efficient means of assessing coping (e.g. the Brief COPE measure; Carver, 1997).

Throughout this care-giving experience, family carers can find themselves increasingly engaged with formal care services as the Alzheimer’s disease progresses. When a care-recipient demands more of the family carer’s resources, support may be sought from nursing care, initially in the form of respite then eventually in the form of a permanent nursing home placement. Family members have reported difficulties with organising respite (Worcester & Hedrick, 1997), coping with their relative’s transition to a nursing home (Kellett, 1999b), and feeling uncertain about their role alongside nursing staff (Gaugler, Anderson, Zarit, & Pearlin, 2004). Knowledge of the factors that affect service utilisation is crucial for family carers to have enough knowledge (Toseland, McCallion, Gerber, & Banks, 2002) and less reluctance (Pedlar & Biegel, 1999) to seek out appropriate support. In general, research has demonstrated a need to assess the dynamic nature of care-giving and the relationship between formal and informal carers (Hertzberg et al., 2001; Lyons & Zarit, 1999), as they are inextricably linked.

Research findings suggest that even when formal services and support are adopted, family members continue to suffer from stress (Ryan & Scullion, 2000), and often carry on providing some sort of care (Kane & Penrod, 1995). In addition, family carers can become ‘essentially invisible’ (Kellett, 1999a) in systems such as nursing care, that are usually defined by practical and functional measures (Nolan, Grant, & Keady, 1996). Empathy has
been found to be an important component within care-giving relationships (Lee, Brennan, & Daly, 2001), and it is possible that this ability can aid nursing care in recognising family carer needs, encouraging more collaborative relationships.

In exploring the relationships between families and nurses, researchers have begun to turn their attention away from simplistic satisfaction surveys to a deeper analysis of the meanings behind care-giving (Kellett, 1999a). The focus has revolved around various aspects pertinent to the understanding of family care, such as the meanings held by the carer for the care-recipient, the caring relationship, receiving service support, and the overall experience of caring for someone (Clarke, 1999). Underlying beliefs and cognitions that are held by the carer not only evolve into a sense of meaning, but have implications for how they perceive the causes of those events that are happening around them. Nurse carers can improve their interactions with families through a greater understanding of these perceptions, to enable a greater knowledge and improved empathy for the experiences of a family carer.

One way in which psychological research has sought to understand these perceptions is through the use of Attribution theory. The basic premise behind this is that people seek to make sense of the world, for the events that they experience and the actions that they observe (Brewin, 1988). In its earliest conception, Heider (1958) proposed that people seek out underlying causes of their experiences, categorising events and actions as either something either internal or external to the person who is performing it.

Subsequent theoretical developments of this approach (Weiner, 1974) proposed that causes were three dimensional, comprising locus of causality (i.e. internal or external to the person), stability (i.e. constant or variable over time), and controllability (i.e. under the control of self or others). In relation to the care-giving experience, attributions reflecting
lower control and stability have been found to be indicative of poorer outcomes (Stanley & Standen, 2000; Sharrock, Day, Qazi, & Brewin, 1990). Unfortunately there is a lack of attribution-based research into Alzheimer’s disease care-giving, so it is still unclear exactly how attributions interact with psychological outcomes and coping styles.

One avenue of exploration that has utilised attribution theory within care-giving, is the application of Weiner’s (1980) model of attributional analysis for help-giving. Subsequent research that has attempted to apply this model to care-giving has had mixed findings. The principle underlying causal dimension of help-giving behaviour has been found to vary between Controllability (Stanley & Standen, 2000; McGuiness & Dagnan, 2001), Stability (Sharrock et al., 1990), or not related to attributions at all (Jones & Hastings, 2003). Clearly further research is needed that can help clarify the nature of how causal dimensions can affect a carer’s help-giving behaviours.

All of these attribution studies utilised hypothetical situations (through vignettes), which are useful for providing comparable data (Hewstone, 1989), but can be biased by external social or organisational pressures (Fopma-Loy, 1997). Utilising vignettes as guidance, but promoting a sense of anonymity for individual results, should encourage a more realistic reflection of actual experiences, and reduce biases.

Existing studies exploring the usefulness of attributions and causal dimensions have tended to take place within learning disability and adult mental health settings, however there is relatively little information available for Alzheimer’s disease care-giving. A study by Tarrier et al. (2002) found that family carers tended to rate their own feelings about the care-recipients’ behaviours as external, uncontrollable, and specific (to certain areas of their lives). However, it is uncertain as to the effects that these attributions had on a carer’s psychological health (i.e. anxiety and depression), and their styles of coping. The study
utilised qualitative methods of analysis and collated attributions into categories, making comparisons difficult, as this and any subsequent replication will create findings that are unique to the sample. Working within a pre-defined attribution framework such as causal dimensions (Weiner, 1974), allows researchers to compare findings more efficiently across studies, and apply these ideas to new areas such as Alzheimer’s disease care-giving.

Due to the significant gap in knowledge surrounding the use of attribution theory for Alzheimer’s disease care, it would be difficult for this research study to cover all aspects of the care-giving experience. Instead the study intends to focus on an area that can sometimes be over-looked by researchers, but remains highly influential and pertinent to nearly all carers, namely the experiences of aggression directed towards a carer from the care-recipient. As a key feature of the behavioural and psychological symptoms of Dementia (BPSD; Finkel et al., 1996), aggression can be extremely common (65%, Ryden, 1988) and has been found to be associated with raised carer stress (Rabins, Mace, & Lucas, 1982), more aggressive responses from carers (Ryden, 1988) and greater likelihood of institutionalising the care-recipient (Cohen, Gold, & Shulman, 1993). The present study intends to gain a greater understanding of some of the carer’s underlying cognitive processes (i.e. their attributions) that are operating when experiencing this type of behaviour from a care-recipient with Alzheimer’s disease.
1.3. Aims of the Present Study

This study aims to replicate existing research that suggests possible links between different care-giver variables, namely for the triad of greater anxiety, depression, and dysfunctional styles of coping. There will also be a comparison between family and nurse carers for these and causal attributions to identify differences in the care-giving experience. In addition the study aims to explore how carers feel about care-recipient aggression and how they attribute the causes of their feelings for this, in both themselves and the other carer group. Examination of these carer differences and their ability to empathise, holds important implications for the relationships that family and nurse carers develop.

1.4. Research Questions and Hypotheses

The research questions are divided between firstly, exploring the within group relationships between psychological morbidity, coping style, and causal attributions; secondly, exploring the differences that may exist between the two carer groups on each measure; and thirdly, exploring the role of causal attributions and aggression within the care-giving experience. Coupling this structure within previous findings, three research questions were investigated utilising six specific hypotheses. These are detailed below:
1.4.1. Research Question 1: What relationships exist between psychological morbidity, coping styles, and causal attributions for the Alzheimer’s care-giving experience?

1.4.1.1. Hypothesis (a):

Greater levels of psychological morbidity (i.e. anxiety and depression) will be significantly and positively correlated with each other and dysfunctional coping styles, for all carers.

1.4.2. Hypothesis (b):

Greater levels of psychological morbidity will be significantly and positively correlated with lower ‘Personal Control’, ‘External Control’ and ‘Stability’ causal dimensions when carers think about the causes of an aggressive care-giving experience.

1.4.2. Research Question 2: Do the levels of psychological morbidity (as indicated by measures of anxiety and depression) and coping styles differ between family and nursing carers of people with Alzheimer’s disease?

1.4.2.1. Hypothesis (a):

Psychological morbidity levels in form of anxiety and depression will be greater for those who provide family care for someone with Alzheimer’s disease, compared to nursing care-givers.

1.4.2.2. Hypothesis (b):

Family carers will report greater levels of emotion-focused and dysfunctional coping, and lower levels of problem-focused coping, compared to nursing care-givers.
1.43. Research Question 3: When the care-recipient displays aggression, are there any differences between each group of carers' causal attributions, and can each relate to how the other carer group might perceive the causes of their feelings if put in the same situation?

1.43.1. Hypothesis (a):

*Family carers will rate themselves lower on the 'Locus of Causality' (indicating more external causality), 'Personal Control', 'External Control', and 'Stability' causal dimensions in comparison to the nurse carer group, when asked to describe the causes of their feelings for a care-giving experience involving aggression from the care-recipient."

1.43.2. Hypothesis (b):

*b) Nurse carers will be better at describing the causes of family feelings towards a vignette depicting aggression, than family carers will be at describing the causes of nurse feelings towards the vignette (The Empathy Exercise)."
2. Method

This section of the report will describe the design of the study, detailing information about the sample, data collection methods, and the rationale for the choice of measures used.

2.1. Design

The present study used a quantitative, between-subjects methodology to explore the experiences of caring for someone with Alzheimer's disease and the impact of aggression directed towards the carer. Two care-giving groups were used to contrast and compare this care, one included a representative sample of carers who are looking after a family member at home and the other included a representative sample of nurse carers who perform care-giving duties as part of their occupation. The design of the present study is shown in diagrammatical form in Figure 6, below.

Due to the reported time and life-style pressures placed on each carer group by either the person (or people) they are caring for or their caring role responsibilities, data collection needed to be flexible and work around these needs. Participants were able to choose from either a postal questionnaire or a research interview, depending upon their time and circumstances. It was hoped that by recognising the differing needs of each sample, response rates would be improved.
2.2. Participants

There were two different types of participant in this study, family and nurse, both of which were chosen specifically to reflect the care-giving experiences of someone with Alzheimer’s disease. The inclusion criteria for family carers required them to have been providing at least six months of unpaid (informal) caring to a relative with a formal diagnosis of Dementia of the Alzheimer’s Type, as outlined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000). The inclusion criteria for nurse carers required them similarly to have been providing (formal) care as part of their occupation for at least six months, for clients with a diagnosis of Alzheimer’s disease. Unfortunately, due to time and financial constraints, the questionnaires could only be offered to participants in the English Language.
A power analysis was performed in advance of the study commencing to establish a sample size necessary to satisfy a specified level of power. This analysis revealed that a sample size of 50 participants in each group would satisfy the recommended power of 80 percent (using the power tables in Clark-Carter, 2004), when applied to either a within-subjects (i.e. a one-tailed Pearson's Product Moment Correlation Co-efficient) or a between-subjects (i.e. df = 1, F-ratio in Analysis of Variance) analysis of the data. These predictions were based on a medium effect size ($n^2 = 0.5$) that has been found previously in dementia care-giving research, which have utilised a range of standardised outcome measures (Brodaty, Green & Koschera, 2003).

2.3. Research Procedure

2.3.1. Ethical approval

This study was approved by the local research ethics committee (Appendix A), and then guided by the NHS Trust’s research and development officer.

2.3.2. Data Collection

Two samples, related by an experience of caring for someone with Alzheimer’s Disease, were recruited from the same geographical area. A diagrammatical representation of the recruitment method and data collection process can be seen in Figure 7 below.

For family carers, each were given a copy of the Family Participant Information Leaflet (See Appendix B) and asked to sign a Consent Form (See Appendix D). Each carer was then contacted by telephone to confirm whether they would still like a questionnaire sent to them and whether they would require some assistance with completion. A reminder letter
(See Appendix E) was sent with a Family Questionnaire Booklet (See Appendix F) to each family carer, along with a pre-paid envelope.

Figure 7. Recruitment Method and Data Collection Flow Chart

For nurse carers, identified staff members were asked if they would be interested in taking part and if they agreed they was given the Nursing Participant Information Leaflet (Appendix C), the Nursing Questionnaire Booklet (See Appendix F), and signed a consent
form (Appendix D). Assistance was available to any staff that requested it. All questionnaire booklets were returned and kept in a confidential manner before being collected by the researcher.

In total, 27 family carers (34%) and 30 nurse carers (35%), completed and returned the questionnaire booklets. It is important to note that 13 of the family carers (48%) asked for additional assistance and this was provided through a home visit. In terms of the planned statistical power of the findings, although these sample numbers were below what was previously expected, a satisfactory level of power could still be obtained if the results indicated a large effect size.

2.4. Measures

All measures were presented within two separate questionnaire booklets, one for family carer participants, and one for nursing carer participants, and both reminded all participants (on the front cover) to complete the booklet in the order presented.

2.4.1. Questionnaire Booklet Development

The development of both questionnaire booklets was completed with the input of both community psychiatric nurses and a family carer with an experience of caring for someone with Alzheimer’s disease. Following some minor revisions, the questionnaire booklets (version 4) were submitted and approved by the ethics committee, and it was estimated that a questionnaire booklet would take 20 to 30 minutes to complete.
The contents of each questionnaire booklet and the order presented is shown in Table 1. below.

Table 1. Summary of Family and Nursing Questionnaire Booklet Measures.

<table>
<thead>
<tr>
<th>Questionnaire Booklet Component</th>
<th>No of Items (No of subscales)</th>
<th>Appendix Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic Information: Family or Nurse</td>
<td>9</td>
<td>F (Page 126/127)</td>
</tr>
<tr>
<td>Hospital Anxiety &amp; Depression Scale</td>
<td>14 (2)</td>
<td>F (Page 128-129)</td>
</tr>
<tr>
<td>Satisfaction Survey*</td>
<td>5</td>
<td>F (Page 130)</td>
</tr>
<tr>
<td>Brief COPE Questionnaire</td>
<td>28 (14)</td>
<td>F (Page 131-132)</td>
</tr>
<tr>
<td>Vignette (Read only)</td>
<td>-</td>
<td>F (Page 133)</td>
</tr>
<tr>
<td>Causal Dimensions Scale – View of Self</td>
<td>12+1 (5)</td>
<td>F (Page 134-135)</td>
</tr>
<tr>
<td>Causal Dimensions Scale – View of Other*</td>
<td>12+1 (5)</td>
<td>F (Page 136-137)</td>
</tr>
</tbody>
</table>

* Questions asked for responses relating to the opposite carer group

All questionnaire booklets were typed using a Times New Roman font of at least size 12, to ensure clarity and good readability, as many family carers would be elderly and be more likely to have visual impairments. All questionnaire booklets were professionally assembled by AVS Printing Services at the University of Leicester.

2.4.2. Demographic Information

Each questionnaire booklet began with a series of demographic questions designed to collect information regarding the participant’s gender, age, length of care-giving, and the amount of support they receive (see Appendix F, Pages 126 and 127). For family carers the demographic information also included their relationship to the person with Alzheimer’s disease, and also any health problems from which they were suffering. For staff carers the demographic information included their job description and any formal qualifications they held.
2.4.3. Measure of Psychological Morbidity

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS was used to record the present state of anxiety and depression for each participant (see pages 128 and 129 of Appendix F). It was originally developed for use within medical outpatient settings and its items were chosen to distinguish the effects of physical illness from mood disorders. Therefore scores on the HADS are not considered to be influenced by physiological symptomatology, which is particularly important in the present study as many of the participants (especially family carers) were likely to have additional health problems as a result of aging. The HADS was also chosen because it is quick and easy to complete, and has been well validated within the literature (Hermann, 1997; Bjelland, Dahl, & Haug, 2002).

The HADS consists of 14 items and its use as a brief screening tool has been found to make it generally well accepted by both patients and non-patients, with high levels of response rates in a variety of settings (Hermann, 1997). The HADS measure has been found to possess a good level of internal consistency (Anxiety = 0.83, Depression = 0.82; Bjelland et al., 2002), face and construct validity (Zigmond & Snaith, 1983), and be a reliable measure of psychological morbidity in family carers of people with dementia (Richards, Moniz-Cook, Duggan, Carr, & Wang, 2003).

The Anxiety and Depression subscales of the HADS consist of seven items, each of which is rated on a 4-point Likert scale, scored 0 to 3, with higher scores reflecting greater levels of anxiety and depression. Each subscale is totalled out of 21, with a score of 11 or more on either subscale (Anxiety or Depression) suggesting a positive caseness with respect to that condition, and a score of 8 – 10 on either scale being borderline. Recent research has
suggested that a cut-off score of 8 is required (Bjelland et al., 2002) in order to gain a greater balance of sensitivity and specificity for caseness of each condition. This was utilised in the present study.

2.4.4. Satisfaction Survey

Running parallel alongside the key research questions posed by this study, information was also sought regarding each participant’s generic opinions of the opposite carer group, to obtain a brief but important glimpse at what some of their underlying beliefs may be. For example a family carer was asked about their opinions of nursing staff whose role it is to care for those with Alzheimer’s Disease, and vice versa for nursing carers (see page 130 of Appendix F). Using ten-point scales (higher scores reflecting a more positive rating), each participant gave opinions on the other carer groups’ ability to be carer, ability to cope with aggression, overall level of coping, understanding of the needs for their own carer group, and how they would feel if being cared for by the other type of carer. The purpose of the five-item opinion questions was to provide a brief insight into the beliefs and assumptions that each carer group held for each other.

2.4.5. Measure of Coping

Coping Orientation to Problems Experienced inventory (COPE-Brief Version; Carver, 1997).

The Brief Cope inventory (Carver, 1997) was used for the present study (See pages 131 and 132 of Appendix F). This is a modified and shortened version of the original COPE questionnaire (Carver et al., 1989).
After acknowledging that the full COPE (60 item) inventory contained items of considerable redundancy and could test some participants’ patience with its length, the scale was reduced from 4 items per scale, to 3 (Carver, 1993), then to 2 in the form of the Brief COPE instrument (Carver, 1997). The use of this form has yet to be validated with Alzheimer’s disease care-givers however there is some evidence of its usefulness when researching carers of other conditions such as AIDS (Vosvick, 2003). The internal reliability data was shown to vary considerably across the subscales, from 0.50 to 0.90 (Carver, 1997), which has led to some criticisms over the usefulness of some of the scales (Parker & Endler, 1992). However there is a relatively stable test-retest reliability of the scales and considerable evidence of construct validity (Carver et al., 1989).

The Brief COPE omits two scales from the full measure (restraint coping and suppression of competing activities), refocuses three other scales, and adds a new scale (self-blame), totalling fourteen scales using 28 items. To aid interpretation and reduce the number of scales, they can be classified into problem-focused, emotion-focused, and dysfunctional coping style categories (Carver et al., 1989); see Figure 8 below.

In the present study the Brief COPE was presented over two booklet pages and participants were asked to rate items in terms of how they are coping with the experience of caring for someone with Alzheimer’s disease. For each item the participant rated each coping strategy on a four-point scale ranging from “I haven’t been doing this at all” to “I have been doing this a lot”, scoring from one to four respectively.
Figure 8. Main Scales and Alternative Factor Scales for the Brief COPE.

<table>
<thead>
<tr>
<th>Brief COPE Scales</th>
<th>Original COPE: Coping Styles</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Carver, 1997)</td>
<td>(Carver et al., 1989)</td>
</tr>
</tbody>
</table>

- Active Coping
- Planning
- Using Instrumental Support
- Acceptance
- Using Emotional Support
- Religion
- Positive Reframing
- Humour
- Denial
- Venting
- Self-Distraction
- Self-Blame
- Behavioural Disengagement
- Substance Use
- Problem-Focused Coping
- Emotion-Focused Coping
- Dysfunctional Coping

2.4.6. Measure of Causal Attributions

Causal Dimensions Scale (2nd Revision; CDS-II; McAuley, Duncan, & Russell, 1992)

The original Causal Dimensions Scale (CDS) was developed by Russell (1982) to solve the "fundamental attributional researcher bias" which is found when researchers fail to adequately translate open-ended reports from participants into causal dimensions. The Causal Dimensions Scale eliminates this problem as participants perform their own coding using nine-point rating scales for questions relating to the attributional dimensions of Locus of Causality, Stability, and Controllability (Weiner, 1974). Subsequent research found that the CDS had a good predictive validity (Russell & McAuley, 1986).
Following criticisms regarding low internal consistency for the Controllability scale and its discriminant validity with the other measures (Russell et al., 1987), a revised version of the scale (CDS-II) was developed (McAuley et al., 1992). The scale asks participants to rate themselves on 12 items, which correspond to four Causal Dimensions. Good internal consistencies were found for the Locus of Causality (0.67), Stability (0.67), Personal Control (0.79), and the External Control (0.82) dimensions (McAuley et al., 1992). A confirmatory factor analysis indicated that the hypothesized four-factor model provided an excellent fit to the data, $X^2 (48, N = 380) = 96.85$, $p < .001$, (McAuley et al., 1992).

In the present study participants were firstly asked to read a vignette (See page 133 of Appendix F), based on a hypothetical situation developed using a combination of clinical experience and DSM-IV-TR (American Psychiatric Association, 2000) criteria for Dementia of the Alzheimer’s Type (DSM Code = 290.0). The vignette’s intention was to direct each participant’s thinking towards the issue of aggression in the care-giving role, and each participant was asked to provide their initial feelings on how such a situation relates to their own experiences. Following this each participant was asked to rate their feelings on the 12 CDS-II items (See pages 134-135 of Appendix F), each of which requires a response along a nine-point Likert-type scale, e.g. item number 1:

1) Do these types of feelings reflect:

<table>
<thead>
<tr>
<th>9</th>
<th>8</th>
<th>7</th>
<th>6</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Something about you</td>
<td>Something about the situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Each participant was then asked to put themselves into the position of the other type of carer, i.e. a family carer is asked about their “beliefs and experiences of how a member of nursing staff might see it”, and vice versa. After providing a brief comment on this they were asked to complete the CDS scale again (Appendix F, page 136-137), then make a judgement on how well they feel the other type of carer would cope in this situation.
3. Results

3.1. Data Analysis

All of the data collected from this study were analysed using the Statistical Package for the Social Sciences (SPSS), version 12.0.1.

3.1.1. Data Screening

Firstly the data was screened in order to aid the selection of appropriate statistical tests for the analysis. Data was checked for its ability to satisfy the three main assumptions of parametric testing, namely homogenous groups, normal distribution, and of interval / ratio measurement (Clark-Carter, 2004).

All measures that were completed by the participants were checked by visual inspection, and statistically for skewness, kurtosis, and normality (using the Kolmogorov-Smirnov test). The only measure that failed to show a normal distribution was the Dysfunctional Scale on the Brief COPE questionnaire. The data here was found to be positively skewed and of a high (leptokurtic) kurtosis, so a square-root transformation was performed on this scale to satisfy the use of parametric analysis on all data collected from the measures. Transforming a data set has been reported to be a more viable option than using non-parametric analysis (Rasmussen & Dunlap, 1991).

A significance (or 'alpha') level of 0.05, was utilised throughout, as is conventional with most social science research (Coolican, 2004). The only exception to this was for research
questions that used multiple comparisons, in which a more stringent level of 0.01 was utilised, to control for the risks of Type 1 errors (Pallant, 2005).

3.1.2. Reliability of the Data

The internal consistency (Cronbach’s alpha) was calculated across both samples to obtain the internal reliability of each measure used, and the results of this can be seen in Table 2 below.

Table 2. Cronbach’s alpha results for all measures.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS</td>
<td></td>
</tr>
<tr>
<td>Anxiety:</td>
<td>0.810</td>
</tr>
<tr>
<td>Depression:</td>
<td>0.843</td>
</tr>
<tr>
<td>Brief COPE</td>
<td></td>
</tr>
<tr>
<td>Problem-Focused Coping:</td>
<td>0.725</td>
</tr>
<tr>
<td>Emotion-Focused Coping:</td>
<td>0.714</td>
</tr>
<tr>
<td>Dysfunctional Coping:</td>
<td>0.726</td>
</tr>
<tr>
<td>CDS-II</td>
<td></td>
</tr>
<tr>
<td>Locus of Causality:</td>
<td>0.543</td>
</tr>
<tr>
<td>External Control:</td>
<td>0.536</td>
</tr>
<tr>
<td>Stability:</td>
<td>0.567</td>
</tr>
<tr>
<td>Personal Control:</td>
<td>0.831</td>
</tr>
</tbody>
</table>

The reliability analysis shows that both the HADS and the Brief COPE measures have an adequate level of internal consistency, with levels that are above the recommended
minimum of 0.7 (Clark-Carter, 2004). It should be noted that some of the individual subscales, used to make up the three Brief COPE measures used in the analysis phase, failed to reach the recommended level. (See Appendix G for subscale reliability scores). Also three of the four CDS-II measures were also below the 0.7 level, as was similarly found in the original CDS-II study (McAuley et al., 1992), possibly reflecting a general deficiency of the measure itself.

3.2. Research Findings

3.2.1. Descriptive Data

Of the 57 participants that took part, 27 were family carers and 30 were nursing staff carers. Table 3 shows some of the demographic details for both the family and nursing carers, with appropriate non-parametric analysis (as the variables were not normally distributed).

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Family Carer (N = 27)</th>
<th>Nurse Carer (N = 30)</th>
<th>X²</th>
<th>U</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>72.41 (1.7)</td>
<td>38.37 (2.32)</td>
<td>-6.21</td>
<td>&lt;0.01</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Male: 11 (40.7%)</td>
<td>3 (10%)</td>
<td>5.68*</td>
<td>0.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female: 16 (59.3%)</td>
<td>27 (90%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in caring role</td>
<td>3.63 (0.37)</td>
<td>6.27 (0.99)</td>
<td>-1.59</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Own Health Problems</td>
<td>Yes: 10 (37%)</td>
<td>2 (6.7%)</td>
<td>6.17*</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No: 17 (63%)</td>
<td>28 (93.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Yates correction for continuity; Bold denotes significance at 0.05 level

It is not surprising that the family carers tended to be older and therefore have greater health problems themselves, particularly as the majority of these carers (93%) were the spouse of the person with Alzheimer’s disease. More importantly, there was no significant
difference in length of caring role, indicating the two sample groups were similar in the amount of time that they had been in their care-giving role.

In terms of aggression in the care-giving relationship, the majority of carers in both groups reported that they had experienced an aggressive outburst towards them between one and five times that month, as can be seen in Figure 9 below.

**Figure 9.** Number of aggressive incidents reported by both carer groups.

In addition to the demographic information, each participant provided an important glimpse at what some of their underlying beliefs may be for the opposite carer group. Five questions on a ten-point scale were posed using the satisfaction survey page of the questionnaire booklet (see appendix F). In each case, higher scores indicated a more positive rating. The results from this are shown in Table 4, below.
Table 4. Satisfaction Survey results.

<table>
<thead>
<tr>
<th>Satisfaction Question</th>
<th>Mean Score (SD)</th>
<th></th>
<th>U</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family's view of nurse carers</td>
<td>Nurse's view of family carers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. How good would you rate their ability to be a carer?</td>
<td>8.00 (1.70)</td>
<td>6.67 (1.97)</td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>2. How well would you rate their ability to deal with aggressive outbursts?</td>
<td>7.27 (2.34)</td>
<td>5.37 (2.50)</td>
<td></td>
<td>0.006</td>
</tr>
<tr>
<td>3. How well do you think overall, they would cope with caring?</td>
<td>8.23 (1.82)</td>
<td>6.13 (2.35)</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>4. What sort of understanding would they have for the needs of families / nurses?</td>
<td>7.85 (2.11)</td>
<td>5.67 (3.16)</td>
<td></td>
<td>0.02</td>
</tr>
<tr>
<td>5. If you yourself had a care-giving need, how satisfied would you be for being cared for by a family member / nurse?</td>
<td>7.35 (2.37)</td>
<td>6.33 (3.26)</td>
<td>-0.99</td>
<td>0.32</td>
</tr>
</tbody>
</table>

Bold denotes significance at 0.05 level

Although all of the mean scores were within the more positive half of the ten-point scale, nurses significantly rated family carers more negatively than vice versa. Nurses’ opinions of family carers were significantly more negative for a family carer’s ability to be a carer, ability to cope with aggressive outbursts, overall coping, and understanding of the needs of nurses.
3.3. Addressing Research Questions

3.3.1. Research Question 1: What relationships exist between psychological morbidity, coping styles, and causal attributions for the Alzheimer’s care-giving experience?

Prior to exploring the differences between the family and nursing carer samples, each was analysed separately to discover the relationships between their levels of psychological morbidity, coping style, and causal attribution dimensions. Taking into account existing research and the attributional dimensions proposed by Weiner (1974), the following hypotheses were investigated:

a) Greater levels of psychological morbidity (i.e. Anxiety and Depression) will be significantly and positively correlated with each other and dysfunctional coping styles, in all carers.

b) Greater levels of psychological morbidity will be significantly and positively correlated with lower ‘Personal Control’, ‘External Control’ and ‘Stability’ causal dimensions when carers think about the causes of an aggressive care-giving experience.

The relationship between the responses on the HADS, the Brief COPE, and the CDS-II, were analysed using a Pearson product-moment correlation and the results are shown below for the family (Table 5) and nurse carers (Table 6).
Table 5. Correlation Analysis of Family Carer Variables

<table>
<thead>
<tr>
<th></th>
<th>HADS Anx</th>
<th>HADS Dep</th>
<th>COPE Prob.</th>
<th>COPE Emot.</th>
<th>COPE Dysfun.</th>
<th>CDS Cause</th>
<th>CDS Ext.</th>
<th>CDS Stab.</th>
<th>CDS Person</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS Anxiety</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS Depression</td>
<td>0.62**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPE Problem</td>
<td>0.13</td>
<td>0.09</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPE Emotion</td>
<td>-0.25</td>
<td>-0.37</td>
<td>0.29</td>
<td>-0.29</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPE Dysfunction</td>
<td>0.38*</td>
<td>0.36</td>
<td>0.08</td>
<td>-0.29</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS-II Causality</td>
<td>-0.09</td>
<td>-0.28</td>
<td>0.26</td>
<td>-0.04</td>
<td>-0.04</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS-II Ext. Control</td>
<td>0.16</td>
<td>-0.05</td>
<td>-0.13</td>
<td>-0.04</td>
<td>-0.03</td>
<td>0.43*</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS-II Stability</td>
<td>-0.09</td>
<td>-0.09</td>
<td>0.41*</td>
<td>0.05</td>
<td>-0.12</td>
<td>0.05</td>
<td>-0.35</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>CDS-II Per Control</td>
<td>0.04</td>
<td>-0.07</td>
<td>0.29</td>
<td>-0.08</td>
<td>-0.13</td>
<td>0.44*</td>
<td>0.11</td>
<td>0.19</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p<0.05; ** p<0.01

In examining the relationships between all of the measures completed by the family carers, a significant positive correlation was found between a carer's anxiety and depression levels (r= 0.62, n=27, p=0.001). This result demonstrates a strong correlation (r>0.5, Cohen, 1988) and indicates that anxiety level helps to explain 39 percent of the variance in a family carer's depression level, and similarly in the other direction. Anxiety (p<0.05) and depression (p<0.10) levels both showed a moderate strength (r = 0.3 to 0.5) of positive correlation with dysfunctional coping scores. Together these results support the hypothesis for a significant association in family carers between anxiety, depression, and a dysfunctional coping style.

No support was found for the hypothesis suggesting a relationship for family carers between psychological morbidity and attribution dimensions. The results did show some other significant positive associations between Locus of Causality attributions and both External and Personal Control attributions.
The results from the nursing carer analysis showed further support for the hypothesis suggesting a relationship between anxiety, depression and dysfunctional coping style. Scores revealed significant positive correlations between anxiety and depression levels ($r=0.75$, $p<0.01$), helping to explain over 55 percent of the variance in each measure, and significant associations between dysfunctional coping style and levels of both anxiety ($r=0.65$, $p<0.01$) and depression ($r=0.67$, $p<0.01$). Together the findings also support the association triad between anxiety, depression, dysfunctional coping in nurse carers.

No support was found for the hypothesis suggesting a relationship between psychological morbidity and attribution dimensions in nurse carers, however significant associations were found between Locus of Causality and both External Control and Stability attributions.
3.3.2. Research Question 2: Do the levels of psychological morbidity (as indicated by measures of anxiety and depression) and coping styles differ between family and nursing carers of people with Alzheimer's disease?

Taking into account the existing research into psychological morbidity and coping styles in family and nurse carers, the following hypotheses were investigated:

a) *Psychological morbidity levels in form of anxiety and depression will both be greater for those who provide family care for someone with Alzheimer's disease, compared to nursing care-givers.*

b) *Family carers will report greater levels of emotion-focused and dysfunctional coping, and lower levels of problem-focused coping, compared to nursing care-givers.*

A (between-subjects) t-test was used to compare the results from the family and nurse carers. Each carer groups' mean score and statistical analysis for psychological morbidity are shown in Table 7 below.

**Table 7. Group comparison of psychological morbidity.**

<table>
<thead>
<tr>
<th>Carer Group</th>
<th>Family Mean (SD)</th>
<th>Nursing Mean (SD)</th>
<th>T</th>
<th>P</th>
<th>Eta Squared (Effect)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS - Anxiety</td>
<td>8.41 (4.09)</td>
<td>5.67 (3.24)</td>
<td>2.82</td>
<td>0.01*</td>
<td>0.13</td>
</tr>
<tr>
<td>HADS - Depression</td>
<td>6.33 (3.83)</td>
<td>2.83 (3.09)</td>
<td>3.81</td>
<td>&lt;0.01*</td>
<td>0.21</td>
</tr>
</tbody>
</table>

(* significant at p<0.01)

The t-test analyses found that family carers reported significantly greater levels of anxiety and depression when compared to nurse carers, which supports the hypothesis. The
magnitude of the differences in the means was of a medium effect size for anxiety and a large effect size for depression. Despite the strong significance (p<0.01) the power of the anxiety result (calculated using tables in Clark-Carter, 2004) may need a bigger sample for clarification.

In terms of clinical caseness for anxiety, 56 percent of family carers results were above the cut-off score of 8 (as recommended by Bjelland et al., 2002), compared to 20 percent of nursing carers. For depression, 30 percent of family carers scored above the cut-off criteria compared to 7 percent of nursing carers. In total 63 percent of all family carers revealed a psychological morbidity problem, compared to 20 percent of nurse carers.

A further t-test was used to compare the scores of family and nurse carers for their styles of coping, and the results can be seen in Table 8 below.

**Table 8. Group comparison of coping styles.**

<table>
<thead>
<tr>
<th>Brief COPE Variable</th>
<th>Carer Group</th>
<th>t</th>
<th>P</th>
<th>Eta Squared (Effect)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family Mean (SD)</td>
<td>Nursing Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>3.41 (1.82)</td>
<td>3.70 (1.84)</td>
<td>-0.60</td>
<td>0.55</td>
</tr>
<tr>
<td>Planning</td>
<td>3.04 (1.81)</td>
<td>3.27 (1.89)</td>
<td>-0.47</td>
<td>0.64</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>3.59 (1.76)</td>
<td>3.50 (2.05)</td>
<td>0.18</td>
<td>0.86</td>
</tr>
<tr>
<td>Acceptance</td>
<td>5.56 (1.09)</td>
<td>3.27 (2.02)</td>
<td>5.25</td>
<td>&lt;0.01* 0.33</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>3.59 (2.06)</td>
<td>3.50 (1.76)</td>
<td>0.18</td>
<td>0.86</td>
</tr>
<tr>
<td>Religion</td>
<td>1.56 (2.24)</td>
<td>1.80 (1.97)</td>
<td>-0.44</td>
<td>0.66</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>2.15 (2.13)</td>
<td>3.40 (1.57)</td>
<td>-2.55</td>
<td>0.01* 0.11</td>
</tr>
<tr>
<td>Humour</td>
<td>1.30 (1.99)</td>
<td>2.77 (1.94)</td>
<td>-2.82</td>
<td>0.01* 0.14</td>
</tr>
<tr>
<td>Denial</td>
<td>1.15 (1.35)</td>
<td>0.63 (1.22)</td>
<td>1.51</td>
<td>0.14</td>
</tr>
<tr>
<td>Ventiing</td>
<td>1.81 (1.15)</td>
<td>1.60 (1.65)</td>
<td>0.56</td>
<td>0.58</td>
</tr>
<tr>
<td>Self- Distraction</td>
<td>3.11 (1.89)</td>
<td>2.50 (1.79)</td>
<td>1.25</td>
<td>0.22</td>
</tr>
<tr>
<td>Self- Blame</td>
<td>1.89 (1.65)</td>
<td>1.90 (1.49)</td>
<td>-0.03</td>
<td>0.98</td>
</tr>
<tr>
<td>Behavioural Disturbance</td>
<td>0.33 (0.73)</td>
<td>0.67 (1.29)</td>
<td>-1.18</td>
<td>0.24</td>
</tr>
<tr>
<td>Substance Use</td>
<td>0.63 (1.36)</td>
<td>0.47 (1.07)</td>
<td>0.50</td>
<td>0.62</td>
</tr>
<tr>
<td>Problem-Focused</td>
<td>10.04 (4.27)</td>
<td>10.47 (4.22)</td>
<td>-0.38</td>
<td>0.70</td>
</tr>
<tr>
<td>Emotion-Focused</td>
<td>14.15 (5.99)</td>
<td>14.73 (5.59)</td>
<td>-0.38</td>
<td>0.70</td>
</tr>
<tr>
<td>Dysfunctional</td>
<td>8.93 (3.81)</td>
<td>7.77 (6.05)</td>
<td>0.85</td>
<td>0.39</td>
</tr>
</tbody>
</table>

(* significant at p<0.01)
The results showed no support for the hypothesis that the two carer groups will differ significantly in either the emotion-focused, problem-focused, or dysfunctional coping style categories. However there were some significant differences found within the emotion-focused variable at the subscale level. These results reveal that family carers were significantly more likely to use ‘Acceptance’ (with a large effect size), whereas nurse carers were significantly more likely to use ‘Humour’ (large effect size) and ‘Positive Reframing’ (medium effect size). The internal reliabilities for these subscales were all above 0.8, as can be seen in Appendix G.

3.3.3. Research Question 3: When relating to an aggressive care-giving experience, are there any differences between each group of carers’ causal attributions, and can they relate to how the other carer group might perceive the causes of their feelings if put in the same situation?

Family carers were previously hypothesised to have greater psychological morbidity compared to nurses, and greater psychological morbidity appears related to lower ‘Control’ and ‘Stability’ attributions. It was also felt that as nurse carers are likely to have greater contact with other family carers than vice-a-versa, they will be better at empathising situations from a family carer’s perspective. This investigatory angle to Alzheimer’s disease care-giving was explored utilising the following hypotheses:
a) Family carers will rate themselves lower on the ‘Locus of Causality’, ‘Personal Control’, ‘External Control’, and ‘Stability’ causal dimensions in comparison to the nurse carer group, when asked to describe the causes of their feelings for a care-giving experience involving aggression from the care-recipient.

b) Nurse carers will be better at describing the causes of family feelings towards a vignette depicting aggression, than family carers will be at describing the causes of nurse feelings towards the vignette (The Empathy Exercise).

Prior to providing ratings regarding their attributions, each participant was asked to briefly describe in one word or sentence their initial feelings concerning aggression. This not only continued to focus the participant on the research topic and direct them towards their own experiences, but provided an important qualitative perspective on their feelings about themselves and later their feelings for the other carer group. These recordings were not be statistically analysed, however the responses can be found in Appendix H. In summary, family carers described their own feelings as angry / frustrated (26%) and sad / low (19%), whilst describing nurse feelings as reflecting the fact that they should be trained to cope (33%). Nurse carers described their own feelings as blaming the disease (23%) and feeling frightened (20%), whilst describing family feelings as frightened (20%) and upset (13%).

Following the satisfaction of additional tests for multivariate normality (i.e. Mahalanobis distances), a MANOVA was used to examine the differences in means between the two carer groups’ scores on each attribution dimension for the aggression situation, and the results are shown in Table 9 below.
There was a statistically significant difference between the two carer groups on the combined dependent variables: F(4, 51)=2.45, p=0.05; Wilks’ Lambda= 0.84; partial eta squared= 0.16. When the dependent variables were examined separately, the only difference to reach statistical significance (p<0.01), was External Control: F(1, 54)=6.81, p=0.01, partial eta squared=0.11. The means indicated that family carers reported lower levels of External Control (M=9.61) than nurse carers (M=14.3). This result provides partial support for the hypothesis, however the moderate effect size suggests that further clarification would be needed from a larger sample.

The second part of this research question is reported by presenting the difference between how family carers viewed how a nurse might feel in the aggressive situation compared to actual nurse scores (Table 10). Next, in parallel to this, the results will show the difference between how nurse carers viewed how a family carer might feel in the aggressive situation compared to actual family scores (Table 11).
Table 10. MANOVA for scores from family, and nurses' view of family:

<table>
<thead>
<tr>
<th>Measure</th>
<th>Group</th>
<th>Mean (SD)</th>
<th>Nurse view of Family Mean (SD)</th>
<th>F</th>
<th>P</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDS - L of Causality</td>
<td>Family</td>
<td>13.85 (5.34)</td>
<td>16.57 (6.17)</td>
<td>3.06</td>
<td>0.09</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Family Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - Personal Control</td>
<td>Family</td>
<td>19.39 (6.15)</td>
<td>14.83 (5.86)</td>
<td>8.03</td>
<td>0.01*</td>
<td>0.13</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Family Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - Stability</td>
<td>Family</td>
<td>13.58 (5.62)</td>
<td>13.63 (5.09)</td>
<td>0.00</td>
<td>0.97</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Family Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - External Control</td>
<td>Family</td>
<td>9.62 (6.19)</td>
<td>15.83 (5.47)</td>
<td>15.92</td>
<td>&lt;0.01*</td>
<td>0.23</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Family Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(df = 1; * denotes significance at 0.01 level)

Table 11. MANOVA for scores from nurses, and family view of nurses':

<table>
<thead>
<tr>
<th>Measure</th>
<th>Group</th>
<th>Mean (SD)</th>
<th>Family view of Nurse Mean (SD)</th>
<th>-F</th>
<th>P</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDS - L of Causality</td>
<td>Family</td>
<td>15.13 (6.09)</td>
<td>12.90 (5.51)</td>
<td>1.95</td>
<td>0.17</td>
<td>0.04</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Nurse Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - Personal Control</td>
<td>Family</td>
<td>20.48 (4.59)</td>
<td>20.23 (5.35)</td>
<td>0.03</td>
<td>0.86</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Nurse Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - Stability</td>
<td>Family</td>
<td>13.57 (7.76)</td>
<td>12.33 (7.22)</td>
<td>0.36</td>
<td>0.55</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Nurse Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDS - External Control</td>
<td>Family</td>
<td>13.22 (7.29)</td>
<td>14.30 (7.11)</td>
<td>0.29</td>
<td>0.589</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>Nurse view of Nurse Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(df = 1; * denotes significance at 0.01 level)

These results fail to support the hypothesis, but provide support for the alternative hypothesis that family carers are significantly better at this task of empathy. Nurses were found to be poorer at this task, with a statistically significant difference on the combined dependent variables: F(4, 51)=6.88, p=<0.01; Wilks' Lambda= 0.65; partial eta squared=0.35. More specifically they demonstrated (significantly) poorer empathy for attributions involving Personal Control: F(1, 54)=8.03, p=0.01, partial eta squared=0.13; and External Control: F(1, 54)=15.92, p=<0.01, partial eta squared=0.23. The families showed a good ability at this task, with no statistically significant difference on the combined dependent variables: F(4, 48)=0.61, p=0.66; Wilks' Lambda=0.95; partial eta squared=0.05.
4. Discussion

Initially the results will be presented and discussed in relation to the hypotheses that were generated from the research questions described in the introduction. The findings will be examined for their relevance to clinical work, and an appraisal of the methodology will address some of strengths and weaknesses of this study. Finally, the ideas and findings from this study will be discussed in terms of their implications for new avenues of research and future work into Alzheimer's disease care-giving.

4.1. Hypotheses

4.1.1. Hypothesis 1a

*Greater levels of psychological morbidity (i.e. anxiety and depression) will be significantly and positively correlated with each other and dysfunctional coping styles, in all carers.*

Based on previous research that has shown associations between these variables (Garand et al., 2005), the findings of the present study support the hypothesis in that significant (moderate to strong strength) positive associations exist between anxiety, depression, and dysfunctional coping style, for both sets of carers.

In terms of coping styles, dysfunctional coping was found to be positively correlated (p<0.05; of at least a moderate strength), with both anxiety and depression within both carer groups. The weaker results found amongst the family carer results may have been affected by a social desirability bias due to many (48%) of the results being collected through interview, compared to the nursing sample which were all self-completion.
It is also likely that, although this study provides support for the associations between anxiety, depression, and dysfunctional coping, these may interact differently between the two types of carers. For instance, psychological morbidity may start off low in family carers and gradually increase as the caring role (and the disease) progresses, whereas nurse carers may find this high at first, but continually reducing with further training, knowledge and experience. As this study was not longitudinal in nature, the effects of role length could not be examined.

4.1.2. Hypothesis 1b

Greater levels of psychological morbidity will be significantly and positively correlated with lower ‘Personal Control’, ‘External Control’ and ‘Stability’ causal dimensions when carers think about the causes of an aggressive care-giving experience.

Despite existing research suggesting that poorer outcomes are associated with lower control (Stanley & Standen, 2000) and stability (Sharrock et al., 1990) attributions, the findings from this study failed to provide any further support for this hypothesis. Self-reported anxiety and depression (as measured by the HADS) was not correlated with any of the causal attribution dimensions, for either carer group.

It is possible that the internal consistency of the Causal Dimensions Scale (Revised) may have had an effect on the reliability of this data. Internal reliability levels were below the recommended minimum standard (Clark-Carter, 2004), which may reflect a weakness in either the way that the questions were presented or of the questionnaire itself. It should be noted however that the authors of the questionnaire found similar low internal
consistencies (McAuley et al., 1992), suggesting that the measure itself may need further validation to justify its future use.

4.1.3. Hypothesis 2a

*Psychological morbidity levels in the form of anxiety and depression will be greater for those who provide family care for someone with Alzheimer’s disease, compared to nursing care-givers.*

The findings from the present study support the hypothesis, with family carers’ self-reported psychological morbidity levels significantly greater (p<0.01) than nursing staff reports, for both anxiety and depression.

When these results are placed in the context of clinical caseness, a clearer picture of the meaning behind the findings emerges. Nearly two-thirds (63%) of the family carer sample satisfied the cut-off criteria for a significant psychological disturbance (anxiety and/or depression), compared to 20% of nurse carers.

These findings further confirm existing research that caring for someone with Alzheimer’s disease can have a significant impact on a carer’s mental health, whether they are a family member (Schultz & Williamson, 1991) or nurse carer (Novak & Chappell, 1996). The findings also suggest that family carers are often suffering from either anxiety, depression, or both, so health service guidelines such as the National Framework for Older People (DOH, 2001) need to go further than purely recognising these issues, to formally including carers in any screening or assessment process.
4.1.4. Hypothesis 2b

Family carers will report greater levels of emotion-focused and dysfunctional coping, and lower levels of problem-focused coping, compared to nursing care-givers.

The present study failed to show any significant differences between the family and nurse carers on emotion, problem, or dysfunctional styles of coping. It is likely that both groups of carers over time have each had to deal with many similar cognitive and behavioural symptoms of Alzheimer’s disease, which may respond better to certain styles of coping, regardless of individual preference or knowledge. Overall, all carers appeared to adopt very similar levels of each coping strategy, with the emotion-focused being utilised the most, then problem-focused, and dysfunctional strategies the least.

At a subscale level, some significant differences (p<0.01) were found within the emotion-focused subscale, with family carers significantly more likely to utilise ‘Acceptance’ as a way of coping, whilst nurse carers were significantly more likely to utilise ‘Positive Reframing’ and ‘Humour’. These results may reflect the position within which each carer is performing their role, namely that family carers are often supporting the care-recipient on their own, whilst nurse carers are working within a team environment. This may have important implications for family-nurse relationships, leading to possible conflicts in attitudes towards care provision and differing opinions as to the most appropriate type of care-giving interaction.

4.1.5. Hypothesis 3a

Family carers will rate themselves lower on the ‘Locus of Causality’, ‘Personal Control’, ‘External Control’, and ‘Stability’ causal dimensions in comparison to the nurse carer group, when asked to describe the causes of their feelings for a care-giving experience involving aggression from the care-recipient.
Based on a sparse knowledge of this area within existing literature, the hypothesis was only partially supported, as the only significant difference (p<0.01) highlighted that family carers have a lower level of External Control attributions compared to nurse carers. This could indicate that a family carer is more likely to have feelings (to a situation where aggression is expressed) that they believe are not under the control of others. However, with only a medium effect size found, this result may need further support from a larger sample.

The overall picture of these results may reflect a similarity in the way that the two groups of carers feel about incidents of aggression when caring for someone with Alzheimer’s disease. However the usefulness of these findings is hampered by a poor internal consistency of the attributions measure (CDS-II) and a small sample size.

4.1.6. Hypothesis 3b

*Nurse carers will be better at describing the causes of family feelings towards a vignette depicting aggression, than family carers will be at describing the causes of nurse feelings towards the vignette (The Empathy Exercise).*

In beginning to explore some of the underlying attributions that carers hold about each other, the findings from the present study fail to support the hypothesis, however there is some partial support for the alternative hypothesis that family carers will be better at describing the causes of nurse feelings compared with nurse carers (for this scenario). This alternative hypothesis gains some support from the findings as there were no significant differences between the family carers’ views of nurse responses compared to actual nurse
responses. Nurse carers failed to replicate this empathy exercise for two out of four of the attribution dimensions (Personal and External Control).

The purpose of this research question is to provide further knowledge about the potential relationships between family and nurse carers, and what factors may be working to help or hinder this interaction. The results from the present study suggest that nurses may have some difficulties in empathising with family carers, despite their frequent interactions with the families of the many care-recipients at the care home in which they work. It could be possible that these problems with empathising may be limited to those families of care-recipients with Alzheimer’s disease. However it was not explored because of the constraints of the current study.

4.2. Clinical Implications

4.2.1. Raising Awareness of Family Carer Needs

With Alzheimer’s disease projected to continue increasing over at least the next forty years (Brookmeyer et al., 1998), greater numbers of family members are going to find themselves with care-giving responsibilities. The present study found that increased psychological morbidity can often be a consequence of this role, with elevated levels of anxiety or depression seen in nearly two-thirds of the family sample, replicating the findings within existing literature (Gonzalez-Salvador et al., 1999; Schultz & Williamson, 1991). Recognition of the difficulties that family carers face is now integrated into UK health policies such as the National Service Framework for Older People (DOH, 2001), however the guidelines still revolve around the care-recipient and how the carer can be supported in providing this care. With such high levels of psychological morbidity in
family carers, assessment processes may benefit from regular screening for anxiety and depression in all carers, so that appropriate interventions, support and psycho-education can be provided early on in the care-giving experience.

The findings from the present study also point towards a strong linkage between anxiety, depression and dysfunctional coping, which replicates results from some other recent research (Garande et al., 2005). These strong patterns between different care-giving variables can potentially provide assessors with branches of clinical investigation, when certain symptoms or difficulties are reported by a family member. A risk assessment style of carer profiling could be utilised, by using existing knowledge of carer health problems to make decisions about each individual’s probability of developing physical and mental disorders based on a carer’s reports. In conjunction with this, research into other carer variables, such as gender, age, ethnicity, or economic status, could be utilised to distinguish between which carers may be more prone to certain difficulties, and which are more likely to seek support. Early identification of potential problems may help reduce the overall stresses and strains of the caring role, and further develop the all-encompassing single assessment process (DOH, 2005), which aims to reduce repetitive information gathering and delays in allocating suitable resources.

4.2.2. Relationship between Family and Nurse Carers

Raising awareness of family carer needs may have begun to filter into more recent health related government guidelines, but this may be fruitless if professionals fail to utilise and develop these ideas. One way to identify if this process is functioning effectively, is to explore the relationships between formal and informal carers. The findings of the present study, as has been found previously (Hertzberg et al., 2001), identify that there may be still
be some mismatch within the relationships between groups of carers, in this case when exploring the attributions that each holds for the other. Empathy is a key component within care-giving relationships (Lee et al., 2001), yet the present findings suggest that nurse carers may have some difficulties in seeing situations (such as aggressive incidents) from the family's perspective. This may have important implications for nurse training, possibly suggesting that greater service user input needs to be involved in this process, so a nurse carer's knowledge can embrace a more realistic view of how families perceive events.

Understanding of the dynamic and complex nature of the family-nurse-patient triad is crucial not just for raising awareness of family carer needs, but enhancing nurse training and knowledge, and giving the care-recipient a sense of continuity and compatibility with those people working to support them. Without effective interactions there is evidence that strain and stresses, and distrust of nurse interventions can increase in family carers (Almberg, 2000). Nurses have the opportunity to nurture family carers into empowering and unambiguous roles, potentially fostering more positive (one-way) carer beliefs and cognitions, and opening more channels of (two-way) communication, to ultimately enhance the quality of this (three-way) care environment.

4.2.3. Utilisation of Formal Services

There is evidence to suggest that even when family carers are suffering from their own psychological health problems, such as anxiety and depression, they are often lacking the knowledge to seek out available services (Toseland et al., 2002). They appear unable to access these services (Morgan et al., 2002) or reluctant to use them if they do not match their needs (Pedlar & Biegel (1999). Results, such as those found in the present study, need not be categorised into yet another coping or stress-related analysis of care-giving, but
analysed more intensively for pockets of information that may aid future development and planning of services. For example, regardless of whether certain findings were significant or not, this study and others (Sharrock et al., 1990; Stanley & Standen, 2000) have highlighted the usefulness of applying a Causal Attribution model to the thinking surrounding care-giving. Overall, psychological models and concepts have more to offer this clinical area, and more resources are needed to ensure that knowledge increases, services improve, and ultimately carers and their families receive the best quality of care available.

4.3. Methodological Critique

4.3.1. Design

It was recognised very early on in the planning stages that this study was embarking on a journey that was relatively unexplored in the literature base. Existing studies appeared to deal with this issue by trying to create a conceptual map using a broad based qualitative approach (Paton et al., 2004), enabling researchers to explore larger areas of unknown territory. The use of Causal Attribution theory was still in its infancy, with existing research utilising both quantitative (McGuiness and Dagnan, 2001) and qualitative (Fopma-Loy, 1997) approaches for nurse dementia carers, however its use with family carers was limited to a qualitative approach (Tarrier et al., 2002). With no existing quantitative family carer research to replicate, the design of this study attempted to utilise the methodologies of similar nurse carer studies (e.g. McGuiness & Dagnan, 2001) and apply them to an analysis of both family and nurse samples. It is possible that the overwhelming gap that this study was attempting to fill may have affected the design by attempting to cover too many variables at the same time.
4.3.2. Participants

Due to a limited amount of time and resources, the samples sizes utilised within this study did not reach expected levels. As has been found with existing research, recruiting family carers can prove troublesome (Kelsey et al., 1989), particularly in rural areas (DiBartolo & McCrone, 2003), as was attempted in this study.

Because of these problems in recruiting, the study could not be too specific about how its sample was selected and information gathered. Clearly some boundaries were adhered to in ensuring potential participants met with the selection criteria, to aid comparisons, however sampling was often opportunistic and based more on participant motivation rather than clinical randomness. Also many of the family carers (who often had their own physical and mental issues) requested that their information be collected by interview. It is well recognised that this method of data collection can produce its own biases (Clark-Carter, 2004), however this data was not treated any differently and included as part of the family carers’ sample.

4.3.3. Measures

One of the overall criticisms of the questionnaire booklet was its length and complexity. Prior to distribution, an initial pilot using one family carer resulted in the questionnaire being modified, in order to make it more easily readable and quicker to complete. Most family carers that asked for an interview to be arranged believed that they would be unable to complete the booklet on their own. However, during the interviews every participant completed the whole booklet with relatively little complaint or complications. Further
information as to the positive and negative aspects of the design of the booklet may have been gathered more efficiently and prevented re-designing delays if a more in-depth pilot study had been completed.

It is likely that if the data collection process had been completed through interview only then carers may have been more motivated to provide an increased quantity and quality of information, in what would feel like a more informal discussion of care-giving experiences. With more opportunities to collect further data, information could have been collected about other aspects of carers or even the care-recipients. For example, more information could have been collected on the carer's support networks or personal circumstances, and the care-recipient's cognitive capabilities or activities of daily living (ADL).

In terms of the measures utilised within the present study, all were chosen as the most suitable method for collecting the required information, although each still is subject to criticism. The HADS is well known and well used within health-related research, however there has been some caution raised concerning an overlap between the dimensions of anxiety and depression (Hermann, 1997), and longitudinal research has found that the scales may be sensitive to change in the severity of anxiety and depression (Flint & Rafit, 1996). Despite other available alternative measures of these constructs, such as the General Health Questionnaire (GHQ-12; Goldberg, 1992), the HADS remains the best instrument for the identification of anxiety disorders and depression (Bjelland et al., 2002).

The Brief COPE measure may have problems with its internal consistency (Parker & Endler, 1992), have questionable use in measuring coping in specific conditions as it was broadly designed to be used in any situation, and lack substantial validation within the
literature. Other measures exist, such as the Ways of Coping Questionnaire (Lazarus & Folkman, 1984), or the Multidimensional Coping Inventory (Endler & Parker, 1990), however these tend to take longer to complete with little extra information gathered, compared to the Brief COPE.

The Causal Dimension Scale (Revised) had low internal consistency levels in both the present study and the original paper by McAuley et al. (1992). Another widely used attribution scale exists, the Attributional Style Questionnaire (Peterson et al., 1982), however this measure has been found to have poor internal consistency, test-retest reliability, construct validity, and criterion validity (Kinderman & Bentall, 1996). The CDS-II is also a better match for the attribution theory and causal dimensions proposed by Weiner (1974).

4.4. Theoretical Implications

Research that investigates the experiences encountered by those people caring for a person with Alzheimer's disease, has typically focused on variables that work to help or hinder this caring role. The literature base is flooded with studies that tap into different carer, care-recipient, or environmental factors, which are measured using a variety of different questionnaires or interviews. Each aims to provide support for a hypothesis about one of these factors at a certain point in time for a particular subgroup of people. The ability to compare these results often is dependent upon the study's definition of the terms it uses and subsequent scales employed to measure them. Instead of continuing to spend time and resources on data from which it may be difficult to generalise, researchers are beginning to delve underneath these measures of carer burden, stress, and health, to explore the meanings, beliefs, and cognitions that make up and guide a carer in this role.
This study did not set out to map a carer’s complete attribution network for the care-giving experience, just as many studies of stress do not aim to cover every factor that may affect stress levels, instead the priority was on the recognition of this approach. With so little research into a carer’s attributions, the study’s underlying aim was to highlight attribution theory as a potential way forward in beginning to understand the meanings behind care-giving, and how carers makes sense of this experience. Knowledge into areas such as this provide clinicians and health services with the potential to work in a preventative way, attempting to reduce problems early on, rather than working retrospectively by waiting until a carer reaches a certain cut-off score on a health scale. The implications of this approach may demand more resources in the short-term, but has the potential to reduce the costs to individuals, families, and health services in the long-term.

4.5. Future Research Opportunities

The results from this study were hampered by the small sample size, which reduced the overall power of some of the significant findings. In the cases where a large effect size was not found, the power will have been below the recommended level, which suggests the findings may need clarification from a larger sample.

The present study utilised an under-researched but potentially useful model of attribution theory, however the scope of this analysis had to be narrow (i.e. focusing on care-recipient aggression towards carers) to match the resources and time available. There are clearly many other areas of the care-giving experience that still needs exploring, not just centring around the family carer, but encompassing an understanding of the perspectives from all members included in this care. Further research may also need to compare existing attribution studies in terms of terminology, design, and methodology, to re-examine some
of the (now 30 year old) core components, to provide a clear way forward for those researchers wanting to utilise this approach.

Another important area for future research is the exploration of the relationships between formal and informal care (such as the family-nurse comparison used here), particularly as projected increases in Alzheimer’s disease are likely to result in more families requiring the use of nursing and respite care. Research needs to continue to find evidence that can support all members involved in a care-providing environment; to improve the knowledge of pre-relationship assumptions and beliefs that can hamper initial interactions; to increase the availability and accessibility of knowledge that can promote communication; and to find ways of encouraging dissemination and feedback of ideas to maintain effective care partnerships.

5. Conclusion

This study has highlighted that, despite some issues surrounding the sample and criticisms of its methodology, family carers are likely to be suffering from their own psychological health problems as a result of the care-giving role, with high incidences and correlations between anxiety, depression, and dysfunctional styles of coping. Although not expected, family carers were found to utilise lower levels of ‘External Control’ attributions compared to nurses, and be better at empathising the feelings of nurse carers, than vice a versa.

In summary, attribution theory has the potential to explore new ground in both family care-giving and relationships between family and nurse carers. The findings showed useful correlations between care-giver variables, and interesting patterns of attributions between families and nurses, that may all act as a catalyst for future research into new avenues of the underlying meanings that guide and affect those responsible for caring for someone with Alzheimer’s disease.
6. References


Section 3

Critical Appraisal
1. Developing my Research Ideas

The conception of this research study began initially from informal conversations with the family carers of clients that I was assessing for a diagnosis of Alzheimer’s disease during my older adult placement. At the time, the National Service Framework for Older People (DOH, 2001) was beginning to filter guidelines into the community mental health service, and throughout the document carers were identified as an important focus for psychological help and support. Alongside this, I was also completing a piece of coursework critically appraising this document and I began to realise that despite the inclusion of carers within the guidelines, there was a lack of detail for clinicians to effectively support family carers. By spending time with carers during my clinical work, it became apparent that they often felt unsupported, unskilled, unhealthy (both physically and mentally), and unable to cope with the demands of the role. This developed my interest into what it was that helped people cope with such a demanding role, battling issues of continual and progressive loss of their loved one, whilst tackling the challenges thrown up by the behavioural, psychological, and social aspects of the disease.

In combination with this, my clinical work also exposed me to many nursing home environments where staff were having to care for a number of different clients with various conditions. When speaking informally to these staff members, the focus of many conversations would centre around those clients with Alzheimer’s disease as they proved to be the most challenging. In particular the topic of verbal and physical aggression was highlighted, with staff often feeling deskilled and burnt out by these frequently occurring behaviours. There was a feeling that acts of aggression not only interfered with their other caring responsibilities, but also had an enormous effect on job satisfaction, their interpersonal relationships with the clients, and their own overall physical and mental health.
With all of these elements in mind I began to think more widely about the Alzheimer’s disease care-giving experience within the framework shown in Figure 10, below.

**Figure 10. Framework for the research ideas.**

I became interested in not just how and why these two different systems of care coped with someone with Alzheimer’s disease, but what psychological processes were operating to cause certain carers to cope better than others. More importantly, I was interested in what beliefs these carers held about the care-giving environment, and how they make sense of the challenges presented to them in these roles.

The combination of all these elements led to the foundations of this research study.

Presenting my ideas to some established contacts within older adult services the ideas were well received, particularly as Alzheimer’s disease was being highlighted in the national media, and also research in this area was often limited to a medical or biological orientation. Clinicians were keen to discover more about the psychological processes surrounding Alzheimer’s disease care-giving, including many interested in finding more
effective ways of supporting family carers, or to gain a wider knowledge with which to improve training members of nursing staff.

As many elements of this study represented new avenues of exploration for this client group, early ideas and proposals centred on using both quantitative and qualitative methodology. Quantitatively I would be able to gather some descriptive data regarding coping outcomes, styles and beliefs, whilst qualitatively I would be able to explore these elements more intensively. However, time and financial limitations required a more economical approach that took into consideration the difficulties that geography and recruitment were going to have. To improve participation and make information collection more user-friendly, a quantitative (questionnaire-based) approach was utilised and submitted to the University of Leicester in October 2003. After a period of time designing and fine-tuning the research protocol and questionnaire booklets, the study was submitted and approved by Lincolnshire Local Research Ethics Committee in September 2004, allowing the study to get underway.

2. Managing the Research: Barriers and Breakthroughs

It was during a preliminary meeting with one of the community psychiatric nurses that I realised how difficult it would be to try and recruit family carers for this research study. The main issues here revolved around the fact that most family carers of people with Alzheimer’s disease may also be suffering from their own physical health problems, and coupled with the extremely time and resource consuming task of caring, would put completing a questionnaire very low on a carer’s list of priorities. It was felt that in order to improve the completion and return of questionnaire booklets, I should attempt to contact carers personally. By doing this I could check whether they required any help in
completing the questionnaire booklet and provide an opportunity to describe the rationale behind the study and answer any questions they may have. Whilst completing this I was mindful of possible bias I might introduce into the equation, so I tried not to be leading or suggestive in any responses asked of me, just curious and positive about the potential of the research.

To prevent discrimination against any potential participants who had difficulties in completing the questionnaire, I had offered my assistance to anyone that requested it. I think I underestimated the amount of help that participants would require and ended up assisting nearly half of my family carer sample in completing the questionnaire booklet. The downside of this was that I had to spend a number of days driving around rural Lincolnshire, which was both very tiring and very time consuming. The upside of this was that I got to spend some useful time with family carers as they not only completed the questionnaire but also gave me a wealth of further knowledge regarding their experiences.

One of the biggest problems I had in overseeing the research process was that despite knowing all of the community mental health team personnel, I was not actually working there on placement at the time. Any research management issues that arose were sometimes subject to a delay in communication. Luckily good secretarial support at my research base minimised some of these issues by keeping in regular telephone and email contact. Also my field supervisor worked within this team and was able to keep communication channels open and maintain a link between myself and the other clinicians. Still this issue minimised the opportunities for informal conversations with other clinicians, restricting some of my ability to discover which aspects of the research may need extra time and resources.
Throughout my time working on this research study, I was often touched by the stories and experiences retold by both sets of carers. In particular I was continually impressed not just by the way family carers were dealing with the challenges presented to them often from the person they love most, but by their motivation and eagerness to give their time to such research. In most cases, carers were keen to learn of the results of the study, and many were interested in helping with any subsequent research that may follow.

As a small-scale piece of research with limited time and resources, many of the ways that I was able to progress and tackle potential barriers were aided by the help and support of many of the other systems working around me. Clinically my placement supervisor was able to give me some flexibility to aid my data collection process, academically my course staff encouraged me to be mindful of theory-practice links and issues around reporting my findings, and personally my partner and children battled intensively to keep me in good physical and mental health.

3. Development of Research Knowledge

One of the most pertinent elements of this whole research study has centred on improving my knowledge of developing, running, and disseminating a major research study, and the learning opportunities along the way. With limited space to detail all of the aspects I have learnt throughout my research journey, some of the major developments have been:

- Developing a realisation of the everyday challenges faced by both family and nursing carers for those people with Alzheimer's disease. The time I have spent in numerous family and nursing systems whilst collecting data, has provided me with a wealth of knowledge not only for answering those research questions posed in this study, but for supplying me with ideas for future research in this clinical area.
• Learning to view my research from the various perspectives of others who may contribute in some way to the development or data gathering elements. I discovered a whole range of reactions to my research ideas including rejection, scepticism, apathy, and optimism, in both carers and other professionals attached to the community mental health team. I learnt to accept criticism, but still hold onto the fundamental research ideas that initially drove me to complete this study. I ultimately learnt to seek out constructive criticism and feedback, as I could see that it not only improved my own research ideas, but also provoked creative thinking in others.

• Learning project management skills by gaining a greater awareness of how much time and energy different research components would require, planning and preparing research activities, maintaining communication channels between all parties involved, and continually reviewing the progress of each. I was able to enhance my skills in being able to hold a number of different research components, at various stages of development, and ensure each stayed within the parameters of the research timetable. One of the most difficult aspects of this role was ensuring that the core themes and fundamental research ideas were properly disseminated to other team members, gatekeepers to potential participants, and the participants themselves. Professionals with their own time pressures and carers with many role responsibilities made it essential that I was able to communicate quickly and efficiently, yet maintain a respectful rapport. Improving the success of this task required a high level of motivation and positive attitude, being able to provide research information without being too complex or containing jargon, and flexible enough to adjust to every individual’s needs and abilities.
• Learning how important it was to involve service users and potential participants, particularly in the designing and development of the research ideas and materials. Despite involving other clinical team members and supervisors in the design phase of this research study, my communication with potential participants remained minimal until the second draft had been completed satisfying the ethics committee requirements. Once some potential carers had attempted my questionnaire booklet it became clear that family carers, who were often over the age of sixty and suffering from their own health problems, found the booklet too long. Trimming the questionnaire with only minimal effects on my research questions was simple enough, but this delayed distribution as the new booklet versions had to be re-approved by the ethical committee. Following this, I continued to actively listen to the comments made by all my participants in order to learn from any further weaknesses, to strengthen my knowledge for any future research.

• Learning about the management and time resources that are required for a quality write-up of the research. A complex interaction of styles and standards of the writing up had to aim to satisfy university coursework marking criteria and be transferable to a suitable peer-reviewed journal for publishing once completed. In addition, changes to the format of the thesis meant that a greater awareness was required for any updates and changes. This piece of work improved my ability to manage a research study alongside regular NHS work, and improve my awareness of the resources that such a piece of research will require.
In summary, what all these learning elements have accomplished is to not only make me feel more competent at running a research study and converting the results into a report of an appropriate standard for disseminating back into the literature, but to motivate me in continuing to develop research ideas and produce quality pieces of research in my future career as a clinical psychologist.
Appendices
Appendix A. Letter of approval from local research ethics committee (LREC)

Lincolnshire Local Research Ethics Committee
Beech House
Witham Park
Waterside South
Lincoln
LN5 7JH
Tel: 01522 806 619
Fax: 01522 806 615

17 September 2004

Mr Wayne Burgoine
Trainee Clinical Psychologist
University of Leicester
University Road
Leicester
LE1 7RH

Dear Mr Burgoine,

Full title of study: Alzheimer’s Disease Caregiving: Causal attributions, coping styles, and empathy among family and nursing staff caregivers.
REC reference number: 04/Q2405/50
Protocol number: 1

Thank you for your letter of 27th August 2004, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The favourable opinion applies to the following research site:

Site: Lincolnshire Partnership Trust
Principal Investigator: Wayne Burgoine, Trainee Clinical Psychologist

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

In addition to the enclosed conditions the Committee have requested that you remove the sentence “and I hope you will now agree to participate” from your Participant Information Sheet and forward a copy to them, for their records.

Approved documents

The documents reviewed and approved at the meeting were:
*Including the following documentation
- Family Caregiver Demographics
- Hospital Anxiety and Depression Scale
- Satisfaction Survey (Pre Study)
- The Brief COPE Scale (Part 1)
- Caregiving Example
- Casual Dimensions Scale (Part 1)
- Casual Dimensions Scale (Part 2)
- The Brief COPE Scale (Part 2)
- Satisfaction Survey (Post Study)

**Including the following documentation
- Nursing Staff Demographics
- Hospital Anxiety and Depression Scale
- Satisfaction Survey (Pre Study)
- The Brief COPE Scale (Part 1)
- Caregiving Example
- Casual Dimensions Scale (Part 1)
- Casual Dimensions Scale (Part 2)
- The Brief COPE Scale (Part 2)
- Satisfaction Survey (Post Study)

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

Notification of other bodies

We shall notify the research sponsor, Lincolnshire Partnership Trust that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q2405/50 Please quote this number on all correspondence

Yours sincerely,

Reverend Keith S Lackenby
Chairman

Enclosures Standard approval conditions

An advisory committee to Trent Strategic Health Authority
Appendix B. Participant Information Leaflet (Family Carer)

A study to explore the experiences of those caring for people with Alzheimer’s disease.

1. What is the purpose of the study?
   - You are invited to take part in a study that looks into the reasons given by different caregivers as to how they cope with aggression, which is experienced when caring for a person with Alzheimer’s disease.
   - The study will also ask of you your opinions of how you feel nursing staff cope with the same care-giving role, get you to think about how they might deal with incidents of aggression, and how you would rate their ability to care.
   - This knowledge will help us develop better services for both family caregivers and nursing staff that find themselves in this care-giving role.

2. What will be involved if I take part in the study?
   - You will be asked to complete a questionnaire booklet that contains eight short questionnaires and a short passage to read.
   - The questionnaire booklet is designed so each participant can complete it easily and then post it back free of charge. Assistance with the Questionnaire Booklet can be requested, where the researcher will complete them with you.
   - The study should take between 15 and 25 minutes of your time.

3. Will information obtained in the study be confidential?
   YES. - The information in the questionnaires will be kept confidential.
   - You will not be identified in any documents related to this study.

4. What if I am harmed by the study?
   - The study does not in any way set out to harm you.
   - However, if you have any cause to complain about your participation in this study, the normal NHS complaints mechanism is available to you.

5. What happens if I do not wish to take part or withdraw from the study?
   - In taking part you are still free to withdraw at any time, without giving reason.
   - A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that you and your family member receives.

Thank you for reading this information.

Principle Investigator: Mr Wayne Burgoine
Supervising Investigator: Dr Shobha Singh (Consultant Clinical Psychologist)
Appendix C. Participant Information Leaflet (Nurse Carer)

A study to explore the experiences of those caring for people with Alzheimer’s disease.

1. What is the purpose of the study?
   - You are invited to take part in a study that looks into the reasons given by different caregivers as to how they cope with aggression, which is experienced when caring for a person with Alzheimer’s disease.
   - The study will also ask of you your opinions of how you feel family members cope with the same care-giving role, get you to think about how they might deal with incidents of aggression, and how you would rate their ability to care.
   - This knowledge will help us develop better services for both family caregivers and nursing staff that find themselves in this care-giving role.

2. What will be involved if I take part in the study?
   - You will be asked to complete a questionnaire booklet that contains eight short questionnaires and a short passage to read.
   - The questionnaire booklet is designed so each participant can complete it easily and then post it back free of charge. The Questionnaire Booklet can be completed with the principle investigator if requested.
   - The study should take between 15 and 25 minutes of your time.

3. Will information obtained in the study be confidential?
   - The information in the questionnaires will be kept confidential.
   - You will not be identified in any documents related to this study.
   - No identifiable information can be passed back to your place of employment.

4. What if I am harmed by the study?
   - The study does not in any way set out to harm you.
   - However, if you have any cause to complain about your participation in this study, please seek advice from your line manager or supervisor.

5. What happens if I do not wish to take part or withdraw from the study?
   - In taking part you are still free to withdraw at any time, without giving reason.
   - Your decision to take part or not will have no consequences at your place of employment.

Thank you for reading this information.

Principle Investigator: Mr Wayne Burgoine
Supervising Investigator: Dr Shobha Singh (Consultant Clinical Psychologist)
CONSENT FORM

Alzheimer’s Disease Care-giving: Causal attributions, coping styles, and empathy among family and nursing staff caregivers.

Research by: Mr Wayne Burgoine
Trainee Clinical Psychologist

1. I confirm that I have read and understood the information sheet (dated 13th October 2004) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I agree to take part in the above study.

Name of Participant ___________________________ Date ________________ Signature ___________________________

Name of person taking Consent ___________________________ Date ________________ Signature ___________________________
Appendix E. Family Carer Reminder Letter

NHS TRUST HEADER

Wayne Burgoine
Trainee Clinical Psychologist

Mr/s ———
Address

Tel:

Date

Dear Mr/s,

Thank you for your interest in my research that I spoke to you about over the telephone a few days ago. I have enclosed a copy of the questionnaire booklet, an information leaflet that explains the study in more detail, and a consent form.

If you are still happy to help me with my research I must ask that you sign and return the consent form with the questionnaire booklet, as I cannot use your answers otherwise.

I have enclosed a self-addressed envelope for you to return the questionnaire booklet and consent form free of charge.

If you have any problems completing the questionnaire, please contact me using the above telephone number and I will be happy to provide some assistance.

Thank you again for your time in helping me to complete this piece of research.

Yours Sincerely,

Wayne Burgoine
Trainee Clinical Psychologist
Appendix F. Questionnaire Booklet Components
Family Care-giver Demographics

I would like to ask you some questions about yourself:

1) What is your Gender? □ Male □ Female

2) What is your age? ________

3) What is your relationship to the person with Alzheimer's disease?
   □ Spouse: Husband / Wife □ Other family member
   □ Child: Son / Daughter □ Other, please specify: ____________________________

4) How long have you known the person with Alzheimer's disease?
   __________ (Months / Years)

5) How long have you cared for the person with Alzheimer's disease?
   __________ (Months / Years)

6) Do you have any health problems yourself? YES / NO
   If YES, please state briefly: ____________________________________________

7) How well would you say you are coping with this care-giving?
   □ Not Very Well □ Not Well □ OK □ Quite Well □ Very Well

8) How much support would you say you receive?
   □ None □ Little □ Quite a bit □ Lots

9) In the past month, how many times have you experienced aggressive outbursts directed toward you, as part of your caring role?
   □ None □ 1 – 5 □ 5 – 10 □ 10 – 20 □ 20+
Nursing Staff Demographics

I would like to ask some questions about yourself:

1) What is your Gender? □ Male □ Female

2) What is your age? ________

3) What is the title of your post? (i.e. Nursing Assistant)

4) Do you hold any formal qualifications? (i.e. NVQ in Nursing)

5) How long have you cared for people with Alzheimer's Disease?

6) Do you have any health problems yourself? YES / NO

   If YES, please state briefly: ________________________________

7) How well would you say you are coping with this caregiving?

   □ Not Very Well □ Not Well □ OK □ Quite Well □ Very Well

8) How much support would you say you receive?

   □ None □ Little □ Quite a bit □ Lots

9) In the past month, how many times have you experienced aggressive outbursts directed towards you, as part of your caring role?

   □ None □ 1 - 5 □ 5 - 10 □ 10 - 20 □ 20+
HADS Questionnaire

These questions are designed to find out how you are feeling at the moment. Read each item below and underline the reply that comes closest to how you have been feeling in the past week.

Don’t take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

1. **I feel tense or ‘wound up’:**
   - Most of the time
   - A lot of the time
   - From time to time, occasionally
   - Not at all

2. **I still enjoy the things I used to enjoy:**
   - Definitely as much
   - Not quite so much
   - Only a little
   - Hardly at all

3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - Very definitely and quite badly
   - Yes, but not too badly
   - A little, but it doesn’t worry me
   - Not at all

4. **I can laugh and see the funny side of things:**
   - As much as I always could
   - Not quite as much now
   - Definitely not so much now
   - Not at all

5. **Worrying thoughts go through my mind:**
   - A great deal of the time
   - A lot of the time
   - Not too often
   - Very little

6. **I feel cheerful:**
   - Never
   - Not often
   - Sometimes
   - Most of the time
7. I can sit at ease and feel relaxed:
   Definitely
   Usually
   Not often
   Not at all

8. I feel as if I am slowed down:
   Nearly all the time
   Very often
   Sometimes
   Not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach:
   Not at all
   Occasionally
   Quite often
   Very often

10. I have lost interest in my appearance:
    Definitely
    I don’t take as much care as I should
    I may not take quite as much care
    I take just as much care as ever

11. I feel restless as if I have to be on the move:
    Very much indeed
    Quite a lot
    Not very much
    Not at all

12. I look forward with enjoyment to things:
    As much as I ever did
    Rather less than I used to
    Definitely less than I used to
    Hardly at all

13. I get sudden feelings of panic:
    Very often indeed
    Quite often
    Not very often
    Not at all

14. I can enjoy a good book or radio or television programme:
    Often
    Sometimes
    Not often
    Very Seldom
Satisfaction Survey

Below are five statements and I would like you to give your initial opinion on each.

Please rate each statement on a scale of zero to ten.

Briefly think about your opinions of nursing staff whose responsibility it would be to care for a person with Alzheimer’s disease. (i.e. such as in a nursing home). Even if you do not have any direct experience of this, I am still interested in your opinion.

1) How good would you rate their ability to be a carer?

0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Not Good Very Good

2) How well would you rate their ability to cope with aggressive outbursts whilst care-giving for someone with Alzheimer’s disease?

0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Not Well Very Well

3) How well do you think overall, they would cope with caring?

0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Not Good Very Good

4) What sort of understanding would they have for the needs of the family of the person with Alzheimer’s disease?

0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Poor Understanding Good Understanding

5) If you yourself had a care-giving need, how satisfied would you be for being cared for by nursing staff?

0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
Not Satisfied Very Satisfied
**Brief COPE Questionnaire**

The items listed below deal with ways that you’ve been coping with the experience of care-giving for someone with Alzheimer’s disease.

There are many ways to try to deal with problems. Obviously, different people deal with things in different ways, but I’m interested in how you’ve tried to deal with it.

Each item says something about a particular way of coping. I want to know to what extent you’ve been doing what the item says. How much or how frequently. Don’t answer on the basis of whether it seems to be working or not – just whether or not you’re doing it.

Try to rate each item separately in your mind from the others, using the response choices. Make your answers as true FOR YOU as you can.

<table>
<thead>
<tr>
<th></th>
<th>I haven’t been doing it at all</th>
<th>I’ve been doing this a little bit</th>
<th>I’ve been doing this a medium amount</th>
<th>I’ve been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I’ve been turning to work or other activities to take my mind off things.</td>
<td></td>
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<td>2</td>
<td>I’ve been concentrating my efforts on doing something about the situation I’m in.</td>
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<tr>
<td>3</td>
<td>I’ve been saying to myself “this isn’t real”.</td>
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<tr>
<td>4</td>
<td>I’ve been using alcohol or other drugs to make myself feel better.</td>
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<tr>
<td>5</td>
<td>I’ve been getting emotional support from others.</td>
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<tr>
<td>6</td>
<td>I’ve been giving up trying to deal with it.</td>
<td></td>
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<tr>
<td>7</td>
<td>I’ve been taking action to try to make the situation better.</td>
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<td>8</td>
<td>I’ve been refusing to believe that it has happened.</td>
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<tr>
<td>9</td>
<td>I’ve been saying things to let my unpleasant feelings escape.</td>
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<tr>
<td>10</td>
<td>I’ve been getting help and advice from other people.</td>
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<tr>
<td>11</td>
<td>I’ve been using alcohol or drugs to help me get through it.</td>
<td></td>
<td></td>
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<tr>
<td>12</td>
<td>I’ve been trying to see it in a different light, to make it seem more positive.</td>
<td></td>
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</tbody>
</table>

Continues over the page...
<table>
<thead>
<tr>
<th></th>
<th>I haven't been doing it at all</th>
<th>I've been doing this a little bit</th>
<th>I've been doing this a medium amount</th>
<th>I've been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>I've been criticising myself.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>14</td>
<td>I've been trying to come up with a strategy about what to do.</td>
<td></td>
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<tr>
<td>15</td>
<td>I've been getting comfort and understanding from someone.</td>
<td></td>
<td></td>
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<tr>
<td>16</td>
<td>I've been giving up the attempt to cope.</td>
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<td></td>
<td></td>
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<tr>
<td>17</td>
<td>I've been looking for something good in what is happening.</td>
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<td></td>
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<tr>
<td>18</td>
<td>I've been making jokes about it.</td>
<td></td>
<td></td>
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<tr>
<td>19</td>
<td>I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping.</td>
<td></td>
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<tr>
<td>20</td>
<td>I've been accepting the reality of the fact that it has happened.</td>
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<tr>
<td>21</td>
<td>I've been expressing my negative feelings.</td>
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<tr>
<td>22</td>
<td>I've been trying to find comfort in my religion or spiritual beliefs.</td>
<td></td>
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<tr>
<td>23</td>
<td>I've been trying to get advice or help from other people about what to do.</td>
<td></td>
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<tr>
<td>24</td>
<td>I've been learning to live with it.</td>
<td></td>
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<tr>
<td>25</td>
<td>I've been thinking hard about what steps to take.</td>
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<tr>
<td>26</td>
<td>I've been blaming myself for things that happened.</td>
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<tr>
<td>27</td>
<td>I've been praying or meditating.</td>
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<tr>
<td>28</td>
<td>I've been making fun of the situation.</td>
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</tbody>
</table>

End of Questionnaire, please continue on to the next page...
Caregiving Example

The following is a hypothetical situation just to get you thinking about the topic area I am going to ask you some questions about.

Please read the following example and then proceed to the next questionnaire

George has a diagnosis of Alzheimer’s disease and he is seventy-one years old. Due to the progression of the disease George now lacks a number of everyday abilities that he once took for granted. He has a poor awareness of time, where he is, and others around him. He is unable to remember things very long, but can remember things from his past when asked. George also has a very short fuse and will occasionally become aggressive towards his carer. This aggression is usually in the form of shouting and swearing, however recently he has begun to hit out and his carer has obtained some bruises on their arms and legs.
Causal Dimensions Questionnaire – Self (E.g. Family Carer)

Think about the situation described in the previous example and how this fits into your own experiences of caregiving.

How would you describe your feelings?

(Briefly or in one word if possible)

The items below concern your impressions or opinions of the causes to the way you feel about this type of situation (i.e. physical aggression experienced during your caregiving role). Circle one number for each of the following questions. (9 indicating a feeling closer to the left hand statement and 1 indicating a feeling closer to the right hand statement).

1) Do these types of feelings reflect:

<table>
<thead>
<tr>
<th>Something about you</th>
<th>Something about the situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

2) Are these feelings:

<table>
<thead>
<tr>
<th>Manageable by you</th>
<th>Not manageable by you</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

3) Are these feelings:

<table>
<thead>
<tr>
<th>Permanent</th>
<th>Temporary</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

4) Are these feelings something:

<table>
<thead>
<tr>
<th>You can regulate</th>
<th>You cannot regulate</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

5) Are these feelings something:

<table>
<thead>
<tr>
<th>Over which others have control</th>
<th>Over which others have no control</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

6) Are these feelings caused by something:

<table>
<thead>
<tr>
<th>Inside of you</th>
<th>Outside of you</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 8 7 6 5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>
7) Are these feelings:

Stable over time

Variable over time

8) Are these feelings:

Under the power of other people

Not under the power of other people

9) Do these feelings:

Reflect an aspect of yourself

Reflect an aspect of the situation

10) Are these feelings:

Over which you have power

Over which you have no power

11) Are these feelings:

Unchangeable

Changeable

12) Are these feelings something that:

Other people can regulate

Other people cannot regulate

13) How well do you feel you would cope in this situation?

Very well

Not very well

End of Questionnaire, please continue on to the next page...
Causal Dimension Scale – Other (E.g. Family View of Nurses)

Now think about the same situation described above, but this time base it upon your beliefs and experiences of how a member of nursing staff might see it, and how they would feel about coping. There are no right or wrong answers and I am interested in your opinions even if you have no direct experience of nursing staff.

How do you think they would feel in this situation?

(briefly, or in one word if possible)

The items below concern your impressions or opinions about how you think a member of nursing staff might view the causes to the way that they may feel about this type of situation (i.e. physical aggression).

Circle one number for each of the following questions. (9 indicating a feeling closer to the left hand statement and 1 indicating a feeling closer to the right hand statement).

1) Do these types of feelings reflect:

| Something about them | 9 8 7 6 5 4 3 2 1 | Something about the situation |

2) Are their feelings:

| Manageable by themselves. | 9 8 7 6 5 4 3 2 1 | Not manageable by themselves. |

3) Are their feelings:

| Permanent | 9 8 7 6 5 4 3 2 1 | Temporary |

4) Are their feelings something:

| They can regulate | 9 8 7 6 5 4 3 2 1 | They cannot regulate |

5) Are their feelings something:

| Over which others have Control | 9 8 7 6 5 4 3 2 1 | Over which others have no control |

6) Are their feelings caused by something:

| Inside of them | 9 8 7 6 5 4 3 2 1 | Outside of them |
7) Are their feelings:
Stable over time 9 8 7 6 5 4 3 2 1 Variable over time

8) Are their feelings:
Under the power of other people 9 8 7 6 5 4 3 2 1 Not under the power of other people

9) Do their feelings:
Reflect an aspect of themselves 9 8 7 6 5 4 3 2 1 Reflect an aspect of the situation

10) Are their feelings:
Over which they have power 9 8 7 6 5 4 3 2 1 Over which they have no power

11) Are their feelings:
Unchangeable 9 8 7 6 5 4 3 2 1 Changeable

12) Are their feelings something that:
Other people can regulate 9 8 7 6 5 4 3 2 1 Other people cannot regulate

13) How well do you feel the person would cope in this situation?
Very well 9 8 7 6 5 4 3 2 1 Not very well

End
Appendix G. Cronbach’s alpha Results for the Brief COPE Subscales

<table>
<thead>
<tr>
<th>Brief COPE Subscale (item numbers)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Coping</td>
<td>0.534</td>
</tr>
<tr>
<td>Planning</td>
<td>0.576</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>0.785</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.841</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>0.755</td>
</tr>
<tr>
<td>Religion</td>
<td>0.816</td>
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<tr>
<td>Positive Reframing</td>
<td>0.813</td>
</tr>
<tr>
<td>Humour</td>
<td>0.886</td>
</tr>
<tr>
<td>Denial</td>
<td>0.602</td>
</tr>
<tr>
<td>Venting</td>
<td>0.606</td>
</tr>
<tr>
<td>Self-Distraction</td>
<td>0.574</td>
</tr>
<tr>
<td>Self-Blame</td>
<td>0.422</td>
</tr>
<tr>
<td>Behavioural Disturbance</td>
<td>0.540</td>
</tr>
<tr>
<td>Substance Use</td>
<td>0.737</td>
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Appendix H. Qualitative responses to the CDS-II scales

<table>
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<tr>
<th>CDS-II Measure</th>
<th>Responses</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family's views of their own Feelings</td>
<td>Frustrated / Angry</td>
<td>7</td>
<td>25.9</td>
</tr>
<tr>
<td></td>
<td>Sad / Upset</td>
<td>5</td>
<td>18.5</td>
</tr>
<tr>
<td></td>
<td>Blaming Self</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Scared / Frightened</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Avoidance</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>OK / Positive</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>No Response</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>Blaming Disease</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Other Response</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>Family's views of Nurses feelings</td>
<td>Trained to Cope</td>
<td>9</td>
<td>33.3</td>
</tr>
<tr>
<td></td>
<td>No Response</td>
<td>4</td>
<td>14.8</td>
</tr>
<tr>
<td></td>
<td>Part of the Job</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Sympathetic / Patience</td>
<td>3</td>
<td>11.1</td>
</tr>
<tr>
<td></td>
<td>Sad / Concerned</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>Confident</td>
<td>2</td>
<td>7.4</td>
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<tr>
<td></td>
<td>Stressed</td>
<td>1</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>Other Response</td>
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<td>11.1</td>
</tr>
<tr>
<td>Nurses views of their own feelings</td>
<td>No Response</td>
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<td>30</td>
</tr>
<tr>
<td></td>
<td>Part of the disease</td>
<td>7</td>
<td>23.3</td>
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<tr>
<td></td>
<td>Frightened / Fearful</td>
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<td>20</td>
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<tr>
<td></td>
<td>Pitiful</td>
<td>2</td>
<td>6.6</td>
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<tr>
<td></td>
<td>Concerned</td>
<td>1</td>
<td>3.3</td>
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<tr>
<td></td>
<td>Frustrated</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td></td>
<td>Other Response</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Nurses views of Family feelings</td>
<td>Frightened</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Upset</td>
<td>4</td>
<td>13.3</td>
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<tr>
<td></td>
<td>Helpless</td>
<td>3</td>
<td>10</td>
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<td></td>
<td>Anxious</td>
<td>3</td>
<td>10</td>
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<tr>
<td></td>
<td>Blame Self</td>
<td>1</td>
<td>3.3</td>
</tr>
<tr>
<td></td>
<td>Sad</td>
<td>1</td>
<td>3.3</td>
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<td></td>
<td>Other Response</td>
<td>3</td>
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</table>
Appendix I: Journal Submission Notes

Notes for Contributors

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations;
- Theoretical papers, provided that these are sufficiently related to the empirical data;
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- Brief reports and comments.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at http://bicip.edmgr.com.

First-time users: click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:
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Abstract

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- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
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