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The effect of ethnicity and family values upon willingness to care and caregiver quality of life

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The effect of ethnicity and family values upon willingness to care and caregiver quality of life.

Ph.D. Thesis

Sahdia Parveen

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2011

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Abstract

The aim of this thesis was to examine the influence of ethnicity on caregiver distress and quality of life. Core psychological models specifically the Transactional model of stress and coping (Lazarus, 1984) were used to identify factors that mediate the relationship between ethnicity and culture on caregiver outcomes of distress and quality of life. The thesis is written as a collection of research papers including a systematic review which explored the influence of ethnicity on caregiver burden and identifying factors which affect this relationship. The systematic review established that familism, coping and use of social support were important factors in the relationship between caregiver ethnicity and outcomes.

The first empirical study (*n* = 88) aimed to investigate what demographic factors were predictive of familism in caregivers and whether familism was associated with their coping. In order to gain a fuller understanding of ethnic variations in the caregiver role and experience the second study (*n* = 30) employed qualitative methods. Differences not only existed between caregivers at the macro level (Asian vs. White British) but also at the micro level (between Bangladeshi, Indian and Pakistani caregivers). The third study (*n* = 235) explored the ethnic differences that had emerged from the qualitative study in a cross-sectional quantitative study of the following factors: familism, willingness to care, coping, use of support and distress. In the final model it emerged that self blame was a significant predictor of South-Asian anxiety and depression. Mean satisfaction with social support was the strongest predictor of White-British caregiver anxiety and care recipient diagnosis, number of hours caregiving per week, use of substances, humour and mean satisfaction with support were significant predictors of White-British caregiver depression.

The final study ($n = 123$) employed a longitudinal design to examine whether motivations to care, familism, illness perceptions, coping, and use of support influenced caregiver distress, gains and quality of life. These results are presented in three separate chapters corresponding to each outcome. It was found that perceptions of illness consequences, use of substances and total use of social support increased over time whereas familism and the use of positive reframing decreased. Using regression residual scores it was found that changes in predictor variables (in particular illness perceptions and coping) influenced change in distress, gains and quality of life at different times.

Across the series of studies presented, key findings indicate that ethnicity, changes in illness perceptions, coping and use of support are predictive of caregiver outcomes. In addition ethnic variations existed within these variables. This suggests that future interventions should not only be time-phased but modified for different ethnic groups and dependent on the target outcome.

Chapter 1

Introduction

Introduction

The rapidly aging population in the U.K. has led to an increase in the number of people suffering from cancer, neurodegenerative and vascular diseases (Takahashi, Tanaka & Miyaoka, 2005). The rising demand for patient support led to the U.K developing a community based care policy and it is estimated that 80% of the care required to maintain patients at home is provided by family members, generally referred to as informal caregivers or carers (Brereton, 1997; 2002). The work presented in this thesis investigates the effect of ethnicity and family values upon willingness to care and caregiver outcomes of mood and quality of life.

The purpose of this introductory chapter is to broadly outline the context of the research and discuss the methodological limitations within the existing database (further reviewed in Chapter 2). Primarily the chapter will discuss current care related issues followed by theories which have been applied to the study of caregiving. The chapter then examines the current evidence base that has applied such theories to caregiver research. A discussion on ethnicity and culture is followed by an examination of the current caregiver research in the U.K related to British South-Asian caregivers. Towards the end of this introduction a summary of subsequent thesis chapters is provided.

Caregiver Statistics

The term caregiver or carer is difficult to define as it is perhaps not used and understood by health/social care professionals and family members in the same way. Most caregiving relationships are extremely complex as they are based upon long-shared histories, for example, marriage (Payne, 2004). In this thesis the term caregiver will be used to describe an individual who provides support including physical, emotional and/or personal support (beyond what is typical for their relationship) for a family member or friend who are experiencing problems due to physical, emotional or cognitive impairments; often without financial compensation (Bridges, 1995). The focus of the thesis will be on informal (family members and friends) caregivers not individuals who have been hired on a professional basis to provide care for the care recipient.

It is estimated that there are currently six million informal caregivers in the UK (Carers UK[1], 2009) of who approximately 1.9 million provide 20 hours of care per week and a further 1.25 million provide care for 50 or more hours per week. 58% of caregivers are female and the peak age for providing care is 50-59 years. Caregiving also varies by ethnic group. Of the six million caregivers in the UK, 285, 000 caregivers are thought to be from Black and minority ethnic background (Carers UK, 2007) although it is thought that the UK census (2001), which is used in the 2007 Carers UK report, may have significantly understated the number of caregivers from a minority ethnic background. This may be due to many ethnic minority caregivers not being known to services. It can also be due to individuals not understanding the term caregiver and describing their role simply as wife or daughter, or some other familial relationship, although this is also likely to influence reporting of non-Asian caregivers also. Carers UK (2001) predict that British-Bangladeshi and British-Pakistani groups are three times more likely to provide care to a relative compared with their White-British counterparts and the UK census (2001) found that of the various ethnic groups in the UK; British-Bangladeshi, British-Pakistani and White-British were the most likely to spend the highest rate of providing care, that is 50 hours or more per week. In terms of age, 1.5% of the British South-Asian caregivers (Bangladeshi, Indian and

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[1] Carers UK is a national organisation set up by caregivers in order to provide support and improve the lives of other caregivers. They provide caregivers with information with regards to caregiver services, collect data related to caregiver needs (by conducting surveys directly with caregivers) and aim to transform the understanding of caregiving.

Pakistani) were below the age of 16 years compared to 0.9% of White-British caregivers. Consistent with the data reported by Carers UK, the General Household Survey (2000) found that 52% of caregivers were adult children, 18% were spouses, 21% were close relatives, a further 21% were neighbours and 8% were parents providing care for an ill or disabled child. 70% of the care recipients were aged 65 years or over.

As said above, there are a number of different relationships between caregiver and care recipient, most commonly spousal, but also including parental, filial, sibling and non kin caregivers. Spouse caregivers may not consider that they are providing care per se but simply acting out of mutual marital obligations. Parental caregivers provide care for an ill or disabled young child but there are also older parental caregivers who provide care for ill or disabled adult children. Filial caregiver is a term used to describe adult children or children-in-law providing care for an ill or disabled parent/parent-in-law. Non kin caregivers include neighbours and friends providing unpaid care and support in the community. Most research studies have focused on spouse caregivers (Vitaliano, Zhang, Young, Caswell, Scanlan & Echeverria, 2009; Adams, 2008; Croog, Burleson, Sudilovsky & Baume, 2006 & Strawbridge et al, 1997); however there has been growing interest in sibling caregivers who have grown up with the ill or disabled sibling and their expectations of the care role in the future, with the strength of family bonds and conflicting responsibilities influencing sibling expectations about their responsibility for future caregiving (Hatfield & Lefley, 2005**;** Greenberg, Seltzer, Orsmond & Krauss, 1999).

Although most research to date has focused on physical aspects of providing care (Payne, 2004) there are several other types of caregiving such as anticipatory care, preventative care, supervisory care, instrumental care, protective care, reconstructive care and reciprocal care, as identified by Nolan, Keady & Grant (1995). These types of care are thought to overlap considerably. In this thesis, we refer to three types of care tasks: emotional caregiving (for example, helping to keep the care recipient's spirits up), instrumental care (for example, preparing meals for the care recipient) and nursing care (for example, helping the care recipient move in and out of bed)

Impact of caregiving

It is predicted that three in five people will be providing care for a family member or friend at some point in their lives (Carers UK, 2007). The care provided by family members and friends is estimated to save social services and the National Health Service (NHS) approximately £87 billion per year. And these caregivers contribute a further one billion pounds to the community by setting up and running self-help groups (Carers UK, 2009). Due to the high socio-economic value and critical role played by these informal caregivers, there has been increasing awareness amongst healthcare professionals and government bodies of the need to support and maintain the health of caregivers. The evidence driving this growing awareness is that negative responses to caregiving such as stress, burden, and social isolation are common and have their own costs in terms of caregiver illness costs as well as that negative experiences may interfere with a caregiver's ability to provide care (Vitaliano, Zhang, Scanlan, 2003).

The impact of caregiving on physical health has been well documented and it appears that there are both direct and indirect effects of caregiving on their own health. In terms of indirect effects, caregivers have been found to be less likely to engage in preventative health behaviour such as visiting GPs for general health checks (Sisk, 2000; Lee, Colditz, Berkman & Kawachi, 2003), and in terms of more direct effects long term caregivers have been found to have lower immunity functions compared to non caregivers (Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991) and experience slower healing time (Kiecolt-Glaser, Marucha, Mercado, Malarkey & Glaser, 1995). Vitaliano et al (2003) conducted a meta analysis to examine the physical health of caregivers supporting an individual with a dementia diagnosis. From 23 observational studies, a sample of 1, 594 caregivers and 1, 478 age and sex matched non caregivers were compared in relation to self reported health and physiological functioning. Caregivers had a 23% higher level of stress hormones and 15% lower level of antibody responses than did non caregivers. These findings suggest that the care role may directly influence the caregiver's immune system. Schulz & Beach (1999) in a prospective population based cohort study with an average of 4.5 years of follow up found that caregiving was associated with a higher mortality rate. After controlling for socio-demographic factors and baseline prevalent and sub-clinical disease in a sample of 392 caregivers and 427 non caregivers, it was found that spouse caregivers who reported experiencing strain were 63% more likely to die during the follow up period than those who did not.

Other less documented effects of the caregiver role include social and financial consequences. Carers UK (2009) found that social exclusion was commonly reported by the caregiver population (although no clear evidence of this is provided from their survey results). Social exclusion was thought to result from the isolating nature of providing care and also from perceived or actual discrimination by service providers. It was found that 23% of families with an ill or disabled person lacked access to transport which limited the caregiver's activities within the role and also left them socially isolated. Many caregivers also cited problems in accessing leisure services and other social activities due to lack of accessibility (no provisions for people with disability) and the cost of such activities. Financial strain is also common amongst caregivers with 72% of caregiver being predicted to be worse off financially as a result of their role (Carers UK, 2009). This may be due a range of factors including the necessity for some of giving up employment, the inadequacy of caregiver welfare benefits and the additional costs of illness and disability (for example for treatments, equipment or home adjustments). Carers UK (2009) reports that many caregivers do not receive appropriate financial support from social services and as a result pay for care and associated costs themselves. 66.6% of caregivers are estimated to spend their own income on care related costs (including their savings); as a result 54% of caregivers surveyed were in debt.

Given the above, there has been growing interest in the past three decades from researchers and health care professionals in the psychological impact of providing care. In the next section the theoretical background for such research will be discussed followed by a brief review of the current literature.

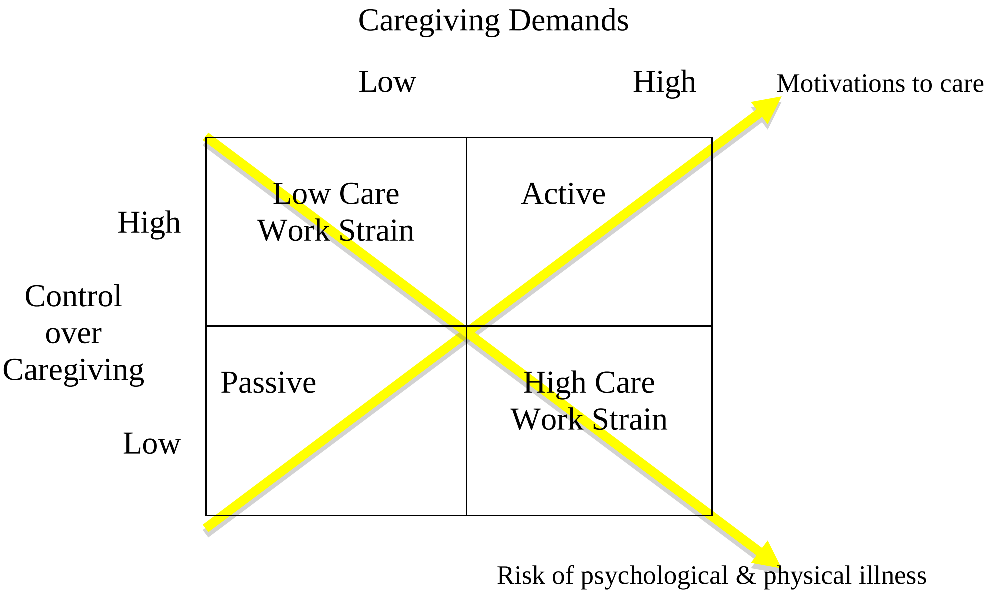
Theoretical models in caregiver research.

Demand-Control Model:

Caregiving has sometimes been conceptualised as an occupational stressor and as a result several studies have utilised job strain models as a theoretical framework from which to study caregiving. Job strain models are considered small as they contain a limited number of predictor variables (as opposed to the Transactional Model of Stress proposed by Lazarus & Folkman, 1984; and described later) and are explicit in terms of effect direction and interactions (Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti et al, 2005). The model most often applied to caregiver wellbeing research is Karasek’s Job Demand-Control Model (1979, Karasek & Theorell, 1990) which has previously been used in a vast number of studies of the physical (Flynn & James, 2009), psychological (Lindeberg, Rosvall, Choi, Canivet, Isacsson Karasek & Ostergren, 2010; Newton & Jimmieson, 2008; Nobelt, Rodwell & McWilliams, 2006) and behavioural outcomes (Taris, Kompier, Geurts, Houtman & Floor, 2010) of occupational stress.

The Job Demand-Control Model (JDCM) proposes that two psychosocial job characteristics are important determinants of occupational health outcomes: psychological demands (resulting from environmental stressors) and decision latitude (potential control an individual has over their tasks and their own behaviour). Decision latitude has a further two components: autonomy and skill discretion. The major two assumptions of the model are illustrated below in Figure 1. Psychological strain is caused by high perceived psychological demands and low decision latitude (control). The second assumption of the model is that if both perceived/actual job demands and control are high, the individual will have opportunities for learning development and work motivation and thus positive outcomes can be achieved. Initially Karasek (1979) advocated that the interaction between demand and control was predictive of stress however research evidence has failed to consistently support this assumption (de Jonge & Kompier, 1997). An alternative explanation may be that there are two main effects of demand and control on stress and a possible interaction, with perceived/actual control moderating the effect of high job demands. The JDC model was further extended by Johnson & Hall (1989) to include a social dimension. The Job Control-Demand-Social Model (JDCSM) proposes that perceived/actual job demands, perceived/actual control and social integration are crucial aspects in the development of health problems. Jobs, in which individuals perceive or have high demands, experience low control and low support, will lead to high levels of strain.

Figure 1. *Karasek's Demand-Control Model applied to caregiving (adapted from* Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti *et al, 2005).*



The application of Karasek's model to caregiving requires consideration of what demands are placed on the caregiver. Two possible components of demands in caregiving may be assistance with daily living activities (such as washing one self) and the care recipient's impaired cognitive functioning. Demands placed on the caregiver are not always psychologically based (such as helping the care recipient in and out of bed) but may have a psychological impact on the caregiver. An early study by Orbell & Gillies (1993) tested the JDCM with a sample of 108 caregivers of elderly people. The results of the study offer partial support to the model in that a main effect for demand as well as a demand-control interaction was found. Caregiver wellbeing was predicted by high levels of demand and the interaction of high demands with control over meeting demands. Perceived control was found to only have a significant impact on wellbeing if the level of demand on the caregiver was high. The results of the study also suggest that the appraisal of care recipient behavioural problems rather than task related effort contributes to caregiver strain.

These results indicate that perceived control may have a buffering role between the demands on the caregiver and their wellbeing.

Molloy et al (2005) also only found partial support for the JDCM in that their longitudinal study found that the model was moderately successful in predicting emotional distress in 138 caregiver/stroke patient dyads but that the main effect for demand and control were found for anxiety and depression only during cross-sectional analysis. The longitudinal findings conflicted with the model in that decreasing control along with increasing demand was associated with reduced distress. More recently Molloy, Johnston, Johnston, Gao, Witham, Struthers & McMurdo (2008) further tested the Demand-Control Model in a cross-sectional study with 60 caregiver/heart failure patient dyads and found that the model components accounted for 15% and 19% of the variance in caregiver burden after controlling for age, gender, and relationship status. Low control was found to be associated with high burden but the model did not predict caregiver satisfaction. This suggests that the JDCM may be a better predictor of negative health outcomes. However this study did not attempt to replicate their previous (Molloy et al 2005) longitudinal analyses where results did not support the demand-control model, and thus conclusive evidence regarding the predictive utility of this model remains limited.

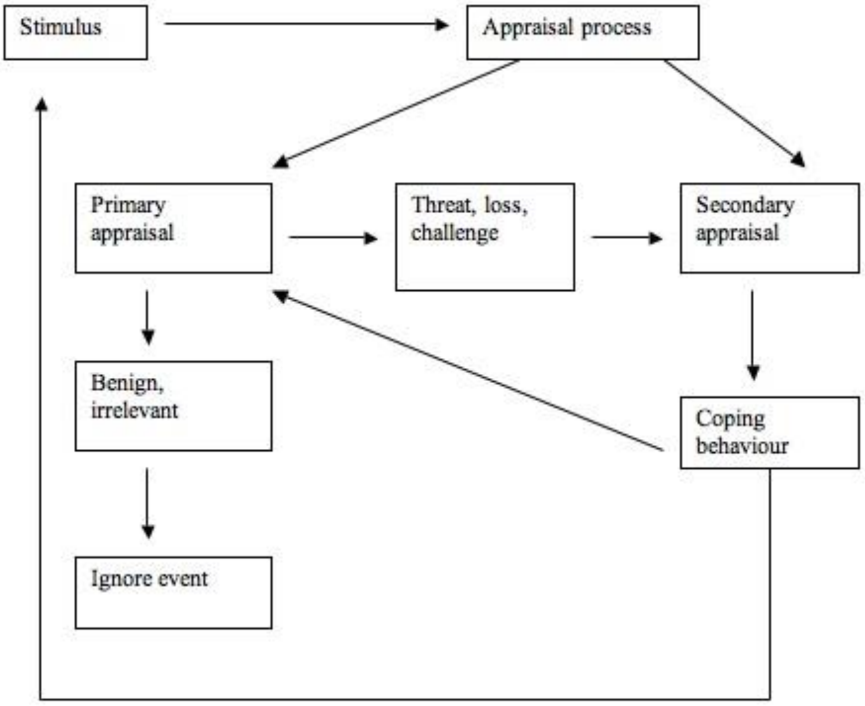
Transactional Model of Stress and Coping (TMSC)

Generic stress theories have also been commonly applied in caregiver research such as the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). Lazarus (1984) defines stress as a psychological transaction between the stimulus event and the cognitive and emotional characteristics of the individual (e.g. the interaction between the onset and severity of the care recipient’s health problems and the cognitive and emotional characteristics of the caregiver). When an individual experiences a new event, they engage in a process of appraisal of which there are two types: primary and secondary appraisals.

Primary appraisal involves a decision based on whether or not the event happening is relevant to the individuals goals, commitments and values. If the event is perceived to be irrelevant to the individual’s wellbeing, there is nothing further to explore and therefore in effect there will be no stress. Alternatively if the event is appraised as potentially stressful, the transaction alternative is harm/loss, threat or challenge. Harm/loss is a damage that has already occurred (e.g. when a family member or friend experiences a stroke, the prospective caregiver may appraise the situation as harmful or sense loss), whereas threat is the possibility of damage in the future (whereby the progression of the care recipient’s illness is slow such as Alzheimer’s disease). Challenge is similar to Selye’s (1974) concept of eustress, that is individuals who feel challenged often enthusiastically pit themselves against obstacles. For example, when an event is perceived as familiar and predictable this will lead to a challenge appraisal. In contrast if the event is considered as imminent, unpredictable and has bad timing (when there are many other stressors), the event will be appraised as a threat. In any transaction both the environmental and person’s variables combine in determining whether there will be a threat or challenge appraisal (Lazarus, 2000).

Lazarus (2000) states that secondary appraisals are also initiated during the primary appraisal process and those secondary appraisals are not independent from primary appraisals. Secondary appraisals are a cognitive evaluation process that is focused on considering changes that can be made to stressful person-environment interaction. The caregiver will assess their resources (such as internal strength, financial and social support) and evaluate their ability to cope with the stressor. Stress will occur when there is a mismatch between perceived demands and the resources perceived to be available to the caregiver. The main difference between primary and secondary appraisals is the content of the appraisal, not the timing. The process of appraisal can be conscious and deliberate or intuitive and unconscious. Individuals are not required to go through all the steps of the appraisal process, in fact if they have previous experience with the event, a minimal cue will initiate the stress reaction and associated coping methods.

Figure 2. *Transactional Model of Stress (adapted from Morrison & Bennett, 2006).*



Lazarus & Smith (1993) extended the transactional model further to include the role of emotions. Lazarus (1991) also later made additions to the primary appraisal stage to include the role of ego involvement. Appraisals of threat to the sense of self would lead to anger, events that conflict with the individual's moral code would cause guilt and threat appraisals would cause anxiety or fear. The secondary appraisal stage was also further extended to include an additional three assessments. The first assessment of blame/credit involves the caregiver attributing responsibility for the care recipient’s problems to others, that is medical professionals (which may lead to anger) or blaming themselves for the care recipient’s health problems (likely feelings of guilt). The second assessment involves the coping potential of the individual, which may involve the use of problem or emotion focused coping to either change the event or deal with it emotionally. If coping potential is perceived to be low, emotions of fear and anxiety will be elicited. The final assessment involves perceptions of future expectancy concerning situational change. Again if the event is perceived as unchangeable, this may cause feelings of fear and sadness.

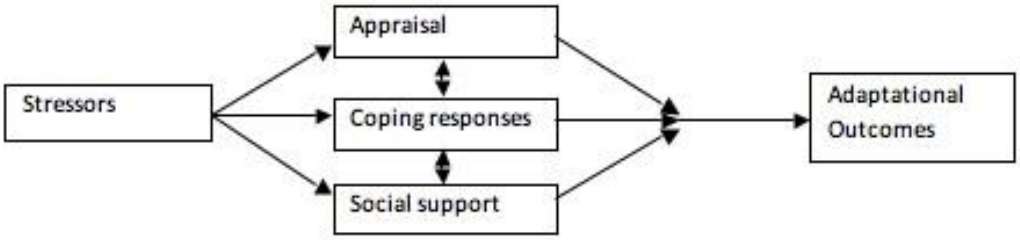
According to these theorists, coping is defined as a process whereby the individual attempts to limit and manage the perceived discrepancy between the demands of the situation they are facing and the resources they have, or believe they have, available to deal with the situation (Lazarus, 1999). Coping is an essential aspect of the model and along with appraisals is theorised as a mediator of the stress reaction. Lazarus (1999) posits that a process approach to coping essentially contains three main themes: firstly, the efficacy of coping depends on the individual, the type of threat faced by the individual and the stage of the stressful encounter (i.e. there is no universally adaptive coping strategy); secondly, all coping thoughts and actions should be described in detail and, finally there are two main aspects of coping (problem focused and emotion focused coping).

Problem focused coping methods may be directed at the event/environment or at the individual and are defined in terms of their goal, which is to alter, reduce, eradicate, manage etc the problem or adapt new ways of dealing with it. The individual actively seeks information, support or technology which will help them manage the stressful person-environment interaction. The purpose of emotion focused coping is to regulate the emotions associated with the stressful situation i.e. to alter, manage etc their response(s) to the event rather than trying to alter, manage etc the event itself. Problem focused coping has been found to be more common when the situation is perceived as controllable and changeable, whereas emotion focused coping is dominant when the situation is perceived as unchangeable; however both types of responses can be used interchangeably to deal with different aspects of the same stressor/situation. Coping is hypothesised to be a strong mediator of the physical and emotional outcome in a stressful situation (Lazarus, 2001).

Support for the Transactional Model of Stress and Coping:

Hayley, Levine, Brown & Bartolucci (1987) were the first to apply and adapt the TMSC to caregiver research. Their adapted model states that the stressors experienced by caregivers include: the severity of care recipient's cognitive, behavioural or physical impairments, and those contextual factors such as age, gender would effect the caregiver's appraisal of how distressing the situation is. Caregivers' appraisals of how distressing the problem is, self efficacy, coping mechanisms and social support were proposed to mediate the relationship between the stressor and caregiver stress. The findings from Hayley et al's (1987) cross-sectional study of 54 family caregivers of dementia patients were supportive of the TMSC. Appraisals, coping, and social support were found to be significant concurrent predictors of caregiver depression. It was also found that the caregiver's subjective appraisals of the situation were better predictors of depression than were the objective severity of the problems. However the study makes use of a small sample size and the cross-sectional design limits the predictive role of appraisal, coping and social support. They also did not test the mediation role of coping and social support in the study.

Figure 3. *A model of stress and coping among caregivers (adapted from* Hayley, *Levine, Brown & Bartolucci, 1987).*



Goode, Hayley, Roth & Ford (1998) subsequently tested the TMSC in a longitudinal study of 122 family caregivers of an individual with an Alzheimer's disease diagnosis. The results of this study were again supportive of the model with appraisals, coping and social support predicting longitudinal changes in caregiver depression. The variables were also found to influence depression through various pathways through mediation analysis. It was found that benign appraisals (i.e. this is not a threat to me), use of problem focused coping and high levels of social support were associated with positive caregiver outcomes. These findings were later supported by Pakenham (2001) in a longitudinal study of 89 caregivers of individuals with a multiple sclerosis diagnosis where low care recipient disability, high social support and less reliance on emotion focused coping were significant predictors of caregiver distress and these associations were found to remain significant 12 months later.

Over the past 30 years caregiver literature has used stress process models such as the TMSC to identify potential risk factors associated with poor outcomes in caregivers. Studies have examined individual differences considered to be risk factors for differential caregiving outcomes (e.g. ethnicity, gender and age) and individual resources (coping and social support) that moderate or mediate relationships between the stressor and outcomes.

There have been various studies examining the ethnic differences in caregiver variables of coping, social support and psychological health (see chapter 2). Most have focused on White American caregivers and used African American, East Asian and Hispanic caregivers as comparison groups. Pinquart & Sorensen (2005) conducted a meta analysis using the results of 116 studies. Overall they found that ethnic minority caregivers had a lower socioeconomic status, were younger and more likely to be adult child caregivers than White American caregivers. Ethnic minority groups were more likely to receive informal support i.e. from family but Asian caregivers were the least likely to receive formal support. Hispanic and Asian caregivers were more depressed than White American caregivers and African American caregivers were the least depressed. The results of this valuable review and meta-analysis suggest that more specific theories are needed to explain the differential effects on ethnic minority caregivers.

Pinquart & Sorensen (2006) also conducted a further meta-analysis using 229 studies to examine gender differences in caregiver psychological health. The meta-analysis found that most gender differences were small with regards to stressors experienced, social resources and health outcomes. Female caregivers were found to report higher levels of burden and depression but male and female caregivers did not differ significantly in their use of formal and informal support. Also when an equal sample of male and female caregivers was compared in regards to level of depression, only 2.8% of the variance was accounted for by gender, whereas the larger gender effect came from an analysis where the sample was highly biased towards females (69% and 31% male). The majority of studies in fact are biased towards female caregivers; the lack of male participants (whether due to a high ratio of female to male caregivers or due to a selection bias towards females) has led to inconclusive findings.

The age of the caregiver has been shown to be an important issue in terms of its influence on caregiver outcomes and also in terms of highlighting sample bias. In relation to this latter point, the majority of studies have recruited a sample which is predominantly mature (i.e. middle aged or above). This may result from bias towards studying illnesses that are prevalent in the older population such as dementia. Rowe & Khan (1998) noted that older caregivers are less resilient to illness in comparison with younger caregivers, which suggests that mature caregivers are at an increased risk of experiencing the negative consequences of providing care such as stress and depression. However Neugarten (1969) suggested that the role of caregiver is more suitable for older individuals due to the life experience they have gained. Whilst older individuals maybe suited to the care role (although further evidence of this is required) this does not suggest that older caregivers will experience reduced distress in comparison to their younger counterparts.

The care recipient’s illness or disability has long been considered as a key factor in predicting caregiver stress. Recently Kim & Schulz (2008) examined differences in caregiver strain in 606 caregivers of individuals with either a dementia, cancer, diabetes diagnosis or the frail elderly. Caregivers in the cancer and dementia groups were found to report significantly greater levels of burden and distress than the diabetes and frail elderly group, after controlling for socio-demographic factors and caregiving duration. This was thought to be due to the higher demands posed by the conditions. The length of time spent in caregiving has also been identified as a risk factor for poor caregiver outcomes, however very few studies have solely examined this influence, as it is usually combined with a number of other factors such as ethnicity, gender, age etc. An exception to this is the longitudinal study described by Gaugler, Kane, Kane, Clay & Newcomer (2005) where a large sample of 4,761 caregivers of dementia patients was utilised over a three year period. It was found that there was a statistically significant positive direct effect of length of care on distress. Individuals who had recently adopted the role of caregiver were also more likely to institutionalise the care recipient compared to caregivers who had been providing support for a longer period of time. Even though long term caregivers had higher distress levels, the duration of care and behavioural problems interaction was not a significant predictor of distress.

The frequency of care (that is the number of tasks that caregiver is involved in) required by the care recipient has been investigated by studies as a possible predictor of caregiver distress. Beach, Schulz, Williamson, Miller, Weiner & Lance (2005) explored the influence of care recipient needs on caregiver depression in a study of 265 caregiver-care recipient dyads. It was found that greater care recipient needs (higher number of tasks performed by the caregiver), the level of cognitive impairment and physical symptoms were significant predictors of caregiver depression. Furthermore Williamson & Schulz (1990) found that the prior relationship quality was also predictive of caregiver depression and that those caregivers who previously had a good relationship with the care recipient experienced lower burden than those with a poor previous relationship.

Hooker, Monahan, Bowman, Frazier & Shifren (1998) examined the influence of the personality characteristics of optimism and neuroticism on caregiver depression. The cross-sectional sample consisted of 88 caregivers of individuals with an Alzheimer’s disease diagnosis and 87 caregivers of individuals with a Parkinson’s disease diagnosis. They found a direct association and an indirect association of personality on depression. High levels of neuroticism and low optimism was related to low social support, higher perceived stress and higher levels of depression. The direct path between social support and depression was not significant. There was a significant direct path between disease group and mental health whereby Alzheimer's caregivers had higher depression than caregivers in the Parkinson's disease group. A significant indirect association between mental health and personality was also found. Gallant & Connell (2003) found similar direct associations of neuroticism on the depression levels of a sample of 233 spouse caregivers of individuals with a dementia diagnosis, and an indirect association by means of the effects of neuroticism on caregiver health behaviours and perceived stress.

In addition to exploring risk factors for poor caregiver psychological outcomes, there has also been interest in caregiver coping. For example, one early study by Stephens, Norris, Kinney, Ritchie & Grotz (1988) found in a sample of 58 family caregivers that avoidant coping was associated with greater depression in caregivers and also more conflict in personal relationships. Positive reappraisal was associated with more positive outcomes. They also found that young female caregivers were the most likely to use avoidant coping methods. Brien (1993) also reports that, amongst a very small sample of 20 caregivers of individuals with a Multiple Sclerosis diagnosis, avoidant coping led to increased stress. A moderate positive relationship was found between problem solving coping and caregiver stress. The findings suggest that as stress in the care role increases, there is an increase in the use of various forms of coping behaviours, both problem and emotion focused, however the above studies utilised cross-sectional designs and a small sample which limits the findings.

Davis, Hermanson, Koopman, Weibel & Spiegel (2000) in a cross-sectional study investigated the various coping strategies employed by 48 couples where one was coping with metastatic breast cancer. From the results of the study it emerged that the partners of the women with cancer who used problem-focused coping had lower levels of stress than those partners who used avoidant coping. More recently Chada, Singh, & Ganguly (2007) examined the associated between coping methods and caregiver burden in a sample of 100 caregivers of individuals with schizophrenia or bipolar affective disorder. As with previous findings avoidant coping was significantly related to high burden but no consistent associations were observed between problem focused coping and depression. With the increasing number of studies now focusing on the different aspects of coping it has led to Lazarus (2000) proposing that research should not separate problem focused coping from emotional coping despite the two being conceptually distinguishable. Lazarus (2000) suggests that the two strategies are interdependent and work together in the overall coping process.

According to Lazarus (1984) social support is an external resource accessed by caregivers during the secondary appraisal stage of the TMSC. Social support has been defined as the process whereby interpersonal relationships protect and aid coping processes in individuals who are experiencing stress (Kessler, Price & Wortman, 1985). Social support has been conceptualised as having two basic elements: the caregiver’s perception that they have sufficient number of people available to turn to during stressful situations and the degree of their satisfaction with the available support (Sarason, Levine, Basham, & Saranson, 1983).

In an early study Fiore, Becker, & Coppel (1983) not only investigated whether levels of support were related to depression, but also the nature of support amongst a small sample of 44 caregivers of spouses with Alzheimer’s disease. Their findings suggest that perceived upset in the network (whereby the caregiver expects support from their network of friends and family but these expectations are not met) was a better predictor of how stressed the individual was rather than perceived helpfulness of the network. The findings also indicated that the perceived quality of social support is a better predictor of caregiver stress than the quantity of social support.

The type of support received by the caregiver is also of importance. Miller, Townsend, Carpenter, Montgomery, Stull & Young (2001) combined the samples from four different studies to examine the influence of instrumental (practical assistance with care tasks), emotional (receiving reassurance from others) and formal support (support from health services) on distress. The analysis examining the patterns between social support and distress produced mixed results, however it was found that low levels of emotional support was associated with higher distress. Miller & Guo (2000) examined the social support available to 210 spouse caregivers of individuals with a dementia diagnosis. The study explored the interaction between caregiver characteristics and the individual supporting the caregiver. It was found that White male caregivers were more likely to receive emotional support from adult children and more likely to receive practical assistance from formal services compared with other types of support and with other race-gender groups. The findings are in accordance with the TMSC as contextual factors influence the amount and nature of social support available to the caregiver, which in turn affects caregiver distress. Despite the deluge of caregiver research supporting stress and coping processes, the models have been mainly developed using Caucasian samples, and it is likely that different factors may be at play in different cultures, therefore the next section will focus on defining ethnicity and culture and how they may affect the caregiver role.

Ethnicity and Culture

Ethnicity:

The concept of race was dominant in early 19^{th} century, whereby the human population was divided based on visible physical characteristics. However the term has been considered to have little descriptive value as there is often greater variation within one racial group than there is between two groups (Hutchinson & Smith, 1996). The term ethnicity is derived from the Greek word ethnos, meaning nation (Bhopal, 2004), however this is misleading as ethnicity may vary within a nation for example the UK consists of a number of different ethnic groups. Ethnic differences are often due to group member constructing boundaries between themselves and other as well as being labelled “other” by the dominant group. Ethnic group membership is not necessarily based on a “blood bond,” individuals in ethnic groups have a subjective belief about their common ancestry based on similarities in physical appearance and/or customs.

The term ethnicity is difficult to define as it encompasses a number of different attributes. MacLachlan (2006) defines ethnicity as essentially a psychological sense of belonging to a group that is based on common physical or social appearance. Hutchinson & Smith (1996) describe six main features of ethnicity:

1. A common name to identify the group.
2. Common ancestry.
3. Shared historical memories.
4. Elements of a common culture (language, customs, and religion).

5. A link with a “homeland” (not necessarily a physical occupation of a country but a symbolic attachment).
6. A sense of group solidarity.

Ethnic groups are separated from one another through boundaries which are not necessarily geographical and are maintained by index features. Index features are required to be visible to everyone and illustrate the minimum requirements of belonging to a certain group. The most common index feature is kinship (presumed biological and descent unity of a group), followed by commensality (equality and peer ship in a group and also perceived promise of further kinship) and religion. The three boundary markers (kinship, commensality and religion) are the basic structure of ethnic group differentiation. Sometimes the member’s basic symbols of ethnicity are not visible in social interaction and therefore other features such as dress; language and diet act as index features.

Religion is important in ethnic group differentiation in particular when the gap between communities is wide. The type of religion endorsed by an ethnic group will determine how porous the ethnic group boundaries are, for example unlike Christian and Muslim groups, the Jewish community is non missionary (does not actively convert people) and thus the group has the least porous boundaries of the three groups. Religion is important in determining how capable an ethnic group will be to withstanding external pressures to assimilate with a more dominant group and how willing the group is in allowing outsiders to join the group through marriage and religious conversion.

Culture:

Ethnicity and culture are closely related but do not directly map onto one another. A common ethnic origin for example “Indian” does not imply a uniform culture for example within India there is a number of different religious groups (Hindu, Muslim, and Sikh) who also speak different languages and dialects. Culture has been defined as a shared set of values, assumptions, perceptions and conventions based on a shared history or language which allow a community to function together (Henry & Schott, 1999). Some aspects of culture are obvious such as language; however other aspects may be less visible such as behavioural values. Unlike ethnicity, culture is not fixed or static; it is a dynamic entity which changes to incorporate new ideas as people interact with the environment in new ways over time.

Within a culture there is a range of norms and values and a multitude of choices leading to the development of micro cultures (Henry & Schott, 1996). Micro cultures are within the range of the main culture (macro culture) but ascribe to slightly different beliefs compared to the main cultural values of the group (similar to the normal distribution bell curve found in statistical charts). Micro cultures can be influenced by social class and geographical region of origin. Individuals are therefore not only influenced by the wider culture of society but also the micro culture within their groups (Henry & Schott, 1996). For example, an Indian Hindu (macro culture) will not only live by the values of the main group (Hinduism) but will also have different experiences based on their caste (similar to social class).

Religion is an important feature in culture. Some societies, such as the Amish community (originally from Switzerland and emigrated to America in the early 18th century) are found to be slower to change (e.g. the Amish community shun modern conveniences such as electricity) as they contain features (religion) that enable them withstand external pressures to change. Societies that have been found to be strongly religious are usually the slowest to change (Henry & Schott, 1999). Communities that often uprooted from their homeland (perhaps due to war) become more conservative as a response to their fear of losing their identity and values due to external pressures (Henry & Schott, 1999).

An interesting line of research has been to examine various psychological dimensions such as health beliefs amongst various cultural groups. Murdock (1980) classified the beliefs of illness causes based on data from a health belief questionnaire conducted in 189 different cultures. Murdock (1980) distinguishes between beliefs of natural causation of illness (infection, stress, accident) and supernatural causation, which is further categorised into mystical causation (fate, ominous sensations that is dreams, contagion that is a polluting person and mystical retribution which causes illness through the violation of a taboo); animistic causation (e.g. loss of soul and spirit aggression) and magical causation (sorcery and witchcraft) which ascribes the cause of an illness to another person who uses magic to cause harm.

Chalmers (1996) further examined African views of health and illness and found that in Southern Africa, spiritual influences on health were emphasised. In contrast to Western views, the African culture had a holistic approach to health i.e. biological, spiritual, social and interpersonal functioning were interlinked. A disruption of this equilibrium could lead to impairment in functioning. Within this holistic approach, the individual is responsible for the wellbeing of the entire group suggesting collectivist values are of importance, whereas in the western society individualist values are more common, encouraging the idea that health is the responsibility of the individual and illness is caused by a poor diet, lack of exercise and bad habits such as smoking and drinking (Furnham, Akande & Baguma, 1996).

As well as individualism (focusing on ones own welfare) and collectivism (concern for the welfare of the wider community) a third cultural value known as familism has been highlighted as influencing obligations to provide care (Killian &

Ganong, 2002). Familism is orientated towards the welfare of one’s own family and involves strong feelings of loyalty and solidarity amongst the family members. It has been proposed that familism is at the root of family caregiving (Ramos, 2004). Familism consists of various attributes with some studies focusing on filial obligation (defined as a general attitude of appropriate behaviour within the context of specific personal relationship with kin) and others on filial responsibility (defined as a societal attitude toward adult children’s duty to meet the needs of aging parents; Stein, Wemmerus, Ward, Gaines, Freeberg & Thomas, 1998).

The Socio-cultural Stress and Coping Model:

Aranda & Knight (1997) adapted Lazarus’ Transactional Model of Stress and Coping and proposed a broader model, the Socio-cultural Stress and Coping Model (SCM) to provide a framework for understanding caregivers stress and coping in diverse cultural groups. This model proposes that ethnicity is associated with specific cultural differences that will directly affect caregiver appraisal and indirectly via appraisals, influence mediating variables such as coping and outcomes.

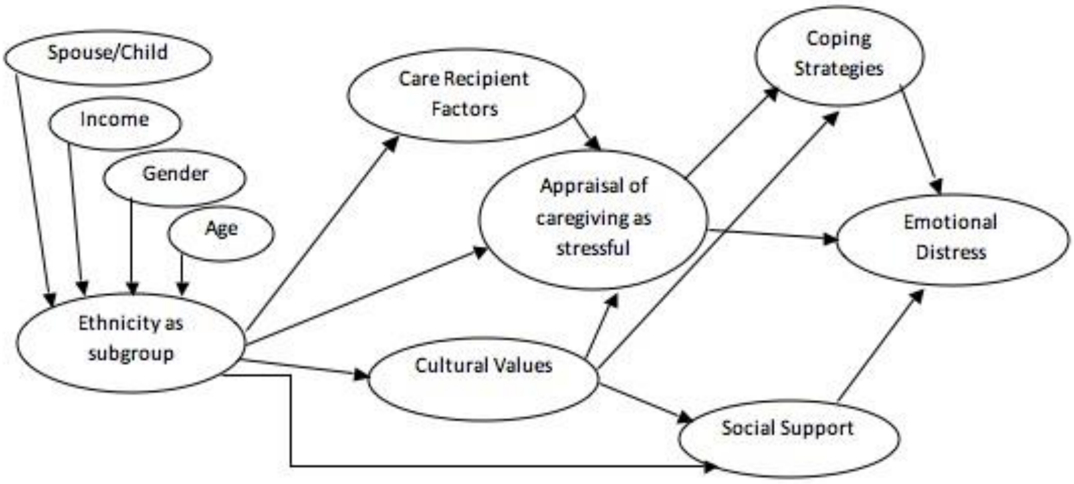
The model proposes ethnicity as a status variable (that is ethnicity is related to disadvantaged minority status which is confounded by socioeconomic status). This model focuses on “ethnicity as culture”, this is in contrast to models described previously which treat ethnicity and culture as separate albeit overlapping constructs. The SCM proposes five components:

1. The influence of ethnicity on status variables (ethnic differences in gender, age, relationship, and other demographic characteristics).
2. The demands of caregiving that may differ by ethnic groups.
3. The appraisal of the caregiver role which will be related to the caregiver’s cultural values.

4. Coping that will be affected by cultural differences.
5. The mental health outcomes of the stress and coping process.

These ethnicity as culture differences can affect each stage of the model simultaneously and in differing directions (Knight, Silverstein, McCallum & Fox, 2000; Knight & Sayegh, 2010).

Figure 3. *Socio-cultural Model of Stress (adapted from Knight & Sayegh, 2010).*



The above model has been tested in a number of ethnic minority caregiver populations including African American (Shurgot & Knight, 2005), Hispanic American (Losada, Shurgot, Knight et al, 2006), Korean and Korean American (Chun, Knight & Youn, 2007), Japanese American (Adams, Aranda, Kemp, Takagi, 2002), Chinese Canadian (Lai, 2007) and also Chinese American (Zhan, 2006). Cultural values such as familism show promise in terms of effects on stress and coping in Eastern Asian (particularly Korean) caregivers. It may be that the role of cultural values in the SCM is group specific (Knight & Sayegh, 2010). In the next section, the research examining the British South-Asian caregiver experience to date will be discussed and critiqued.

Current British South-Asian caregiver research

There has been a particular lack of research conducted with the British South-Asian caregiver community. As discussed earlier in the chapter, the biggest ethnic minority group in the UK is British South-Asian and individuals from this group are the most likely to be providing care from the entire population. The lack of research focusing on British South-Asian caregivers may be due to language barriers in accessing this group and the common held myth that Asian families “look after their own” and have an extended family as a support network (Atkin & Rollings, 1992).

Patterns of family based care on the Indian subcontinent have led to generalisations being made about British South-Asian families in the UK. The stereotype of the virtuous caring Asian family (Atkin & Rollings, 1992) fails to take into account the diversity of perspectives and behaviour within an ethnic group. Katbamna (1998) proposes four arguments as to why the assumption that “Asians look after their own” is not necessarily the case in the UK.

1. Family based care may be common in South-Asian families but it is not universal.
2. When the welfare system of a country is lacking, family caregiving can become a compulsory form of altruism.
3. Society is largely agrarian on the Indian subcontinent. Land is inherited by children from parents in return for providing care. Failure to provide care could thus be costly for adult children. The penalty is unlikely to be considered costly by South-Asian adult children in the UK.
4. Religious and cultural teachings are important in forming family care values; however these values may conflict with the more individualistic aspects of British society.

The structure of South-Asian families has been changing as a result of a number of external pressures such as the 1971 Immigration Act, and further economic changes in Britain have increased pressure on individuals to relocate with their jobs. This has led to British South-Asian families fragmenting and the extended family is no longer the norm (Katbamna, 1998). Although feelings of obligation to provide care may still exist among British South-Asian families, the change in family structure will make it more difficult for British South-Asian families to fulfil these obligations. This in turn could have psychological consequences for the caregiver due to feelings of guilt caused by being unable to fulfil one's responsibilities and obligations (Ahmad & Atkin, 1996).

As noted elsewhere there has been very little research exploring British South-Asian caregiver's motivations and obligations for providing care. One exception is that of Katbamna (1998) who conducted a large exploratory qualitative study to examine British South-Asian caregiver's motivations for role adoption and experience in the care role. The study used three focus groups involving a total of 86 caregivers and a further 34 caregivers participated in an individual in-depth interview. The study found that the rationale behind caregiver role adoption was very complex and the main themes identified were: duty to care and cultural upbringing, lack of choice, religious beliefs, societal expectations, love and reciprocation. It is often thought that the extended British South-Asian family shares care responsibilities but caregivers in this study reported that other relatives commonly avoided their responsibilities. Due to strong religious beliefs (that is caregivers believed they had a religious obligation to provide care), many caregivers were found to be enduring an extremely difficult situation that is tolerating abusive behaviour from the care recipient.

More recently, Lawrence, Murray, Samsi & Banerjee (2008) explored South-Asian caregiver's attitudes towards providing care and how this influenced their use of formal services. In depth interviews were conducted with 10 South-Asian, 10 Black-Caribbean and 12 White-British caregivers. It was found that the majority of South-Asian, half the Black-Caribbean and a minority of White-British caregivers possessed a traditional ideology of caregiving (that is caregiving is "natural, expected and virtuous"). South-Asian caregivers identified asking for help as a failure to fulfil their responsibilities but valued knowing what support is available.

The majority of the limited numbers of studies exploring the British South-Asian caregiver experience have focused on perceptions of, and actual use of, social support. Katbamna, Ahmad, Bhakta, Baker & Parker (2004) examined the quantity and quality of support available to British South-Asian caregivers. 105 caregivers of individuals with a physical and/or mental illness participated in focus groups. It was found that the main caregivers irrespective of gender had limited support from both nuclear and extended family networks. Attitudes towards disability and fear of societal disapproval prevented the caregiver from seeking and accepting support from wider networks. It is worth noting that this may not be exclusive to the Asian community as fear of societal disapproval exists in all groups. The study does not make use of a comparison non Asian sample thus rendering it difficult to assess if fear of disapproval is stronger within the Asian community.

With regards to the use of formal services by British South-Asian caregivers; Perry, Hsu, Brooks & Cherry (1999) conducted in depth interviews with 15 South-Asian and 13 White-British caregivers of stroke survivors. Their findings suggest that feelings of isolation and depression were more common amongst South-Asian caregivers than White-British caregivers; however both groups were concerned about the availability of services in the community. Although South-Asian families were aware of available services, problems with access and financial cost deterred them from using the service. In contrast, Hepworth (2005) used a semi structured interview methodology (supplemented with workshop discussions) with 26 South-Asian caregivers and found that many caregivers were unaware of what support they were entitled to and what services were available in the community. The concept of friendship with health care professionals was also found to be very important for South-Asian caregivers. Merrell, Kinsella, Murphy, Philpin & Ali (2005) using data from in depth interviews with 20 Bangladeshi caregivers also found that caregivers lacked awareness of the health and social services available to them.

Bowes & Wilkinson (2003) examined the experience of South-Asian caregivers of persons with a dementia diagnosis with formal services. The study made use of four case studies of South-Asian families as well as in depth interviews with 11 health care professionals. The study found that South-Asian families had very little knowledge about dementia and had a very negative experience in the care role. The caregivers also had a very poor quality of life due to isolation from the family and the wider community. In regards to support, the caregivers were in desperate need of support but lacked access to appropriate services. Health care professionals also voiced the need for culturally appropriate services for South-Asian caregivers.

With regards to the quality of formal support available to South-Asian caregivers; Mir & Tovey (2003) interviewed 20 South-Asian caregivers of children with a cerebral palsy diagnosis. The study found that the quality of the relationship between the caregiver and service provider was associated with the wellbeing of the individual diagnosed with cerebral palsy. Many caregivers had a poor relationship with service providers due to poor levels of communication. This resulted in lack of information for the caregiver and emotional support from the service provider. Katbamna, Bhakta, Parker & Ahmad (1997) suggest that the lack of awareness amongst South-Asian caregivers is not the only barrier to accessing support. They propose that the service providers can create further barriers due to their lack of understanding about the lifestyle and healthcare needs of ethnic minority communities. Other barriers include the inability of services to meet the needs of people who are unable to speak English (Gerrish, 2001); and the existence of services that are culturally inappropriate or inflexible.

The current research examining the British South-Asian caregiver experience has a number of limitations that need to be taken into account. Primarily the majority of the studies lack any theoretical context and are mainly exploratory qualitative studies, although these studies have provided detailed evidence of the British South-Asian caregiver experience; the research to date has mainly been descriptive and based on small scale local samples that are difficult to generalise to a larger population. However the studies do highlight the important factors in the caregiver experience such as care role motivations. The majority of studies do not utilise a comparative sample but make assertions regarding similarities and differences amongst ethnic groups (Katbamna, 1998). Although there have been some studies examining obligations to provide care in British South-Asian families (Katbamna, 1998; Lawrence et al, 2008), the empirical evidence related to how factors such as motivations and willingness to care operate in British South-Asian families remains limited. Whilst much of British South-Asian caregiver research has focused on perceptions and use of informal and formal support, very little, if any, research has addressed the critical role played by illness perceptions and coping, factors which likely interact with support use and caregiver outcomes.

The Present Thesis

The South-Asian population is the largest ethnic minority group in the U.K. (Census 2001) yet little research has explored the British South-Asian caregiver experience. This group may be particularly vulnerable to stress due to low social economic status, language barriers and low perceptions of social support; all factors that have been associated with poor coping and negative outcomes amongst White-British caregiver samples. There is also a limited body of evidence regarding the influences upon their caregiving outcomes. The aim of this PhD thesis was, by means of a series of studies, to examine the influence of ethnicity on caregiver distress and quality of life. Core psychological models specifically the Transactional Model of Stress and Coping (Lazarus, 1984) are used to identify factors that mediate the relationship between ethnicity and culture on caregiver outcomes of distress and quality of life.

Aims:

1. To critically review the literature and establish a number of recommendations to lend impetus and give direction to the field.

From the critical review, further aims were established:

2. Explore ethnic differences in caregiver cultural values (familism), appraisals, coping and use of social support.
3. Examine the influence of ethnicity and familism on caregiver outcomes of anxiety, depression and quality of life.
4. Conduct longitudinal empirical work to establish changes in the caregiver experience overtime and examine how *change* affects caregiver outcomes.

The following is a brief overview of the structure of the thesis which comprises of a critical research review, a qualitative study, three quantitative empirical studies and a discussion chapter which aims to integrate and explore the implications of the findings. The thesis is written as a collection of research papers which are summarised below.

Chapter 2. Ethnicity, Mediators and Caregiver Outcomes: A systematic review

A systematic review of existing quantitative caregiver research was conducted to explore the influence of ethnicity on caregiver burden and identify factors which affect this relationship. A systematic search was conducted using 9 databases and 259 studies were identified, 62 of which made use of an Asian (including Chinese, Japanese, Korean, Taiwanese) caregiver sample. Only 33 of the 62 studies were found to be relevant to the research questions, and of these 33 studies only 3 made use of a South-Asian caregiver sample (one British) and there was no ethnic comparison group. This suggests that there is a “gap” in the research field in regards to exploring ethnicity and caregiver burden and the process by which the effect occurs in British South-Asian caregivers.

Chapter 3. Predictors of Familism: A Pilot Study

The second study aimed to investigate whether age, gender and ethnicity were predictive of familism in caregivers; and whether familism was associated with coping in a sample of 45 British South-Asian and 43 White-British caregivers. Using a cross-sectional questionnaire methodology it was found that British South-Asian and younger caregivers endorsed higher levels of familsim than White-British and older caregivers. In the final regression model, demographic variables, humour, religious, active and instrumental coping explained 41% of the variance in caregiver familism.

Chapter 4. Ethnic Variations in the Caregiver Role: A Qualitative Study

The next stage of the research was to explore ethnic variations in the caregiver role in a qualitative study. Eight Bangladeshi, nine Indian, four Pakistani and nine White-British caregivers participated in five focus groups. The following themes emerged from thematic content analysis: motivations for role adoption, willingness to provide care, experience of role, adaptation to care role, coping, use of and satisfaction with support. Differences not only existed between caregivers at the macro level (British South-Asian vs. White-British) but also at the micro level.

Chapter 5. Ethnicity, Familism and Willingness to Care: Important influences on caregiver mood?

The fourth research study involved further examining the ethnic differences identified in the previous qualitative study, in a cross-sectional questionnaire study of 163 White-British and 73 British South-Asian caregivers. British South-Asian caregivers had significantly higher levels of familism than White-British caregivers. They were also more reliant on the use of religious coping and behavioral disengagement whereas White-British caregivers were more likely to make use of substances or humour as coping methods. There was no significant difference in levels of willingness to care. The final model predicted 45% of variance in anxiety in British South-Asian caregivers and 26% in White-British caregivers. The depression model accounted for 36% of variance in British South-Asian depression and 29% in White-British caregiver depression.

Chapter 6, 7 and 8. Predicting Longitudinal Change in Caregiver Outcomes.

Using a longitudinal design (baseline, 3 months from baseline and 9 months from baseline), the influence of changes in motivations to care, familism, illness perceptions, coping and social support was examined on caregiver outcomes in a sample of 123 caregivers. The results of the study are presented as three separate chapters: caregiver anxiety and depression (chapter 6), caregiver gains (chapter 7) and caregiver quality of life (chapter 8). When exploring the influence of independent variables on caregiver outcomes, the IV scores were converted into residual change scores to examine change in predictor variables and the effect on absolute outcomes at nine months from baseline. Early illness perceptions were associated with longitudinal anxiety and depression and changes in coping remained an important factor through out. Ethnicity, care recipient diagnosis and early changes in illness perceptions were important predictors of quality of life. With regards to caregiver gains early changes in familism, illness coherence, use of self distraction and denial were significant predictors of gains. Later change in use of emotional support was a stronger predictor of caregiver gains.

Chapter 2

Ethnicity, Mediators and Caregiver Outcomes: A Systematic Review

The material presented in this chapter is currently in review as

Parveen, S & Morrison, V. Ethnicity, mediators and caregiver outcomes: A systematic review. *Health Psychology Review*

Abstract

The purpose of this systematic review is to examine whether ethnicity is related to caregiver outcomes of burden/strain, anxiety, depression and quality of life and what factors mediate this process. The review specifically includes adult family caregivers of Asian ethnicity with Caucasian caregivers used as a comparison group. A systematic search using nine electronic databases identified 259 studies but only 17 studies met the review criteria and addressed relevant research questions. Of these, nine explored ethnic differences in outcomes. Four studies found that Asian caregivers experienced significantly more burden than Caucasian caregivers; one study found that Caucasian caregivers experienced significantly higher levels of distress than Asian caregivers; the remaining four studies found no significant effect of ethnicity on caregiver outcomes. Common mediators examined included familism and social support. Asian caregivers were found to have higher levels of familism and lower levels of social support than Caucasian caregivers however only social support was a mediator between ethnicity and outcomes. The findings have implications for the development of culturally sensitive services and caregiver policy.

Introduction

It is estimated that 80% of the care required to maintain patients at home is now provided by informal caregivers (Brereton, 2002). Informal caregivers are individuals who support (beyond what is typical for their relationship) a family member or friend who are experiencing problems due to physical, emotional or cognitive impairments; often without financial compensation (Bridges, 1995). There are approximately six million caregivers in the U.K with 1.25 million caregivers providing more than 50 hours of care per week (Carers UK, 2009).

The UK census (2001) reports that of the various ethnic groups in the UK, individuals from a White-British and British Asian (Bangladeshi, Indian and Pakistani) ethnic groups were the most likely to be providing informal care. This report further estimates that there are 285, 000 ethnic minority caregivers. British-Bangladeshi and British-Pakistani caregivers were found to have the highest rate of spending more than 50 hours per week providing care to a family member.

Ethnicity is thought to encompass a number of components such as a similar language, religion, experience of migration and ancestry. Each component singularly or in combination can contribute towards differences in health between groups (Nazroo, 1997). Culture is very closely linked to ethnicity but is thought to be more amenable to change and is defined as a set of values based on shared ancestral history and language which enable members of a community to function together (Henry & Schott, 1999). According to Gaines, Marelich, Bledsoe et al. (1997), the three main cultural values include individualism (concern towards ones own welfare), collectivism (concern regarding the welfare of the community) and familism (inclination towards the welfare of ones own family). Familism is often thought to be at the root of caregiving (Ramos, 2004) and specific ethnic minority caregivers

(Hispanic and Asian) caregivers have been found to have high levels of familism (Losada, Robinson, Knight, Marquez, Montorio, Izal, & Ruiz, 2006 & Chun, Knight, & Youn, 2007).

Stress and coping theories have commonly been applied to the study of caregiving, for example the Transactional model of stress and coping (Lazarus & Folkman, 1984), highlights the transaction between an individual's cognitive appraisals and reappraisals of an event, the experience of various emotions, and resulting coping response (Lazarus, 1999). Coping is defined as the process whereby an individual attempts to limit or manage the perceived discrepancy between the real or perceived demands of a situation and the resources the individual considers they have available to deal with it (Lazarus, 2000). Haley, Levine, Brown & Bartolucci (1987) were the first to apply and adapt this model to caregivers and suggest that contextual factors such as caregiver age and gender alongside the demands on the caregiver caused by for example care recipient's behavioural problems, will affect the caregiver's appraisal of the situation. Coping, including the use of social support, were found to mediate the relationship between the caregiver's appraisal of the situation and outcomes such as distress. Although the model has clear relevance in caregiver literature, it has mainly been developed using Caucasian caregivers and has not been applied to the ethnic minority caregiver population in the UK.

Reviews by Dilworth-Anderson, Williams & Gibson (2002) and Pinquart & Sorensen (2005) suggest that ethnic groups (the reviews included samples of White-American, African American, Hispanic American and Asian American caregivers) may differ in contextual factors (socioeconomic status, adult child vs. spouse caregiver); interpersonal factors (extent of family obligations); situational factors (severity of care recipient’s condition); temporal factors (timing of caregiving in life cycle); and personal factors (coping style and use of social support).

This is in accordance with the Socio-cultural model of stress and coping proposed by Aranda & Knight (1997), which states that ethnicity implies specific cultural differences that will directly affect the appraisal of caregiving and this will influence potential mediating variables such as coping responses. Their model contains five main components with the first consisting of status variables such as whether the caregiver is an adult child or a spouse. The second component includes perceived demands of caregiving that may differ by ethnic group, which leads to the overall appraisal of the situation. The caregiver’s appraisals are related to the caregiver’s cultural values for example familism (third component) and these cultural values will affect the fourth component of the model that is the coping response and the use of social support (fifth component) which mediate the effect of cultural values on mental health outcomes. In summary this model extends Lazarus’s model by adding emphasis on ethnicity as culture and proposes that “ethnicity as culture” can affect each component of the model simultaneously and in differing directions.

The purpose of the current systematic review is to identify studies which have utilised Asian caregiver samples in order to examine the caregiver experience. Unlike previous reviews (Dilworth-Anderson et al, 2002 and Pinquart & Sorensen, 2005), this review will exclusively focus on Asian caregivers in comparison to Caucasian caregivers. The review is exploratory in nature and it is hoped that the systematic review will not only integrate existing research but also identify research gaps in the field. The main questions to be addressed are as follows:

1) Do Asian and Caucasian caregivers differ in caregiver outcomes including burden, strain, stress, anxiety, depression and quality of life?

2a) What caregiver factors (e.g. use of social support) have been examined in past research?

2b) Do ethnic groups differ in caregiver factors?

3) What is the association between caregiver factors and caregiver outcomes?

Method

Data sources:

A systematic literature search was conducted using the following electronic databases: Medline (CSA), Medline (First Search), Psych articles, Psych Info, Science Citation Index, Applied Social Sciences Index and Abstracts, CAB Direct, CINAHL and Aids and Cancer Research Abstracts. Combinations of the following search terms were used: *care**, *ethnic**, *race**, *Asian**, *burden, strain, distress, anxiety, depression* and *quality of life*. Further studies were identified through cross referencing.

Study selection:

Inclusion criteria: Empirical, quantitative study, current informal adult caregivers, with at least a proportion representing an Asian caregiver population; assessment of one of the following outcomes: burden, strain, distress, anxiety, depression or quality of life. Only studies reported in the English language were included. No restrictions were applied on caregiver relationship type e.g. spouse/non spouse, gender, care recipient’s age, gender or care recipient’s diagnosis.

Exclusion criteria: Common reasons for study exclusion included: qualitative data only, no empirical data pertaining to any of the key outcomes outlined above and multiple papers using the same data to test different hypotheses.

From the nine electronic databases searched, 259 studies were identified on the basis of key words in their titles. Of the 259 studies, only 60 included an Asian caregiver sample and these then had their abstracts screened by two researchers to ensure the studies met the inclusion criteria. The full text of the 60 studies were retrieved and reviewed according to the study criteria and 17 were deemed eligible for full review with an inter-rater agreement rate of 89.2%.

Data extraction:

Data extraction was completed by the first author (SP) for the 17 relevant studies to be included in the review. Five main categories of data were recorded: study characteristics (authors, location and date of publication); sample characteristics (caregiver ethnic groups, gender, age, relationship with care recipient, time in care role and care recipient diagnosis); outcomes measured (ethnic differences in outcomes); caregiver factors such as use of social support (ethnic differences in caregiver factors) and the influence of caregiver factors on outcomes. A number of studies included African American, Hispanic American samples as well as Asian and Caucasian however for this review, only data pertaining to Caucasian and Asian caregivers were recorded.

Results

The sample descriptions of the studies included in the review are presented in Table 1. The 17 studies included in the review were published during 1997-2009. Of the 17 studies, 12 studies were American, two were based in Taiwan, one was Canadian, one was based in China and one in the UK. Of the 17 studies, 13 studies used a sample of Eastern Asian (Chinese, Korean) caregivers and three included South-Asian (Indian) caregiver samples. All studies made use of a cross-sectional design.

Table 1. Sample description of the studies included in the review.

		Sample characteristics					
Paper ID	Author/ Location	Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
1	Adams et al/USA (2002)	Japanese American (41), Anglo American (67), African American (49), Mexican American (45)	JA Male = 12, Female = 29. AA Male = 31 Female = 36. AfA Male = 13, Female = 36. MA Male = 10, Female = 35	JA Male = 75, Female = 70. AA Male = 76 Female = 67. AfA Male = 68, Female = 66. MA Male = 77, Female = 68.	Spouse	JA = 45, AA = 45, AfA = 34.6, MA = 68.8	Dementia
2	Chun et al/South Korea & USA (2007)	Korean (64), Korean American (53), White American (54)	K Male = 8%, Female = 92% KA Male = 24%, Female = 76% WA Male = 35%, Female = 65%	K = 53 KA= 58 WA= 67	Spouse: K = 7.7%, KA = 41.5%, WA = 70.4% Children: K = 16.9%, KA = 43.4%, WA = 29.6% Children in law: K = 75.4%, KA = 15.1%, WA = 0%	K = 2.7, KA = 4.2, WA = 4.5	Dementia

Paper ID	Author/ Location	Sample characteristics Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
3	Fredriksen-Goldsen et al/USA (2004)	White American (61%), Latino (25%), African American (6%), Asian/Native Hawaiian (5%). Full sample = 1643 caregivers.	Male = 25% Female = 75%	WA = 54.36, L = 43.7, AA = 49.3, A/Nat Hawaiian = 49.3	Parent: WA = 45.8%, L = 56.8%, AA = 38.1%, A/Nat = 64%. Spouse: WA = 15.1%, L = 8.1%, AA = 9.3%, A/Nat = 8% Friend: WA = 12.6%, L = 9.8%, AA = 12.4%, A/Nat = 4%.	Unspecified	Unspecified
4	Giunta et al/USA (2004)	White American (61%), Latino (25%), African American (6%), Asian/Native Hawaiian (5%). Full sample = 1643 caregivers.	Male = 25% Female = 75%	WA = 54.36, L = 43.7, AA = 49.3, A/Nat Hawaiian = 49.3	Parent: WA = 45.8%, L = 56.8%, AA = 38.1%, A/Nat = 64%. Spouse: WA = 15.1%, L = 8.1%, AA = 9.3%, A/Nat = 8% Friend: WA = 12.6%, L = 9.8%, AA = 12.4%, A/Nat = 4%.	Unspecified	Unspecified
5	Gupta et al/USA (2009)	Asian Indian (263) (Recruited from India)	Male = 69 Female = 194	Unspecified	Unspecified	Unspecified	Unspecified

Paper ID	Author/ Location	Sample characteristics					
		Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
6	Gupta & Pillai/USA (2002)	Asian Indian American (118) (Recruited from Texas, USA)	Male = 39.8% Female = 60.2%	Mean = 30 years	Daughter = 20.3% Son = 33.9% Daughter-in-law = 38.1% Son-in-law = 3.4% Others = 4.2%	Unspecified	Unspecified
7	Lai/ Canada (2007)	Chinese Canadian (339)	Male = 34.5% Female = 65.5%	Range = 18-75 years	Daughters = 35.4% Sons = 22.4% Spouse = 18.6% Daughters-in-law = 11.8% Sons-in-law = 4.1%	Unspecified	Dementia
8	Lee & Farran/ USA (2004)	Korean (100), Korean American (59), White American (78)	All female	K= 50 KA= 58 WA = 60	Spouse: K = 16%, KA = 23.7%, WA = 48.7%.Daughter: K = 31%, KA = 42.4%, WA = 46.2%. Daughter-in-law: K = 50%, KA = 28.8%, WA = 3.8%	Unspecified	Dementia
9	Lee/ Taiwan (2007)	130 caregivers from Taiwan	Male = 55 Female = 75	Mean = 47.2 years	Son = 48, Daughter = 43, Daughter in law = 29, Other = 10	Mean = 63.5 months	Cardio-vascular and diabetes.

		Sample characteristics					
Paper ID	Author/ Location	Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
10	Levy et al/USA (2000)	Chinese American (10), African American (10), Latino American (10), White American (10).	Male = 12% Female = 88%	Mean age = 57 Range = 29-84	Daughters = 70% Spouse = 22% Sons = 8%	Unspecified	Dementia
11	Mackenzie et al/UK (2007)	White British (28), Black British (4), Asian British (5)	Male = 13 Female = 24	Mean age = 61.7 Age range = 28-84	Spouse = 24 Daughters = 8	Unspecified	Stroke
12	McCabe et al/ USA (2003)	White American (43.2%), Latino American (29.9%), African American (18.4%), Asian American (8.5%) Full sample = 1715	Unspecified	Unspecified	Parents	Unspecified	Emotional and behavioural problems

		Sample characteristics					
Paper ID	Author/ Location	Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
13	Shaw et al/China & USA (1997)	Chinese caregivers (110) Chinese control group (110) White American (139) WA control group (51)	Chinese caregivers: Male = 47, Female = 63. White American caregivers: Male = 49, Female = 90	Chinese caregivers = 58 White American caregivers = 70.7	Spouse: Chinese = 31%. White American = 100% Adult Child: Chinese = 60%	Unspecified	Dementia
14	Tsai & Wang/ Taiwan (2009)	127 caregivers from Taiwan	All female	Mean = 38 Range = 23-51	Parent	Mean = 9 Range = 7-12 yrs	Intellectually disabled
15	Yeung et al/Hong Kong & U.K (2007)	Hong Kong (70)	Male = 22 Female = 48	Below 60 = 38 61-70 = 21 70+ = 11	Spouse = 37 Adult child = 23 Other = 10	Unspecified	Stroke

Paper ID	Author/ Location	Sample characteristics					
		Ethnic Groups	Gender	Mean age (yrs)	Relationship with care recipient	Mean time in care role (yrs)	Patient diagnosis
16	Youn et al/Korea & USA (1999)	Korean (44), Korean American (32), White American (54)	K Male = 6.8%, Female = 93.2% KA Male = 12.5%, Female = 87.5% WA Male = 35.2%, Female = 64.8%	K= 52.8 KA= 56.4 WA= 67.7	Spouse: K = 6.8%, KA = 40.4%, WA = 70.3% Daughter: K = 6.8%, KA = 37.5%, WA = 20.4% Daughter-in-law: K = 79.5%, KA = 18.8%, WA = 0%	K = 2.9 KA = 3.8 WA = 4.5	Dementia
17	Zhan/USA (2006)	110 Chinese American	Male = 35 Female = 75	Range = 27-60	Daughters = 50.9% Sons = 30% Daughter-in-laws = 17.1%	Unspecified	Unspecified

Note:

JA = Japanese American

AA= Anglo American

AfA = African American

MA = Mexican American

K = Korean

KA = Korean American

WA = White American

L = Latino American

Ethnicity and outcomes:

The first question the review aimed to address was whether Asian and Caucasian caregivers differed in outcomes of burden, strain, anxiety and depression (no studies were found to explore ethnic differences in caregiver stress or quality of life). Nine studies were found to address this question and the results are summarised in Table 2.

Burden: Three studies (Chun et al, 2007; Mackenzie et al, 2007 and Youn et al, 1999) examined differences in burden amongst Asian and Caucasian caregivers and it is worth noting that one (Mackenzie et al) uses a European/British sample, whilst the other two are American. Chun et al (2007) and Youn et al (1999) explored the experience of Korean, Korean American and White American caregivers of care recipient's with a dementia diagnosis. Korean caregivers were younger than White American caregivers and more likely to be daughter-in-laws. Korean caregivers had spent the least number of years providing care and White American caregivers had spent the most time in the care role. Both studies found that Korean caregivers reported significantly more burden than White American caregivers. The third study in this group by Mackenzie et al (2007) examined White-British and British Asian caregivers of a family member with a stroke diagnosis. The study mainly consisted of female caregivers (65%) and did not provide any other demographic characteristics for the ethnic groups. They also found that Asian caregivers reported significantly higher levels of burden than White-British caregivers, however only five Asian caregivers were included in the sample and during analysis, Asian caregivers were combined with other non-White caregivers, which precludes clear interpretation of findings in relation to our research questions.

Strain: Three studies (Fredriksen-Goldsen et al, 2004; Giunta et al, 2004 and McCabe et al., 2003) examined ethnic differences in caregiver strain using large multi ethnic samples consisting of White American, African American, Latino American and Asian American caregivers. All three studies provide very little demographic detail of ethnic groups and care recipient diagnosis is not made clear.

Fredriksen-Goldsen et al (2004) found that Asian caregivers were more often female, but finds no significant difference in strain experienced by the Asian and White American caregivers. Giunta et al (2004) report that Asian and White American caregivers were similar in age and relationship status, but do not provide any other demographic information. They also found that whilst Asian and White American caregivers did not differ significantly in terms of physical or emotional strain, Asian caregivers experienced significantly higher financial strain than White American caregivers. As with the previous two studies, McCabe et al (2003) also found no significant difference in strain between Asian and White American caregivers of a youth with behavioural and emotional problems.

Anxiety and Depression: Five studies (all conducted in the USA) explored ethnic differences in caregiver anxiety and depression, three of which included Korean caregivers providing care for an individual with a dementia diagnosis and in each instance Korean caregivers were younger and more likely to be daughter-in-laws than the other caregiver groups. Chun et al (2007), Youn et al (1999) and Lee & Farran (2004) compared Korean, Korean American and White American caregivers and found that Korean caregivers reported significantly higher levels of anxiety and depression than White American caregivers (and Korean American). However in Lee & Farran’s (2004) study Korean American caregivers were those individuals who had been born in American whilst in Chun et al (2007) and Youn et al’s (1999) study, the label Korean American was applied to Korean caregivers who lived in America (but not necessarily born there).

Adams et al (2002) describe findings from a study of Japanese American and White American spouse caregivers who were providing care for an individual with a dementia diagnosis. Japanese American caregivers were more likely to be female but did not differ in age or time spent caregiving from the White American caregivers. No significant difference in depression between Japanese American and White American caregivers was found. In contrast to the above studies, Shaw et al (1997) found that their sample of White American caregivers, also of an individual with a dementia diagnosis were significantly more depressed (observed and self reported) than their sample of Chinese caregivers. However the caregiver groups differed in age (Chinese caregivers were younger) and relationship status (White American caregivers were all spouses whereas the majority of Chinese caregivers were adult children).

Table 2. Ethnic differences in caregiver outcomes

Study ID	Outcome (Measure)	Results
2	Burden (Burden interview, Zarit, 1980) Anxiety (State anxiety scale, Spielberger, 1985) Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	*Burden:* K = 50.3, KA = 42.6, WA = 42.6. $p < .05$ *Anxiety:* K = 57.7, KA = 51.7, WA = 37.1. $p < .05$ *Depression:* K = 25.4, KA = 20.3, WA = 16.2. $p < .05$ Effect size not reported
8	Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	*Depression:* K caregivers ($M = 27.4$, $CI = 25.8\text{-}30.0$) significantly more depressed than KA ($M = 21.7$, $CI = 18.7\text{-}24.8$) and WA ($M = 20.00$, $CI = 15.7\text{-}24.6$) $p < .001$ Effect size not reported
11	Burden (The sense of competence questionnaire, Scholte, 1998).	*Burden:* White British reported significantly lower levels of burden (median = 48) compared to non white British groups (median = 53.5). $Z = -2.096$, $p < .05$. Effect size not reported
13	Observed depression. Self reported depression (Hamilton rating scale for depression). Self reported anxiety (Brief symptom inventory, Hopkins).	*Observer depression:* C = 2.6, WA = 5.3. $F = 6.03$, $p < .05$ *Self reported depression:* C = 0.26, WA = 0.67. $F = 8.79$, $p < .05$ *Self reported anxiety:* C = 0.23, WA = 0.55. $F = 14.17$, $p < .05$ Effect size not reported
16	Burden (Subjective burden interview, Zarit, 1980) Anxiety (State anxiety scale, Spielberger, 1985) Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	*Burden:* K = 31.5, KA = 33.4, WA = 26.9. $F(2, 127) = 6.33$, $p < .01$). *Anxiety:* K = 58.7, KA = 52.8, WA = 37.1. $F(2, 127) = 43.59$, $p < .001$ *Depression:* K = 25.4, KA = 19.7, WA = 16.2. $F(2, 127) = 10.43$, $p < .001$. Effect size not reported

Table 2 *continued*

Study ID	Outcome (Measure)	Results
1	Depression (The older adult health and mood questionnaire, Kemp & Adams, 1995).	*Depression:* Anglo American mean score = 6.5 Japanese American = 7.7 (NS)
3	Strain (5 item scale devised by researchers)	*Strain:* Scores could range from 1-4. White American = 2.68. Asian = 2.60. NS
4	Strain (3 single likert scale items determined emotional, physical and financial strain.	Descriptive data not provided. *Physical strain*: NS *Emotional strain*: NS *Financial strain:* All non white caregivers experience higher strain then white caregiver ($p < .001$).
12	Strain (caregiver strain questionnaire, Brannan, 1997).	*Strain:* WA = 2.50 Asian = 2.25. NS

Note:

K = Korean

KA = Korean American

WA = White American

C = Chinese

NS = Non significant

Ethnic differences in caregiver variables:

The second research question of the review was to establish what caregiver factors were considered in the studies and whether ethnic differences existed in caregiver variables. Studies were found to examine ethnic differences in caregiver familism, illness appraisals/attributions, caregiver coping and use of social support. The results of these studies are summarised in Table 3.

Familism: Two studies (Chun et al, 2007& Youn et al, 1999) examined ethnic differences in familism amongst Korean, Korean American and White American caregivers of an individual with a dementia diagnosis. Korean caregivers were found to have significantly higher levels of familism than Korean American and White American caregivers.

Illness attributions: Two studies examined ethnic differences in illness appraisals and attributions in relation to caregiving in dementia. Adams et al (2002) compared Japanese American and White American caregivers and Levy et al (2000) compared Chinese American and White American caregivers. Adams et al (2002) found no significant differences between their two samples in terms of positive (learning about life through caregiving) and perfectionist appraisal (not wanting to show any signs of weakness as a caregiver); however Japanese American caregivers were significantly more pessimistic. Levy et al (2000) found no significant difference in the number of illness attributions held by their two groups of caregivers; however Chinese caregivers were more likely to make psychosocial attributions for dementia onset whereas White American caregivers made more biomedical attributions.

Coping: Adams et al (2002) compared the coping responses of Japanese American and White American caregivers and found no significant difference with regards to use of active or avoidant coping styles. Japanese American caregivers were significantly higher in religiosity than White American caregivers. Shaw et al (1997) compared coping between Chinese and White American caregivers and two matched ethnicity non-caregiver control groups. Chinese caregivers used significantly more behavioural distancing and cognitive confronting than White American caregivers but there was no significant difference in behavioural confronting and cognitive distancing coping styles. Chinese caregivers furthermore used more cognitive confronting than the Chinese non-caregiver control group. Compared to their non-caregiver control group White American caregivers also made more use of cognitive confronting and behavioural distancing.

Social Support: Five studies examined ethnic differences in caregiver social support. Adams et al (2002) found no significant difference in the size of the social support network however Japanese American caregivers were significantly more likely to seek social support than White American caregivers. Chun et al (2007) found that Korean caregivers had significantly lower emotional and instrumental support than White Americans. Fredriksen-Goldsen et al (2004) recruited White American and Asian American caregivers from the same university workplace and found that Asian caregivers reported significantly lower workplace support than White American caregivers.

The above three studies had small samples in contrast to that of Giunta et al (2004) who, as previously indicated, conducted a large scale multi ethnic group study. In this study White American caregivers were more likely to use formal services than Asian American caregivers. In spite of having a large sample, the researchers combined the Asian sample with Hawaiian and Pacific Island caregivers which may have masked specific cultural/ethnic differences. McCabe et al (2003) also report findings from a large multi ethnic sample of caregivers, and although they provide very little demographic information, Asian American caregivers perceived significantly lower levels of support than White American caregivers.

Table 3. Ethnic differences in potential mediator variables

Study ID	Mediator (Measure)	Results
2	Familism (Familism scale, Bardis, 1959).	K = 60.9, KA = 56.4, WA = 42.6. $p < .05$
16	Familism (Familism scale, Bardis, 1959).	*Familism:* K = 58.7, KA = 52.8, WA = 37.1. $F(2, 127) = 80.46$, $p < .001$
1	Illness perceptions (The caregiver appraisals questionnaire, Kemp & Adams, 1995).	*Positive appraisal*: Anglo = 39.3, JA = 42.8. NS *Perfectionist:* Anglo = 14.7, JA = 16.5. NS *Pessimistic*: Anglo = 10.7, JA = 12.8. $p < .05$
10	Illness attributions (Researchers coded interview data and categorised responses into attributions).	No significant differences in number of illness attributions reported. White caregivers were more likely to report biomedical attributions than ethnic minority caregivers. Asian caregivers were more likely to report psycho/social attributions.
1	Coping (The ways of coping scale, Lazarus & Folkman, 1988). Social support (The Lubben social network scale, Lunben 1988).	*Active coping:* Anglo = 1.2, JA = 1.2. NS *Avoidant coping:* Anglo = 0.6, JA = 0.8. NS *Religiosity:* Anglo = 16.9, JA = 11.8. $p < .05$
13	Coping (The ways of coping scale, Lazarus & Folkman, 1988).	Chinese caregivers significantly made more use of behavioural distancing and cognitive confronting than White American caregiver ($p < .05$). No significant difference in use of behavioural confronting and cognitive distancing.

Table 3 *continued*

Study ID	Mediator (Measure)	Results
1	Social support (The Lubben social network scale, Lunben 1988).	*Seeking social support:* Anglo = 0.9, JA = 1.4. $p < .05$ *Social network:* Anglo = 16.9, JA = 11.8. NS
2	Social support (asked caregivers to state how many people provided instrumental and emotional support.	*Emotional support:* K = 1.3, KA = 2.2, WA = 3.9. Sig difference between K and WA ($p < .05$) *Instrumental support:* K = 0.8, KA = 1.3, WA = 1.4. Significant difference between K and WA ($p < .05$)
3	Social Support (single item rating how much support caregiver received).	White caregivers reported significantly higher levels of workplace support than Asian caregivers ($F = 7.20$, $p < .001$)
4	Social Support (researchers asked what support do you use?)	White American caregivers 2.6 times more likely to use formal services than Asian caregivers.
13	Social Support (social provisions scale, Cutrona & Russell, 1987)	White American = 4.07, Asian = 3.61. $t = 2.17$, $p < .05$

Note:

K = Korean

KA = Korean American

WA = White American

C = Chinese

Anglo = Anglo American

JA = Japanese American

NS = Non significant

Caregiver Variables and Outcomes:

The final research question of the review pertained to the influence of the identified caregiver variables (familism, illness appraisals, coping and social support) on outcomes (burden, strain, anxiety and depression). The results of the studies examining the relationship between caregiver variables and outcomes are presented in Table 4.

Familism: Lai et al (2007) explored the cross-sectional relationship between familism and burden in 339 Chinese Canadian caregivers who consisted of adult children, spouse and child-in-law caregivers with a broad age range of 18-75 years (mean time in care role was not specified) Familism was found to be a negative predictor of burden; that is caregivers with high familism experienced lower levels of burden. Gupta & Pillai (2002) explored the same question amongst 118 South Asian (Indian American) caregivers (mainly female spouse and adult child caregivers with a mean age of 30 years). In this study familism was also significantly negatively related to caregiver burden. There was very little information provided about the measures used in this study and descriptive data regarding burden scores was also unspecified. Lee (2007) explored the relationship between familism and strain and between social support and strain. 130 caregivers from Taiwan who were providing care for a mixed group of patients (either cardiovascular disease or diabetes) were balanced with regards to gender, were mainly daughters, sons or daughter-in-laws, had a mean age of 47 years, and had been providing care for an average of 63.5 months. Familism and social support were significantly and negatively correlated with strain. In contrast to the above studies, Zhan (2006) and Gupta (2009) both found that familism was positively correlated with depression and burden in a sample of Chinese Canadian and Indian caregivers that is high levels of familism were associated with higher burden and depression. Chun et al (2007) in a sample of Korean, Korean American and White American found no significant effect of familism on burden, anxiety or depression in any of the three groups.

Illness attributions: Only one study explored the influence of illness attribution on caregiver burden and that was conducted by Levy et al (2000) in a small sample of 10 Chinese American and 10 White American caregivers. The number of attributions a caregiver held about their care recipient's dementia diagnosis, and the specific type i.e. internal and temporary attributions were all significantly positively related to burden, however this study is significantly limited by its small sample size and as a result of the low N the correlation analysis was conducted on the sample as a whole, not by ethnic group.

Coping: Two studies were found to examine the influence of coping on caregiver outcomes, Yeung et al (2007) examined the relationship between coping and depression among 70 female and mainly young (below the age of 60 years) caregivers from Hong Kong. The caregivers were all spouses of an individual who had experienced a stroke. Problem focussed coping was significantly and positively related to depression in that those who use problem solving were more depressed. Avoidance coping was also found to be positively related to depression, however this association was not found to be statistically significant. Shaw et al (1997) explored the influence of coping on anxiety and depression (using both an observer rating on the Hamilton rating scale for depression and a self reported measure) in Chinese and White American caregivers. Behavioural distancing, cognitive confronting, behavioural confronting and cognitive distancing were not significantly related to observed depression and anxiety in Chinese caregivers but were for White American caregivers, whereby all four coping strategies were associated with high observed depression and anxiety for White American caregivers. With regards to self reported depression, only behavioural confronting was significantly negatively related for Chinese caregivers. Behavioural confronting, behavioural distancing and cognitive confronting had a significant positive relationship with self reported depression for White American caregivers.

Social Support: Tsai & Wang (2009) explored the effect of social support (in terms of support seeking behaviour) on strain in 127 female caregivers from Taiwan who were all mothers providing care for an intellectually disabled child. Notably, these caregivers had been providing care for an average of 9 years. Instrumental, emotional and informational support seeking behaviour was significantly and negatively related to strain. Lee (2007) reports similar findings from a sample of 130 caregivers also from Taiwan providing support to family members with cardio vascular and diabetes diagnoses. High levels of actual support were found to be negatively related to strain. McCabe et al's (2003) study also found that perceived support was a significant negative predictor of strain in a sample of Asian American caregivers of individuals with emotional and behavioural problems. Chun et al (2007) found in a sample of Korean, Korean American and White American caregivers that high levels of instrumental and emotional support were significantly related to low anxiety and depression in all three ethnic groups.

Table 4. The effect of potential mediating variables on caregiver outcomes

Study ID	Mediator (Measure)	Outcome (Measure)	Results
2	Familism (Familism scale, Bardis, 1959).	Burden (Burden interview, Zarit, 1980) Anxiety (State anxiety scale, Spielberger, 1985) Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	No effect of familism on social support, burden, anxiety or depression.
5	Familism (Filial piety scale, Ho & Lee, 1974).	Burden (Perceived caregiver burden, Stommel, 1990).	Female caregiver who strongly adhere to familism norms experience substantial increases in burden and role overload.
6	Familism (Filial piety scale, Ho & Lee, 1974).	Burden (Perceived caregiver burden, Stommel, 1990).	Significant negative effect of familism on caregiver burden (beta = -0.242, p <.05). Significant positive effect of role conflict on burden (beta = 0.582, p <.05). The effect of role conflict on burden differs by familism levels i.e. . The effect of is greater for caregivers with low familism.
7	Familism (Filial piety scale, Gallois, 1996).	Burden (Chinese Zarit burden interview, Chan 2002).	Familism is a negative predictor of burden. Beta = -0.09, p < .05
9	Familism (Youngs filial obligation scale, Hsuech, 2001)	Strain (Chinese caregiver burden inventory, Chou, 1999).	*Familism:* correlated with strain (r = -0.27, p < .01). High expectation is related to low strain.

Table 4 *continued*

Study ID	Mediator (Measure)	Outcome (Measure)	Results
17	Familism (combined items from measures developed by Montgomery, 1996; Gallois, 1997 and Choi, 1993).	Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	Familism was positively related to depression. $r = .20$, $p < .05$
10	Illness attributions (Researchers coded interview data and categorised responses into attributions).	Burden: qualitative data was used to assess burden. No descriptive data in relation to burden levels in each ethnic group is provided	Number of attributions correlated with burden: $r = 0.36$, $p < .05$ Internal attribution correlated with burden: $r = 0.40$, $p < .05$ Temporary attributions correlated with burden: $r = 0.48$, $p < .01$
15	Coping (Problem solving inventory, Heppner, 1988).	Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	Total problem solving as significantly related to depression. $r = 0.35$, $p < .01$
13	Coping (The ways of coping scale, Lazarus & Folkman, 1988).	Observed depression (Hamilton rating scale for depression). Self reported depression (Brief symptom inventory, Hopkins). Self reported anxiety (Brief symptom inventory, Hopkins).	Chinese caregivers: BC and self reported depression r = -.20, p <.05 BD, CC, CD and outcomes = NS White American caregivers: BC, BD, CC are significantly related to observed depression, self reported depression and anxiety. CD is only significantly related to observed depression and anxiety.

Table 4 *continued*

Study ID	Mediators (Measure)	Outcome (Measure)	Results
2	Social support (asked caregivers to state how many people provided instrumental and emotional support.	Burden (Burden interview, Zarit, 1980) Anxiety (State anxiety scale, Spielberger, 1985) Depression (Centre for epidemiologic studies depression scale, Radloff, 1977).	High instrumental and emotional support was significantly predictive of low anxiety and depression.
9	Social Support (Caregiving resources scale, Archibold, 1995).	Strain (Chinese caregiver burden inventory, Chou, 1999).	Correlated with strain (*r* = -0.22, *p* < .05). More support is related to low strain.
12	Social Support (social provisions scale, Cutrona & Russell, 1987)	Strain (caregiver strain questionnaire, Brannan, 1997).	Perceived social support remained significantly related to caregiver strain (Beta = -0.22, *p* < .001) once the effects of demographics and illness severity were controlled.
14	Social Support (Social support scale, Tang, 1992).	Strain (Caregiver strain index, Robinson, 1983).	Correlations with strain *IS*: *r* = -0.44, *p* < .001 *ES*: *r* = -0.36, *p* < .001 *Informational*: *r* = -0.28, *p* < .001 Overall support: *r* = -0.42, *p* < .001

Note:

WA = White American
NS = Non significant
BC = Behavioural confronting
CC = Cognitive confronting

BD = Behavioural distancing
CD = Cognitive distancing
IS = Instrumental support
ES = Emotional support

Discussion

This systematic review examined whether ethnicity is associated with caregiver outcomes (burden, strain, anxiety and depression) and sought to identify factors that may mediate this relationship. Of the nine studies focusing on ethnic differences in caregiver outcomes, five were conducted in the USA (Adams et al, 2002; Fredriksen-Goldsen et al 2004; Giunta et al 2004; Lee et al 2004 & McCabe et al, 2003) , three in Asia/USA (Chun et al, 2007; Shaw etal, 1997 & Youn et al 1999), one in the UK (Mackenzie et al 2007) Four of these (Chun et al, 2007; Lee & Farran, 2004; Youn et al, 1999; Mackenzie et al, 2007) found a significant direct effect of ethnicity on outcomes of distress and burden. Asian caregiver's experiences significantly higher levels of burden and distress compared to Caucasian caregivers. In contrast, one study (Shaw et al, 1997) found that White American caregivers were significantly more anxious and depressed than Chinese caregivers and four other studies (Adams et al, 2002; Fredriksen-Goldsen et al, 2004; Giunta et al, 2004 and McCabe et al, 2003) found no significant difference between the strain reported by Asian and White American caregivers.

Interestingly ethnic differences only emerge when studies used burden or distress as an index of caregiver response/outcome whereas there were no significant ethnic differences in the experience of caregiver strain. This may be due to the differences in measures of strain used in the studies. For example Fredriksen-Goldsen et al (2004) and Giunta et al (2004) both used new purpose built scales for measuring strain; the former devised a 5 item likert scale whereas Giunta and colleagues used 3 items to measure emotional, physical and financial strain. Lee (2007) used the Chinese Caregiver Burden Inventory to measure strain and McCabe et al (2003) used the more commonly employed Caregiver Strain questionnaire (Brannan, 1997). The use of invalidated (within the specific ethnic groups) and diverse range of strain measures makes it difficult to compare findings and may possibly account for the conflicting findings reported between ethnic differences in strain and burden.

Furthermore, the studies do not consider the possibility that the ethnic differences found in distress may be due to factors other than the care situation such as baseline distress levels among different ethnic groups. For example Asian caregivers may not be more distressed than Caucasian caregivers due to their role but due to the possibility that the prevalence rate for affective disorders may be higher in the Asian population. Also Chun et al (2007) and Youn et al (1999) compare caregivers from different countries (Korea Vs America) and differences in distress may be due to the difference in service provision in the two countries. Not only will there be macro differences in support available to caregivers from different ethnic groups (i.e. Korea Vs USA) but there may be micro differences in access to support.

An ethnic minority status is usually related to a poorer socio-economic status (Morrison & Bennett, 2006) which would affect access to health services in countries such as the USA whereby health care is based on income but not in the UK where a National Health Service exists. Indeed Pinquart & Sorensen (2005) found in their meta-analysis that Asian American, Hispanic American and African American caregivers were from a lower socio-economic status group compared to the Caucasian caregivers. The only study to examine financial strain in the current review was reported by Giunta et al (2004) which reports a higher financial strain in the Asian American group compared to the Caucasian caregiver group.

Another limitation of the findings is that often the Asian caregivers had a very different socio-demographic profile from the Caucasian caregivers which may have influenced the results. However the studies provide little if any information on how confounding factors such as, caregiver relationship with care recipient or the amount of time spent in the care role, previously shown to be associated with caregiver outcomes were controlled. For example Rhee, Yun, Park, Shin, Lee & Yoo (2006) report from a cross-sectional study of 310 cancer caregivers that spouse caregivers were more likely to experience depression than non-spouse caregivers. In general, the studies included in the review utilised small samples which prevented further subgroup analyses, with some studies (Mackenzie et al 2007 & Giunta ee al 2004) actually combining samples of ethnic minority caregivers which render specific ethnic comparisons impossible. The majority of the studies also fail to report effect sizes.

With regards to the second research question posed by the review, familism, illness appraisals, coping and social support were the main caregiver variables explored by the studies. Two studies (Chun et al, 2007 & Youn et al, 1999) found that Asian caregivers had higher familism than White American caregivers. However as Korean caregivers included within the Asian samples of both these studies were also more likely to be young females this may suggest that the difference in familism may not be entirely due to ethnicity, but an effect of age or gender. A number of previous studies have found that age has a negative relationship with familism (Dellman-Jenkins & Brittain, 2003; Hung, Loong, Liu & Weatherall, 2000; Stein, Wemmerus, Ward, Gaines, Freeberg & Thomas; 1998) and that female caregivers report higher levels of familism and cultural expectations that women should be the caregivers in the family (Kolb, 2000).

The relationship between familism and caregiver outcomes remains unclear. Whilst two studies (Gupta, 2009 & Zhan 2006) found a positive relationship between familism and burden, three studies (Gupta et al, 2002; Lai, 2007 & Lee, 2007) found a negative relationship between familism and caregiver outcomes of burden and strain.

A further study (Chun et al, 2007) found no significant relationship between familism and outcomes of burden, anxiety and depression.

However as the above studies provide little descriptive data i.e. care recipient's diagnosis, and inadequately consider/analyse the effects of confounding factors such as age and length of time caregiving, a detailed understanding of what may underlie these relationships is not available. The studies that found a significant association between familism and outcomes do not provide details on effect sizes but observation of the correlations suggest the relationship was modest (correlations were below 0.30).

It is worth noting that although no clear relationship between familism and outcomes of burden, strain anxiety and depression emerged from this review, this does not suggest that familism is not related to caregiver outcomes. Familism may be related to other outcomes not currently assessed, such as the positive outcomes of caregiver satisfaction or caregiver gains and further research is required to explore these relationships. Another possible explanation for the contradictory findings of the relationship between familism and outcomes may be that familism influences ethnic groups in a different way. The studies that examined familism in relation to caregiver outcomes only used Asian caregivers perhaps familism in Caucasian caregivers would be more strongly related to outcomes as familism is not a strong Western concept (Killian & Ganong, 2002) and may lead to increased feelings of burden. Also familism may not have a direct effect on caregiver outcomes but may itself be mediated, for example by coping or the use of social support. Further longitudinal research is needed to examine the relationship between familism and other components of the stress and coping models.

Findings regarding illness appraisals, ethnicity and caregiver outcomes also remain inconclusive. Adams et al (2004) found that Japanese American caregivers were significantly more pessimistic than White American caregivers. Although the study utilised a small sample, the demographic profile of the two groups is matched with regards to gender, age and relationship status. Levy et al (2000) found that the two groups did not significantly differ in number of illness attribution but did by type of attributions held, however this study is severely limited by its use of a non-validated measure of illness attributions (e.g. the well validated illness perceptions questionnaires contains a causal scale), use of qualitative data to produce quantitative results and a sample of only 10 caregivers per ethnic group (total 20).

Adams et al (2002) found no significant differences between Japanese American and White American in active or avoidant coping, however Japanese American caregivers had significantly higher religiosity coping levels than White American caregivers. Shaw et al (1997) also found significant differences in coping among Chinese and White American caregivers and further highlight that coping differs by caregiver/non caregiver status. Unlike many of the studies reviewed here this study contained a comparison non-caregiver sample.

This review identified few studies exploring ethnic differences in illness appraisals and coping and the influence of these variables on outcomes; however the included studies offered more consistent evidence concerning social support. All five studies (Adams et al, 2004; Chun et al, 2007; Fredriksen-Goldsen et al, 2004; Giunta et al, 2004 & McCabe et al, 2005) addressing this issue found that Asian caregivers had significantly less social support compared to White American caregivers, and social support was a consistently related to caregiver outcomes. High levels of social support were related to lower concurrent levels of strain, anxiety and depression (Chun et al, 2007; Lee et al, 2007; McCabe et al, 2003; Tsai & Wang, 2009).

Such evidence suggests that social support may be the main mediating factor between ethnicity and outcomes. Although some of the reviewed studies had small samples and did not always consider confounding factors such as age, the findings regarding social support are consistent with previous literature which has found that Asian caregiver have low amounts of social support (Li, 2004 & Katbamna, Ahmad, Bhakta, Baker & Parker, 2004). Again this difference in social support may be due to the low socio-economic status associated with an ethnic minority label and the availability of health care services in the USA being income dependent. However qualitative studies using Asian caregivers in the UK have also found that social support is limited for this group perhaps due to language barriers in accessing support (Gerrish, 2001), lack of awareness (Hepworth, 2005), or the stigma attached to seeking support (Lawrence, Murray, Samsi & Banerjee, 2008). This has implications for the development of support based caregiver interventions aimed at reducing strain and distress.

It is important to note that studies have assessed social support differently, either focusing on total support, satisfaction with support or even type of support, and a few assessing a combination of these. In some studies (e.g Chun et al 2007 & Giunta et al 2004) the type of support has further been extended by measuring the types of task (e.g. instrumental vs. emotional support) or formal (health services) vs. informal family support. The operationalisation of social support will likely influence the relationship with outcomes for example satisfaction with support has consistently been found to be predictive of carer reported gains (Kim et al 2007; Kramer, 1997) whereas total support has been found to be predictive of depression (Goode et al, 1998; Pakenham, 2001 & Grunfeld et al, 2004). There has been little if any research examining different operationalitstaions of social support and influence on different outcomes within the same study.

Although this review has revealed several new and interesting findings, there are a number of limitations which need to be addressed. Whilst a number of studies addressed the direct relationships between familism and social support and caregiver outcomes, none explored the fact that familism effects may themselves be mediated, for example via influence of familism on specific coping strategies such as seeking social support in Asian caregivers. The influence of motivations and willingness to provide care on caregiver outcomes was also not considered in the studies, and this may itself be influenced by the type (and quality) of relationship between caregiver and care recipient. Neither the caregiver relationship type nor quality of relationship was addressed in the majority of the studies included in the current review. As the studies exploring the relationship between familism and caregiver outcomes produced inconclusive findings, perhaps broader categories of motivations to provide care and their influence on outcomes should be examined. For example Lyonette & Yardley (2003) identify extrinsic motivations (which include familism) and intrinsic motivations to provide care (such as a caring nature). Extrinsic motivations have been found to be significant predictors of stress and intrinsic motivations are related to greater caregiver satisfaction. Furthermore motivations to provide care maybe related to willingness to provide care, which has been found to influence caregiver burden (Wells, 1999).

The majority of the studies include Eastern Asian/Eastern Asian American caregivers therefore it may not be possible to generalise the findings to South-Asian caregivers particularly given that the social and economic development of the South-

Asian population contrasts with the East Asian population. There is also a difference in family structure which may have an impact on the caregiver role, for example, Western culture has an increasingly bilateral family system (whereby both the paternal and maternal side of the family are equal in providing support) as do a number of East Asian countries such as the Philippines and Thailand and Singapore has a combination of a bilateral and patrilineal family system (Ofstedal, Knodel & Chayovan, 1999), however South Asia has continued with a patrilineal family system, which may reduce the availability of support for caregivers further. A further issue arises concerning the Asian caregivers acculturalisation levels and whether they are naturalised Americans. The studies reviewed frequently contained small Asian caregiver samples in comparison to non-Asian caregiver samples. This may be due to difficulties in accessing ethnic minority communities due to language barriers and points therefore to a need for validation of current measures in other languages.

The majority of the studies that were eligible for this review focused on caregivers providing support for an individual with a dementia diagnosis. It would be of interest to explore the Asian caregiver experience in other conditions whereby the onset may be sudden or impairment may be more physical than cognitive. Previous studies including only Caucasian caregivers have found that caregiver distress may be influenced by the condition of the care recipient (Kim, & Schulz, 2008)

An important limitation of the studies available for the review is that all 17 of the eligible made use of a cross-sectional design. Although a cross-sectional design is useful in providing descriptive information with respect to caregiver outcomes and risk factors, no causal inferences can be made. With the use of a longitudinal design the directional effect of variables can be explored further, for example we could better explore change in outcomes over time.

Another potential influence on what we can derive from these findings is that the included studies used varied recruitment approaches. Caregivers were often recruited from very different countries and it is highly feasible that regional differences (geographic variation in service provisions for caregivers and health care for the care recipient) contributed towards some of the variation seen. Variation also existed in the inclusion/exclusion criteria applied, with some having very clear criteria for the types of caregiver to be included (e.g. caregivers had to live in the same home as the care recipient, had to provide a minimum number of hours of care per day), whereas many studies do not describe any inclusion criteria. Also multiple data collection methods were used between and within studies, with some caregivers completing the measures on their own whereas others were interviewed face to face by a researcher which may have led to self preservation bias.

Studies often assessed similar constructs in caregivers such as social support; but a variety of measures was being used to test social support and strain. Some consistency was observed with familism measures with the Filial Piety Scale (Ho & Lee, 1974) proving popular and the CES-D (Radloff, 1977) for measuring depression; rendering the findings of these studies to be more easily considered as a whole. Although studies report the use of validated measures, studies rarely used the original validated measure, most researchers removed items from the measures which they thought would be inappropriate to use with the Asian sample. Many of the studies made use of translation and back translation to ensure measures retained equivalence of meaning.

Despite the shortcomings of the research reviewed here, a number of conclusions can be drawn. Primarily longitudinal research is clearly required to examine the process of effects of ethnicity upon beliefs/familism, coping and outcomes further in detail, given the huge body of evidence from studies of patients and healthy population showing that stress and coping processes have a dynamic relationship with outcomes. Further research is required on illness appraisals and coping in Asian caregivers and the effect on outcomes as this is an under researched area yet we know that differences exist in how cultures (and thus likely, ethnic groups) consider health and illness (Killian & Ganong, 2002 & Chalmers, 1996). Furthermore research needs to examine broader motivations to care and also the influence of willingness to care because cultural values such as familism may not be amenable to change through interventions but factors such as willingness to care may be easier to target. There are also clear implications for the development of culturally sensitive support services for caregivers. Ethnic differences in social support emerged in all studies and support has been consistently found to be related to caregiver outcomes. Future research should attempt to use culturally validated assessments and also attempt to make use of theoretical perspectives that are culturally relevant.

Chapter 3

Predictors of Familism: A Pilot Study

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Abstract

This study aimed to investigate whether age, gender and ethnicity were predictive of familism in caregivers; and whether familism was associated with coping. Forty-five British South-Asian and 43 White-British caregivers completed a cross-sectional questionnaire of demographics, the brief Cope and the Heller Familism scale. Asian and younger caregivers endorsed higher levels of familsim than White-British and older caregivers. In the final model, demographic variables, humour, religious, active and instrumental coping explained 41% of the variance in caregiver familism. The findings suggest the need to consider familism values when providing caregiver services to minimise the potential negative impact of caregiving.

Introduction

The advances in technology over the last century have led to a rapidly aging population resulting in an increasing number of individuals with dependency needs, much of which will be met by family members and friends. Informal caregivers give up or reduce their usual activities, often without financial compensation, to support a family member or friend who is experiencing problems due to physical, emotional or cognitive impairments (Bridges, 1995). A large body of evidence points to detrimental physical and mental health consequences of providing care (Vitaliano, Zhang & Scanlan, 2003), as well as the moderating effects of coping and social support on such outcomes (Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000). However little is known about the intrinsic values that guide the process of providing care to an ill family member.

Gaines, Marelich, Bledsoe et al. (1997) identify three distinct cultural value orientations: individualism (inclination towards one's own welfare), collectivism (orientation towards the welfare of the larger community) and familism (bearing towards the welfare of one's own family). Ramos (2004) proposes that the cultural value of familism is at the root of family care provision. Familism has been defined in the care literature as "strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity and solidarity among members of the same family" (Sabogal, Marin & Otero-Sabogal, Marin & Perez-Stable, 1987, 397-398). Various aspects of familism have been observed in studies with some focusing on filial obligations and others on filial responsibility. Filial obligation is defined as a general attitude of appropriate behaviour within the context of specific personal relationship with kin (e.g spousal) whereas filial responsibility is considered as a societal attitude toward adult children's duty to meet the needs of aging parents (Stein, Wemmerus, Ward, Gaines, Freeberg & Thomas, 1998).

Age and familism

Familism is considered relevant to all individuals regardless of age, gender, and generation and whether or not they have parents or children, although levels of familism are thought to develop and change across the individual’s lifespan. Two main theories have been proposed to explain the dynamic nature of familism: the attitudinal approach and the relational approach.

The attitudinal approach to the study of filial norms suggests that familism is an attitude that induces adult children to assume certain responsibilities. This approach claims that familism should peak in middle age, when an adult child begins to anticipate the increasing needs of their aging parents. In contrast the relational approach predicts that familism would be strongest for young adults; based on the assumption that obligation to provide care is based on the caregiver “repaying” the parent for the sacrifices they made whilst bringing them up. Younger individuals would express higher levels of familism due to having experienced fewer opportunities to “repay” parents. As increasing number of recent studies of family caregivers make use of younger samples (under 40 years of age), it is perhaps not surprising that the body of evidence supports the relational approach (Dellman-Jenkins & Brittain, 2003; Hung, Loong, Liu & Weatherall, 2000; Stein et al., 1998).

Groger and Mayberry (2001) conducted eight focus groups with American non-caregiver adults in homogenous age groups and found that whilst all age groups expressed filial obligations, the youngest participants in the focus groups held the most rigid norms of filial obligations, as they were unable to recognise the constraints in family care (for example, they were willing to struggle in order to avoid nursing home placement of the elder). This is proposed to be due to the younger individuals being the least likely to be called on to provide care. Middle-aged adults reported weaker filial obligations due to experiencing the increasingly demanding role of providing care and the oldest adults held the weakest filial obligations. Filial obligations were found to have a linear relationship with age, that is, it decreased with age. This may be due to the young only anticipating the caregiver situation. One exception is the study reported by Dellmann-Jenkins and Brittain (2003) who compared young (18-40 years) American adult caregivers and non-caregivers in their attitudes toward filial responsibility and their actual caregiver behaviours. They found that both caregivers and non-caregivers were in agreement that any negative traits of the ill family member (for example unpleasantness) should not affect their obligations to provide care. However three main significant differences in opinion were found between the two groups. Firstly non-caregivers were more likely to state that they would not provide care if the care situation caused turmoil in their own home, for example where caring for a parent may affect marital relationship/relationship with children. Secondly caregivers felt that an adult child should provide care despite the conflict it may cause between the older and younger generations. Finally caregivers were significantly more likely than non-caregivers to convey that they would provide care without regarding the feelings of their spouse. These findings suggest that the caregiver group had higher levels of filial responsibility and were willing to tolerate the burden associated with the role. Interestingly the main concern of both caregivers and non-caregivers was avoiding nursing home placement for elderly family members, which is consistent with other American studies (Groger & Mayberry, 2001; Hung et al, 2000).

Very few studies have made use of a longitudinal methodology. One exception is that of Gans and Silverstein (2006) who conducted a 15-year longitudinal study of 1,627 American individuals from three generations of 333 families aged between 16 to 91 years who were questioned in relation to their expectations that adult children should provide care for their aging parents. The results revealed that levels of felt obligation peaked at 37.5 years of age; however once social factors associated with age (for example generational norms) were controlled for, the average age that felt obligation peaked increased to 48-58 years. Felt obligation weakened after middle age but were strengthened in later generations. This longitudinal study is a useful addition to the field but requires replication in the UK before findings could be applied to British caregivers. Furthermore, the mixed evidence regarding the influence of age on familism suggests that other possible predictors of familism may exist, thus we turn attention now to gender.

Gender and familism

There is some evidence of an influence of gender upon familism. Women are more likely to adopt the role of caregiver than men, perhaps due to the care tasks being more consistent with the socialised female role. This raises the question of whether males would require higher levels of filial obligation to provide care than females. Stein et al. (1998) explored this in an American intergenerational sample of 460 young (17-26 years) and middle aged (36-60 years) male and female non-caregivers. Males and females who reported high levels of filial responsibility also reported higher levels of filial obligation and parental care, thus failing to support the notion that males and females have different thresholds of filial obligation to provide care to parents.

Further exploration of the association between gender and familism is provided by Kolb (2000). Using semi-structured interviews she found that female American Latina caregivers reported high levels of familism and cultural expectations that females should be the primary caregiver. It is likely that male caregivers complete tasks that are considered gender appropriate by society, as illustrated by Campbell and Mathew (2003) who found that the perceived gender appropriateness of the task is important in how familism influences males in adopting the caregiver role. Hung et al. (2000) did not find any gender differences in filial obligation in either Chinese or European families, suggesting that the current evidence regarding gender and familism associations is inconsistent and worthy of further investigation. The inconsistent findings of the effect of age and gender on familism have prompted increasing interest in the influence of ethnicity, which is the third factor we explore here.

Ethnicity and familism

Ethnicity is a term used to refer to groups of people on the basis of their race and culture. Phinney (1996) suggests three main aspects of ethnicity that account for its psychological importance: the first being the cultural values that distinguish ethnic groups, secondly, the sense of ethnic group membership held by the individuals in the group and finally the experience of a minority status such as prejudice. Ramos (2004) suggests that ethnicity can either encumber or assist the likelihood that familism values guide the caregiver role. In a focus group setting 68 American Puerto Rican caregivers for the frail elderly were interviewed. It emerged that many caregivers found it challenging to practice filial obligations due to other stressors related to occupying an ethnic minority status (for example low social economic status). Hung et al (2000) conducted two surveys of filial obligations amongst 100 Chinese and 103

European families in New Zealand and found that Chinese families displayed higher levels of filial obligation than European families (specifically in the case of providing financial support and demonstrating obedience). The younger generation's filial obligations correlated with the expectations of the elder generation.

Sabogal et al (1987) compared 452 American Hispanics to 227 American white non-Hispanics and found that Hispanics continued to hold higher levels of familism than white non-Hispanics despite the high level of acculturation. Fulingi, Tseng and Lam (1999) examined attitudes towards filial obligation in adolescents from Chinese, Mexican, Filipino, European and central and South American backgrounds. The researchers observed that Asian and Latin American adolescents held higher levels of filial obligation in comparison to their European counterparts. These differences remained consistent across genders, generations, family composition and also socio-economic background. Youn, Knight, Jeong and Benton (1999) studied levels of familism in 44 Korean, 32 Korean Americans and compared them to 54 White American caregivers. It was found that Korean caregivers and Korean American caregivers held stronger familism values than the White American caregivers. Korean caregivers who held the strongest familism values of the three groups were also found to report higher levels of burden, anxiety and depression. It has also recently been found that familism influences the use of specific coping strategies in caregivers, and thus this section concludes by addressing this body of evidence.

Familism and coping

Most familism research has attributed differences in coping styles to differences in ethnicity, however recently Kim, Knight and Longmire (2007) using a socio-cultural stress model (Aranda & Knight, 1997) propose that cultural values such as familism may influence the appraisal and coping process in caregivers. Their sample of 95 African American and 65 White-American caregivers found that familism was linked to an avoidant coping style and African Americans (who had lower levels of familism) showed greater levels of active coping.

A limited number of studies have explored predictors of familism amongst caregivers. There has been very little, if any, research investigating familism in British caregivers and few have examined the general experience of British South-Asian (Indian, Pakistani and Bangladeshi) caregivers; however government statistics highlight this as a growing population (Census, 2001) whereby 10% of the U.K caregiver population consists of South-Asians.

This study therefore aims to address some of the gaps in the current literature by examining familism values in British South-Asian and White-British caregivers. A cross-sectional questionnaire study was conducted to investigate the following hypotheses: (a) Demographic variables (age, gender and ethnicity) will influence familism values held by caregivers; (b) familism will be associated with use of specific coping strategies.

Method

Sample

A sample of 45 British South-Asian caregivers was obtained (41 female and 4 male caregivers; mean age 34.69 years, *SD* = 14.08; 40% adult child caregivers; 58% married; 62% had other dependents and 27% declared health problems of their own). A further sample of 43 White-British caregivers was obtained (32 female and 11 male caregivers; mean age 64.95 years, *SD* = 9.52; 75% were providing care for a spouse; 84% were married; 30% had other dependents and 67% reported health problems of their own). All caregivers were aged 18 years or over, considered themselves the primary caregiver and had to provide at least one hour of care per day for an individual. Caregivers were recruited from three main diagnosis groups (cancer, stroke and dementia) to enable comparisons to be made between diagnosis groups. British South-Asian caregivers were more likely to be providing care for an individual with a cancer diagnosis (49%) followed by stroke (29%) and dementia (18%). White-British caregivers were mainly providing care for individuals with a diagnosis of dementia (63%) followed by stroke (28%) and cancer (2%).

Table 1. Demographic data of caregivers

		Ethnicity			
		British South-Asian		White-British	
Variable	Status	*n*	%	*n*	%
Diagnosis	Cancer	22	49	1	2
	Stroke	13	29	12	28
	Dementia	8	18	27	63
	Multiple of above	2	4	3	7
Relationship to care recipient	Spouse	4	9	32	75
	Parent	0	0	1	2
	Adult child	18	40	7	16
	Sibling	4	9	1	2
	Daughter in law	8	18	0	0
	Grandchild	6	13	0	0
	Friend	1	2	1	2
	Other	2	4	0	0
Marital	Single	14	31	0	0
	Married	26	58	36	84
	Divorced	2	4	2	5
	Widowed	0	0	2	5
	Unspecified	3	7	3	7

Measures

The demographic section of the questionnaire assessed: caregiver's age, gender, ethnicity, occupation, marital status, care receiver's diagnosis, relationship to care receiver, other dependents, caregiver's health problems, hours caring per week and number of years caring.

The Heller Familism Scale (1976)[2] consists of 15 items, rated on a 5 point Likert Scale, where a high score (max score = 60) indicates high levels of familism. The scale was used to measure how strongly an individual believes the family should be valued and contains items such as "Married children should live close to their parents so that they can help each other". This scale has demonstrated good levels of reliability in previous studies (Cronbach's alpha .80, Killian & Ganong, 2002), and also demonstrated good reliability in the current study (Cronbach's alpha of .73).

Caregiver coping was assessed using the Brief COPE (Carver, 1997), which is a reduced version of the well-validated COPE (Carver, Scheier & Weintraub, 1989). The Brief COPE consists of 14 subscales, each with 2 items and assesses: positive reframing, self-blame, active coping, humour, religion, self-distraction, venting, instrumental support, emotional support, denial, acceptance, substance use, planning and behaviour disengagement. Each item is rated using a 4-point Likert scale based on how often the caregiver makes use of the method. Briggs and Cheek (1986; as cited in Pallant, 2003) recommended that, for scales containing less than seven items, mean inter-item correlations within an optimal range of .2.to .4. In this study the inter-item correlations ranged from .2 (positive reframing) to .85 (religion). The "acceptance" items were removed from the measure due to the inter-item correlation falling below the 0.2 cut off point and thus demonstrating low internal consistency.

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[2] All measures can be found in Appendix 5, page 408.

Procedure

Departmental ethical approval was obtained before commencement of data collection. The White-British sample was recruited from the Gwynedd area through support groups via opportunistic sampling (The Alzheimer's Society, Carers Outreach, the respite charity Crossroads, Ysbyty Gwynedd Cancer Support Group and the Stroke Association). British South-Asian caregivers were recruited in Yorkshire through the use of poster advertisements and snowball sampling (Breakwell, Hammond & Fife-Schaw; 2000). Packs consisting of an information sheet, consent form, a questionnaire and contact details for support services were sent to interested caregivers. British South-Asian caregivers who did not speak English were visited at home or in the local community centre and completed the questionnaire with the translational aid of the first author.

Data analysis

Data were entered and analysed using SPSSv12. Before data analysis commenced, data were screened for incomplete responses (missing data was substituted using an average based on previous responses) followed by descriptive analysis of demographic data. Inferential statistics investigated group differences (age, gender, ethnicity and diagnosis group) in levels of familism. Partial correlation analysis tested the relationship between familism and the cope subscales whilst controlling for demographic factors. Hierarchical multiple regression was used to explore the predictive ability of age, gender and ethnicity on familism. Only those cope subscales, which were significantly related to familism when demographic variables were controlled for were included in the regression analysis (active coping, religious coping, humour and instrumental coping).

Results

Using SPSS, the continuous variable of age was converted into a categorical variable with the division of the sample into 3 equal groups (18-43 years, 44-61 years and 62+ years). An one-way ANOVA determined a significant difference between the 3 age groups in familism (F (2, 78) = 7.62, $p < .001$) with post hoc tests revealing that the 18-43 years age group (M = 43.32, SD = 17.51) were significantly higher in familism than the 44-61 year age group (M = 32.07, SD = 13.93; p = .03) and the 62+ years age group (M = 26.92, SD = 15.57, p = .001). A significant gender difference in familism was found between White-British male and females (U = -2.24, $p < .05$; sum of ranks = 27.65 for males and 18.12 for females) but not British South-Asian males and females. An independent samples t-test was conducted to compare the familism scores for the total British South-Asian group (M = 42.04, SD = 15.77) and White-British (M = 26.03, SD = 13.70) caregivers and a significant effect of ethnicity on levels of familism (t (83) = -4.97, p = .001) emerged. Using an ANCOVA the possible confounding effect of age on ethnicity was investigated. After the variable of age was controlled, the difference between familism in British South-Asian caregivers (marginal mean = 4.16; CI = 35.55, 47.62) and White-British caregivers (marginal mean = 2.66; CI = 20.24, 32.97) remained statistically significant (F (1, 78) = 8.05, p = .01). A one-way ANOVA revealed a significant difference between diagnosis groups (F (3, 81) = 4.0, $p < .01$). Using post hoc analysis it was revealed that there was a significant difference ($p < .05$) in familism between the cancer group (M = 42.48, SD = 16.49) and the dementia group (M = 30.00, SD = 15.89)

As shown in Table 2, there was a significant positive correlation between familism and religious coping and a significant negative correlation between familism and use of substances whilst controlling for age for British South-Asian caregivers but not White-British caregivers. For White-British caregivers there was a significant positive correlation between familism and active and also instrumental coping whilst controlling for age effects.

Table 2. Partial correlation analysis investigating the relationship between familism and coping whilst controlling for the effect of age.

		Familism	
Scales	Subscales	British South-Asian	White-British
Brief Cope	Active coping	0.12	0.35*
	Instrumental coping	0.16	0.45***
	Planning	0.05	-0.09
	Positive reframing	0.03	0.14
	Humour	-0.34*	0.05
	Self distraction	0.29	-0.06
	Religion	0.40**	-0.01
	Denial	-0.26	-0.10
	Substance use	-0.19	-0.22
	Emotional support	0.09	0.07
	Venting	-0.20	0.07
	Behavioural disengagement	0.06	0.17
	Self blame	-0.25	0.20

Note.

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

Hierarchical multiple regression was conducted to investigate the predictive value of age, gender, ethnicity, active coping, religious coping, humour and instrumental coping on familism. Age was found to be a significant predictor of familism and accounted for 18% of the variance in scores. Gender explained a further 4%, ethnicity explained an additional 6% and diagnosis of care recipient explained 1% of the variance in familism scores. The overall model explained 41% of the variance in familism and was significant at the $p < .01$ level, however in the final model only ethnicity and religious coping remained significant predictors of familism.

Table 3. Summary of hierarchical regression analysis for variables predicting familism in caregivers (N = 88)

	Model 1			Model 2			Model 3			Model 4			Model 5		
Variable	*B*	*SE B*	*Beta*	*B*	*SE B*	*Beta*	*B*	*SE B*	*Beta*	*B*	*SE B*	*Beta*	*B*	*SE B*	*Beta*
Age	-0.37	0.09	-0.42***	-0.42	0.09	-0.12	-0.48	0.14	-0.18	-0.17	0.13	-0.19	-0.15	0.13	-0.17
Gender				-9.38	4.63	-0.21*	-9.62	4.49	-0.22*	-6.98	4.42	-0.16	-7.04	4.41	-0.16
Ethnicity							13.00	5.26	0.39***	10.79	5.12	0.32***	10.53	5.12	0.32*
Diagnosis										-1.95	1.85	-0.11	-1.99	1.74	-0.11
Active cop													0.42	1.04	0.04
Religious													1.49	0.66	0.22*
Humour													-1.30	0.88	-0.14
Instru cope													1.85	1.05	0.19
R^2		0.18			0.22			0.28			0.29			0.41	
R^2 change		0.18			0.04			0.06			0.01			0.12	
F for change in R^2		17.06***			4.10*			6.10*			1.18			3.71**	

Note.

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

Religious = Religious coping

Instru cope = Instrumental coping

Active cope = Active coping

Discussion

The primary aim of this study was to investigate the effect of demographic variables (age, gender and ethnicity) on familism values in British caregivers. As hypothesised and in support of the relational approach to familism, caregivers in the youngest group (18 to 43 years) had higher familism levels than caregivers aged 43 to 64 years or 65 years and above. These findings are similar to other cross-sectional studies (Stein et al, 1998) but deviate from longitudinal data described earlier (Gans & Silverstein, 2006). However the longitudinal study reported by Gans & Silverstein (2006) requires replication in the U.K and with individuals who have adopted the caregiver role as opposed to anticipating the adoption of the role.

Although this question cannot be explored fully due to the low numbers of male caregivers in the current sample, there is some evidence of a gender association with familism, with a significant difference found in familism between White-British males and females. Ethnicity was found to be significantly predictive of familism with British South-Asian caregivers endorsing higher levels of familism than White-British caregivers. Whilst there has been very little research using British South-Asian caregivers, a number of previous studies have established that caregivers from various ethnic backgrounds differ in their level of endorsement of filial obligations (e.g. Sabogal, Marin & Otero-Sabogal, Marin & Perez-Stable; 1987)

In the current study we have also found that familism is associated with coping, specifically religious coping and seeking instrumental support. This is a relatively new finding, although there is some evidence that ethnic minority groups make more use of religion as a coping method (Hussain & Cochrane, 2003; Ramos, 2004). As the Asian and Hispanic caregivers in these studies, in addition to the British South-Asian caregivers in the current study, report the highest level of familism and of religious coping, it could be that the predictive association between familism and religious coping may be due to ethnicity. However, in the current study religious coping continued to be related to familism, once ethnicity was controlled for, and therefore an independent relationship exists.

Finally, when considering the implications of these findings, some limitations need to be acknowledged. There was a large difference in the health care status of the caregivers in this study with 73% of British South-Asian caregivers declaring they had no health problems of their own whereas only 33% of the White-British caregiver sample stated no health problems. The influence of gender on familism norms should be interpreted with caution as the sample contains a small ratio of male to female caregivers. It is possible that the variable of age may have confounded the effect of ethnicity on familism values as the British South-Asian sample consisted of younger caregivers than the White British caregivers. However this is consistent with the general caregiver population as government statistics reveal that British South-Asian caregivers are more likely to be younger (1.5% of the British South-Asian caregivers being below the age of 16 years compared to 0.9% of White-British caregivers; Census, 2001). The difference in familism between diagnosis groups may also be partly due to the effect of ethnicity and this needs to be explored further in a larger sample of caregivers. Future research should not only attempt to make use of gender matched ethnic group samples but the generational position of the caregiver should also be taken into account. Future research should employ a longitudinal design in order to investigate the change in endorsement of familism across the lifespan. In addition we acknowledge that self-reports may contain self-presentation bias.

Despite the limitations the findings of this study contribute to an area in need of further research. The findings suggest that ethnicity is an important factor in predicting familism in caregivers with young British South-Asian caregivers being the most likely to endorse high levels of familism norms, which may lead to unrealistic expectations of the caregiver role. Familism values are also related to coping strategies, which will likely affect caregiver role outcomes such as burden, anxiety and depression (Cox & Monk, 1993; Losada, Shurgot, Knight, Marquez, Montorio, Izal & Ruiz, 2006). Familism may also be an extrinsic motivation for an individual to adapt the care role and affect willingness to continue providing care. This suggests that certain caregivers may be at risk of poor physical and psychological health. Identifying caregivers, who may hold unrealistically high levels of familism, will enable culturally sensitive services to target interventions to vulnerable individuals. The U.K health care system is reliant on caregivers to maintain patients at home and therefore it is important to provide support to ensure they are able to continue in their role.

Unlike much existing research, the current study used a sample of individuals who have already adopted the caregiver role rather than a sample anticipating adopting the caregiver role. This pilot study highlights a number of important issues that need to be considered and explored further in a larger, longitudinal study. Further research is required to examine how familism levels change as the caregiver becomes more experienced in the role.

Chapter 4

Ethnic Variations in the Caregiver Role: A Qualitative Study

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Abstract

The present study aimed to establish an in-depth qualitative analysis of the convergence and divergence of the experiences of caregivers from four ethnic groups. Eight Bangladeshi, nine Indian, four Pakistani and nine White-British caregivers participated in five focus groups. Differences and similarities between motivations for role adoption, willingness to care, experience of role, adaptation to role, coping, use of and satisfaction with support were discussed. Key differences were found in adaptation to care role and use of social support. The study highlights the need for further study of the ethnic minority caregiver experience and has implications for service development.

Introduction

A family or informal caregiver is an individual who provides assistance to a family member or friend who is experiencing difficulties due to physical, emotional and or cognitive impairments, often without financial compensation (Bridges, 1995). There are approximately six million informal caregivers in the UK with as many as three in five likely to become caregivers in their lifetime (Carers UK, 2003). UK Government census statistics point to significant variations between ethnic groups in terms of frequency and extent of caregiving. For example individuals from White-British and British-Indian ethnic groups were most likely to be providing care at home (10% from each group) as compared to Chinese (5.8%), Black African (5.6%), and mixed ethnicity individuals (5.1%). British-Bangladeshi and British-Pakistani caregivers reported spending the most time per week providing care followed by White-British caregivers. An age difference is also seen whereby 1.5% of British South-Asian (British-Bangladeshi, British-Indian and British-Pakistani) caregivers recorded in the Census were under the age of 16 years compared to 0.9% of less than 16 years White-British caregivers. This latter finding reflects the younger age structure of British South-Asians in comparison to the White-British population (Census 2001).

There has been much debate regarding the definition of ethnicity due to its various features. Hutchinson and Smith (1996) identified six main attributes of ethnicity including: common ancestry, shared historical memories, elements of a common culture (language, religion, diet), a symbolic attachment to a homeland and a sense of solidarity. A common ethnic group does not indicate a uniform culture although there is a relationship between culture and ethnicity (Kelleher & Hillier, 1996). Culture enables a community to function through a shared set of values based on a common language, religion, history. Culture is thought to be flexible and amenable to change in response to new pressures. Strongly religious groups have been found to be slower to change and uprooted communities become more conservative as a response to fear of losing their values (Kelleher & Hillier, 1996).

Racial inequalities and poverty disadvantage ethnic minority caregivers and can create additional barriers to gaining service support (Ahmad & Atkin, 1996). Barriers to research within this population can include language difficulties exacerbated by the non-availability of standardised, validated assessment measures in languages other than English. There is also a common misconception that British South-Asian caregivers have an extended support network and thus do not have support needs beyond the family (Atkin & Rollings, 1992). However many British South-Asian family networks will have disintegrated as a response to immigration (with the nuclear family members moving to the U.K. and the extended family members remaining behind) and thus social community support is essential (Bowes & Wilkinson, 2003). This assumption is further challenged by the findings of Katbamna, Ahmad, Bhakta, Baker and Parker (2004) who interviewed 105 British South-Asian caregivers of individuals with physical or mental health problems. Data from focus groups and in-depth interviews revealed that caregivers, irrespective of gender, had limited support within both the nuclear and extended family network. Feelings of obligation to provide care and the general British South-Asian community’s negative attitude towards illness and disability rendered it difficult for the caregiver to seek support from wider networks. These effects persisted when caregivers were further grouped by religion, language ability, socio-economic background and migration history.

A great deal of ethnic minority caregiver research has adopted a service perspective focusing on problems of access and suitability of health services (Lawrence, Murray, Samsi, & Banarjee, 2008; Hepworth, 2005; Milne & Chryssanthopoulou, 2005; Katbamna, Ahmad, Bhakta, Baker and Parker, 2004; Ahmad, 2000; Perry, Hsu, Brooks, Cherry, 1999). Despite the growing literature regarding ethnic minority caregivers' use of services in the UK there has been a dearth of literature exploring coping responses with regards to their caregiver role. Familial attitudes towards caregiving and how individuals appraise and adjust to their role have strong implications for support service needs.

The current study therefore aims to explore the experience of British South-Asian sub-ethnic groups (British-Bangladeshi, British-Indian and British-Pakistani) caregivers and compare with White-British caregivers in order to address gaps in the current caregiver literature. The study reported here is exploratory, and utilized qualitative methods of data collection so as to gain detailed personal accounts of the caregivers' motivations and willingness to provide care, coping, use of support and how they perceive their experience to have changed over time.

Method

Sample

A sample of 30 caregivers (28 female and 2 male) was obtained from which 8 caregivers identified themselves as British-Bangladeshi (BB); 9 British-Indian (BI) caregivers; 4 British-Pakistani (BP) caregivers; and 9 White-British (WB) caregivers participated in 5 focus groups. Caregivers ranged from 24-80 years old. 18 of the caregivers were spousal caregivers, a further 2 were daughters, 5 were daughter-in-laws, 4 were parental caregivers and one caregiver was providing support for an aunt. Group differences and further demographic information are presented in Table 1. One way ANOVAs and equivalent non parametric tests were conducted to explore differences between the four groups regarding age, number of hours per week of providing care and number of years providing care. The post hoc analysis revealed that there were significant differences in age between BB and BI caregivers ($p < .01$), BB and WB caregivers ($p < .001$), and WB and BP caregivers ($p < .05$). There were no significant differences between groups regarding hours and years providing care. Qualitative data is treated as a whole for analysis with only ethnic differences being highlighted within themes.

Table 1. Demographic characteristics of caregivers

		Ethnicity				Total
Variable		British-Bangladeshi (n = 8)	British-Indian (n = 9)	British-Pakistani (n = 4)	White-British (n = 9)	
Gender	Male	0	2	0	0	2
	Female	8	7	4	9	28
Diagnosis	Cancer	1 (12.5%)	1 (11.1%)	0	3 (33.3%)	5
	Dementia	4 (50%)	3 (33.3%)	2 (50%)	3 (33.3%)	12
	Stroke	0	2 (22.2%)	2 (50%)	2 (22.2%)	6
	Multiple	0	0	0	1 (11.1%)	1
	Other	3 (37.5%)	3 (33.3%)	0	0	6
Other care	Yes	1 (12.5%)	3 (33.3%)	0	4 (44.4%)	8
	No	7 (87.5%)	6 (66.6%)	4 (100%)	5 (55.6%)	22
Age	*M*	37.17	58.63	42.67	64.44	-
	SD	12.38	14.79	7.77	8.56	-
Hours	*M*	152	147.75	123.67	144.14	-
	SD	45.25	57.28	76.79	57.19	-
Years	*M*	8.31	11.14	7.00	18.75	-
	SD	4.24	8.40	6.93	14.45	-

Family members that considered themselves as the primary caregiver were included in the study if they provided a minimum of 7 hours per week of unpaid care. Caregivers providing support to more than one person were asked to discuss their role in relation to the individual they considered as the main care recipient. The focus groups were conducted in the caregiver’s preferred language using a translator.

Procedure

Prior to recruitment, full ethical approval was obtained from the School of Psychology’s research ethics committee. Caregivers were recruited through existing caregiver support groups who agreed to recruitment taking place on their premises. The support groups were located in similar geographical areas and served the same purpose, providing an opportunity for caregivers, of those with mixed diagnoses, to meet other caregivers and share their experiences in a relaxed environment. The researcher (SP) visited each centre to provide information about the study to the caregivers. All caregivers attending the sessions were approached and only two White-British caregivers did not attend a focus group due to illness.

A focus group methodology was selected as such a format minimises pressure on individual participants to contribute throughout, enables participants to build on each other’s responses, and are relatively easy to assemble. One BB, two mixed BI and BP and two WB caregiver focus groups were conducted. British-Pakistani and British-Indian caregivers shared their focus groups due to them speaking similar languages (Urdu/Hindi). The two male BI caregivers were given the opportunity to participate in a single sex group but were happy to join a mixed sex group. Prior to each focus group, caregivers provided written consent and completed a short questionnaire which requested information regarding their gender, age, ethnic group, main diagnosis of care recipient, relationship to the care recipient, number of hours per week of providing care, number of years of providing care, whether care was provided for more than one individual, how long the caregiver had been involved with a support group and how regularly they attended.

A semi-structured framework was developed to guide the focus group sessions, which aimed to examine motivations and willingness to provide care, caregiver coping, use of support and general experience of care role. The groups were asked similar open-ended questions such as: “Why did you become a caregiver?” The focus groups were conducted by a bilingual researcher (SP) with the aid of a moderator who noted non-verbal behaviors amongst the caregivers. Translational services were only required for the British-Bangladeshi caregiver group and these were provided by the support group. The recording was then back-translated by an impartial translator to ensure accuracy of the translation. Sessions ranged from 33 minutes to 93 minutes. The length of each focus group was influenced by the degree of translation and repetition required by caregivers. Audio tapes were transcribed verbatim by the first author. All caregivers received debriefing information which included contact details for support services. Participants received a ‘surprise’ payment of £10 (i.e. payment was not offered as part of the consent procedure).

Data analysis

The data was analysed using thematic content analysis. Thematic analysis is a flexible method of analysis in comparison to grounded theory and interpretative phenomenological analysis as it is not theoretically bound. The method is compatible with both the essentialist and constructionist paradigm (Braun & Clarke, 2006). Members of the research team familiarised themselves with the content of the transcripts through repeated readings and devised an outline coding scheme to highlight what Patton (2002) referred to as “units of meaning.” A series of codes was used to assign a conceptual label to sections of the transcripts. More detailed analysis allowed the identification of commonalities and contrasts and resulted in a more complex coding framework represented as hierarchical code groups. Team discussion (with VM, CR and postdoctoral colleagues) about code definitions and patterns in the thematic analysis facilitated the interpretation of the data. Coping data obtained in the focus group was coded using Carver’s (1997) coping model as a framework. This model includes 14 types of coping strategies: active coping, instrumental coping, positive reframing, humour, self-distraction, religion, acceptance, denial, substance use, emotional support, venting, behavioural-disengagement, self-blame and planning.

The reliability of the coding process was checked by a second researcher (health psychologist) who reviewed the coding applied to 3 focus group transcripts. Inter-rater agreement of 74% was reached. The 26% of disagreements were related to whether the quote was related to motivations to provide care or willingness to provide care. Motivations to provide care were identified using Lyonette and Yardley’s (2003) Motivations in Elder Care Scale (MECS) which includes extrinsic pressures to provide care such as perceived disapproval of others and intrinsic desires for care role adoption such as a sense of responsibility. Willingness to care was defined as the caregiver’s current and future thoughts that they would be willing to continue providing care. The codes that had caused disagreement were discussed and recoded with a final inter-rater agreement of 97%.

Results

The findings will be discussed in regards to similarities and differences between the four ethnic groups within the following main themes: motivations for care role adoption, willingness to provide care, experience of role, adaptation to care role, coping, use of and satisfaction with support.

Motivations for care role adoption:

All caregivers stated that they felt they had no choice but to adopt the role of the caregiver as there had been no one else to carry out the care role. BB, BI and BP caregivers stated that their role adoption was due to the care recipient not accepting help from any other individual (extrinsic motivation). BB, BI and BP caregivers believed that it was their duty or obligation and responsibility to provide care (extrinsic motivation).

> *"It is our duty towards our family, we wouldn't get anybody else to come and do it. We will have to do it. We won't hand our family over to anyone else, it's our blood. We'll do it ourselves. We will try as long as we are here. We don't want anybody else to look after our family."*
>
> (British-Bangladeshi female, age 37, caring for husband).

WB caregivers stated that the motivation behind their role adoption was their caring nature (intrinsic motivation) and they further believed that they had adopted the role due to their emotional attachments with the care recipient (intrinsic motivation) and because of their marriage vows.

> *"It's your husband, you've been married to him a long time, its in your marriage vows, its something you want to do for him."*
>
> (White-British female, age 80, caring for husband).

Willingness to care:

There was disagreement between BI/BP daughter-in-law and daughter caregivers over whose duty it should be to provide care in the family with many daughter caregivers stating they were forced to adopt the role due to the daughter-in-law failing to fulfill her responsibilities.

> "*I feel that the brothers should take responsibility and sister- in-laws, especially in my situation, sister- in-laws are not working at all but they do not want to take any responsibility to do anything and I think its not right, they should understand that I'm a carer for 2 persons, I go to work but they don't want to take any role at all, even when I take my mum to hospital, my sister-in-law doesn't want to do anything at all. She doesn't even want to take my mum to hospital so I have to take a day off from my other job to take my mum to hospital."*
>
> (British-Indian female caring for mother and her son.)

BB caregivers in contrast were very willing to provide care and this willingness was linked to fulfilling cultural duties as well as fear of an outsider not providing the same level of care.

"We are happy to be taking care, we find it rewarding, culturally we have to care for our own, it's rewarding. They (someone else) will get fed up of doing it, if we give up our kids, they'll look after them once but they won't carry on like we do."

(British-Bangladeshi female, age 40, caring for daughter and husband)

Perhaps due to feelings of emotional attachments to the care recipient, seven of the WB caregivers were willing to provide care, with five caregivers claiming "it was in their nature" to provide care

"I think it just comes into your life and you you're more than willing and you want to do it, you have for a long time hoped that they would get better and there would be an improvement, and you aim for that."

(White-British female, age 80, caring for husband).

However two WB caregivers felt unwilling to provide care and this led to feelings of guilt. Interestingly both these caregivers were non-spousal caregivers who were providing care out of a sense of duty (extrinsic motivation) suggesting that the nature of the relationship to care recipient may need further exploration: different motivations to care may lead to varying levels of willingness to care.

All caregivers were very willing to continue providing care. BB, BI and BP caregivers acknowledged that the motivation underlying their willingness to continue providing care was related to cultural and religious obligation.

"However long we are here for, we will give help, we need to do our duty. As long as God gives us strength and enough help to carry out the duties for as long as they live." (British-Bangladeshi female, age 40, caring for husband).

WB caregiver's willingness to continue providing care appeared to be linked to fear of losing the care recipient or avoiding nursing home placement.

Experience of caregiver role:

All caregivers stated that there were positive and negative aspects of the caregiver role and all highlighted the strengthened bond between themselves and their care recipient as the main positive aspect. They also reported that they perceived the care role to be made more difficult by having multiple roles, such as parent, employee and if they had other dependents.

BI and BP caregivers referred to sacrifices they had made (such as not being able to provide equal care for other dependents in the family) in order to provide care as the main negative aspect of the role; however BB caregivers appeared more accepting of the negative aspects as they did not perceive any other alternative.

> *"Even if it's a burden, you have to do it. If there's no one else in the family, how else is it going to get done?"*
>
> (British-Bangladeshi female, age 40, caring for husband).

BB, BI and BP caregivers also discussed a number of positive aspects to the caregiver role such as gaining satisfaction from fulfilling cultural obligations and gaining blessings from God and from the care recipient.

WB caregivers discussed the personal changes associated with the caregiver role such as losing time for themselves and not being able to do the things they had planned as a negative consequence of caregiving.

> *"Its bloody awful! You feel lonely, frustrated, angry, lots and lots of things, completely changes your life, can't do what you want and it spoils your retirement."*
>
> (White-British female, age 70, caring for husband).

WB caregiver's positive care role experiences were related to learning new skills and discovering who their real friends were.

Adaptation to care role:

BI, BP and WB caregivers perceived that the care role became more difficult as time passed with some care recipients becoming increasingly dependent on the caregiver.

"Being a carer for the time being is alright but as it gets longer you do need a bit of time for yourself, and the person you are caring for they depend on you and they rely on you and they trust you."

(British-Pakistani female, age 59, caring for Aunt).

BP, BI and WB considered that the role became more demanding over time regardless of the care recipient's illness. For BI and BP caregivers this led to conflicting responsibilities, whereas for WB caregivers this was linked to the development of their own health problems. BP, BI and WB caregivers also discussed the difficulty in dealing with changes in the care recipient resultant of their condition, which led to feelings of resentment and increased burden.

"He's not the man you married is he? That's how I feel about mine. I do begrudge that."

(White-British female, age 58, caring for husband).

In contrast BB caregivers considered that their role became easier over time due to the care duties becoming habitual and no longer burdensome. Even if they did find it difficult, they felt it was pointless dwelling on the negative aspects, as they still had to carry out their duties.

"It becomes like a habit. It's not hard now, and if it was, what else would we do? However much we are doing, we have to do. God gave us them (the care recipient), 6 or 7 months ago it was hard but now I'm used to it."

(British-Bangladeshi female, age 39, caring for daughter).

Coping:

All caregivers used some form of behavioral-disengagement coping such as being involved in activities outside the care role (e.g. part time employment, meditation and exercise classes). All caregivers also used some method of venting; for example BB, BI and BP caregivers reported crying and WB caregivers reported "moaning" and feeling angry. However the use of venting led to many caregivers feeling guilty.

"If I have a moan to somebody, then I feel really guilty about it."

(White-British female, age 62, caring for mother).

WB caregivers were also accepting of their role, displayed a "fighting spirit" (Charlton & Barrow, 2002) to encourage a positive attitude from the care recipient and used aspects of positive reframing. They also made use of alternative therapies such as St Johns Wort. In contrast BB, BI and BP caregivers relied more heavily on religious coping.

"The only thing that kept me going is prayers. I pray everyday to God, God has really helped me a lot".

(British-Indian female, age 50, caring for mother in law and son).

Use of and satisfaction with support:

All caregivers reported that they had very little support from their nuclear and extended families. The little support that they did receive was related to help with instrumental care tasks such as attending doctor appointments or in the case of the

British South-Asian females providing care for a male, support received from their sons in helping the care recipient with personal hygiene tasks. White-British caregivers accepted the lack of family support as part of the modern lifestyle however British South-Asian caregivers were resentful of it. In contrast WB caregivers were resentful of a lack of support from friends or other non-family members:

> *"Even your neighbours, when we used to be in the garden, they used to stop and chat but once the neighbours knew that he had cancer, it was like an invisible wall around us, didn't talk to us, and that's when I needed the support. When you need the support, people back off.*
>
> (White-British female, age 71, caring for husband).

Four WB caregivers also felt strongly about the lack of support for those who were no longer caregiving following the death of the care recipient and many believed that there should be more formal services for ex-caregivers. The WB caregivers also felt very strongly about the lack of education for new caregivers. Surprisingly this did not emerge in the data from the British South-Asian groups. WB caregivers believed that if they had been more prepared for the caregiver role they would have found it less challenging. Interestingly a number of WB caregivers also thought that caregivers in other cultures would have an "easier" experience in the care role as they would have the support of their extended family.

> *"They still got the big families to look after them, grandmother, when she's fine she looks after the baby for the mum, when the grandmother is not well they look after her, that's what's wrong with us now."*
>
> (White-British female, age 62, caring for husband).

BB, BI and BP caregivers did not acknowledge friends as a source of support with many stating that they would never think to ask friends for help, preferring help from family and/or formal services. When asked about their experience with formal services, the BB, BI and BP caregivers had very negative views. Many stated that would like to make more use of formal services but felt frustrated as they had been pushed from "pillar to post" in their efforts to seek help. They felt that many service providers took advantage of the language barriers, as they believed if ethnic minority caregivers were not able to understand what they were entitled to they did not have to provide it. The services that they had managed to access they felt lacked understanding of their culture. Many had lost faith in formal services.

> *"The most important thing I want to say is lots of agency and professional people don't understand our culture, don't understand our faith, and the most important thing is our voice not being heard."*
>
> (British-Indian female, age 50, caring for mother in law).

This is in sharp contrast to the generally positive attitude of the WB sample towards formal services, although even they suggested there was room for improvement. All caregivers stressed that they were grateful for whatever support they did receive, whether it was from family members, friends or formal services.

Discussion

The aim of the present study was to provide an in-depth qualitative comparative examination of the experience of British-Bangladeshi, British-Indian and British-Pakistani and White-British caregivers. BB, BI and BP caregivers were more often extrinsically motivated by a sense of duty and obligation (familism) to adopt the caregiver role whereas WB caregivers in this study provided care due to intrinsic motivations (emotional attachment with the care recipient). This is consistent with the findings reported by Parveen and Morrison (2009) that British South-Asian ethnicity predicts high levels of familism (obligation to provide care) in caregivers regardless of age and gender. However due to the diverse age range between the groups, it is possible that age is also a factor in influencing motivations to provide care. Obligation appears to be a key motivation for the younger British South-Asian caregivers which is inline with the relational approach to familism (Dellmann-Jenkins & Brittain, 2003) which predicts that familism will be highest in young adults based on caregivers wanting to “repay” their parents. BB caregivers were also willing to provide care as they felt they were fulfilling their cultural and religious duties. BI and BP caregivers reported feeling unwilling to provide care, mainly due to feeling that others in the family were not fulfilling their part of the care-duties whereas WB caregivers claimed they were very willing to provide care, as it was part of their nature to do so. It is notable that in spite of differences in initial motivation, all caregivers were willing to *continue* providing care. BB, BI and BP caregiver’s willingness to provide care was related to fulfilling their cultural and religious duty whereas WB caregiver’s willingness to provide care was due to fear of losing the care recipient and or reluctance to consider nursing home placement.

Consistent with the quantitative literature on caregiving all participants reported both positive and negative aspects of their care role. For many the most important aspect of the role was a strengthened bond with the care recipient, and the main cause of anxiety and concern was change in the care recipient’s behavior or condition. As opposed to the American-Indian caregivers in Hennessy and John’s (1996) study who discussed burden in a non-individualistic manner, BI and BP caregivers in this study discussed the negative aspects of the role in relation to sacrificing their other duties to provide care which was a great cause of strain. BB, BI and BP caregivers mainly discussed the positive experience of gaining satisfaction due to receiving religious blessings for fulfilling their duty. This contrasts significantly with WB caregivers who gained satisfaction from the role through learning new skills and gaining life experience. However the loss of time for these WB caregivers was considered a source of burden. This divergence may have been influenced by the different motivations underlying role adoption and coping strategies used by the caregivers. BB, BI and BP caregivers were more likely to use religion as a coping method and therefore may focus on the spiritual gains from the role.

Not only are there differences in the expression of burden between British South-Asian and WB caregivers, differences also exist within British South-Asian subcultures. BB caregivers diverged from BP and BI caregivers in that they mainly discussed the positive aspects of caregiving such as fulfilling ones cultural and religious obligations of providing care, and they also perceived the role had become easier over time as care related duties became habitual. Those that did acknowledge some strain in the role stated there was no need to dwell or indeed discuss this. BB caregivers believed that focusing on the negative side would only lead to increased stress. This difference in attitude to BI and BP caregivers may be due to the BB caregivers holding stronger religious beliefs. The BB caregivers in the current study were noted to follow stricter Islamic clothing rules whereas BI and BP caregivers had a slightly more western style of dress. This is consistent with Merrel, Kinsella, Murphy, Philpin and Ali’s (2005) findings who reported that the experience of caregiving within the BB community is viewed positively with very little use of services due to fears of being accused by the community of abandoning the family member. Another possible cause for the divergence in expression of burden may be the factor of age. The BB caregivers in the current study are significantly younger than the other ethnic groups. The British-Bangladeshi caregivers in Merrel et al’s

(2005) study were mainly aged between 41-62 years and thus older than caregivers in the current study, but they nonetheless expressed similar views.

Given the differences observed in the beliefs about and responses to caregiving, it is not perhaps unexpected that our data reflects differences in coping responses. All caregivers used behavioral disengagement, which involved the caregiver taking part in activities outside the care role such as part time employment. Venting was also another common method of coping however caregivers were reluctant to use this form of coping as it often led to feelings of guilt. BB, BI and BP caregivers were found to be very reliant on religious coping whereas WB caregivers made use of a positive reframing coping method. A number of WB caregivers also made use of alternative therapies such as herbal remedies to reduce stress.

Obtaining social support is known to be an important moderator of the stress experience (Thoits, 1995). In the current context, BB, BI and BP and WB caregivers reported that they received very little support from family and friends. However the groups differed in their attitude towards this. BB, BI and BP caregivers expressed anger at the lack of family and formal service support whereas WB caregivers directed their anger towards the lack of support from friends, and were accepting of the lack of support from family (perhaps due to lack of family nearby). Our findings are consistent with those of Katbamna, Ahmad, Bhakta, Baker and Parker (2004) who found that British South-Asian caregiver had limited support within the family and due to cultural obligations were unable or unwilling to seek support from wider networks.

Finally our data produced interesting ethnic variations in the use of formal services. British-Bangladeshi, British-Indian and British-Pakistani caregivers had a very negative attitude towards social and health services which contrasts with that reported by Katbamna et al (2004). In Katbamna's study British South-Asian caregivers were unwilling to seek formal support due to societal attitudes, whereas in the current study caregivers did in fact report making a number of attempts to seek formal assistance. However due to language barriers and lack of cultural sensitivity from services many had failed to gain the required aid. Gerrish (2000) offers support to this in terms of communication difficulties between nurses and British South-Asian caregivers and patients where over half of the British South-Asian patients had little or no understanding of English. The limited use of professional interpreters meant that British South-Asian caregivers were left disadvantaged and lacking psychological support. In the current study many of the BB, BI and BP caregivers adopted the attitude that they "would care for their own", perhaps as a result of being unable to access the formal services and having no other alternatives. WB caregivers in contrast had a positive view of the formal services available to caregivers however claimed that services could better serve the needs of new caregivers and caregivers who no longer were providing care.

Before concluding, several limitations need to be noted, the primary one being that the differences in caregiver experience reported here may not be solely due to ethnicity, but may in part be due to other factors such as age, socio-economic status, care recipient diagnosis, caregiver relationship and the number of roles the caregiver is involved in. In the current study British South-Asian caregivers were younger; however this is consistent with the general population of British South-Asian caregivers (Census, 2001). The sample also contained only two male caregivers who did not contribute very much to the focus group discussions. Whilst the research team felt it important to seek the views of male caregivers, particularly Asian males who are atypically found in this role, it may be that their presence altered the group dynamic. However feedback from female participants did not suggest this as they were keen to discuss their own experiences and encouraged the male caregivers to do the same. Another potential limitation is that British-Indian and British-Pakistani groups were mixed and therefore may have influenced the results. However as there were only four British-Pakistani caregivers who were in diverse locations, it was not possible to hold a separate focus group for British-Pakistani caregivers. Also all participants were attending community-based voluntary support groups which may have influenced their responses in relation to support from statutory services. The primary aim of the study was to highlight the ethnic similarities and differences within the caregiver experience; however it would also be of interest in future research to consider the experience of caregivers based on the care recipient's diagnosis.

In spite of these limitations a major strength of the current study was that caregivers were able to discuss their experience in their preferred language, using their own terminology, which removed many of the barriers to sharing their experiences that they alluded to when describing their experiences of formal services. Our findings point to an important gap in current understanding of caregiving: that of ethnic variation both at a macro level, that is White-British and British South-Asian, and importantly at a micro level, that is within the British South-Asian group itself. Our findings highlight the need to examine cultural variations within ethnic groups suggesting as they do that British-Bangladeshi caregivers differ in their experience of caregiving in comparison to British-Indian or British-Pakistani caregivers. Responses made by the BB caregivers may however reflect some self-presentation bias as these caregivers were particularly strong in their belief about duty and may not have wanted to appear as failing to do their duty by acknowledging the negative aspects of the role.

We also have to consider the challenge in assessing burden in different ethnic groups due to linguistic variations in idioms of distress. Finally, the findings also require validation and thus we are currently developing a questionnaire to quantitatively validate the qualitative findings through triangulation methods. Investigating cultural differences in a larger population and examining sub-ethnic differences in more detail could also extend the current study. Whilst much of previous ethnic minority caregiver research has focused on service use or use of family support, this study indicates that motivations of role adoption, willingness to care and coping will also be associated with caregiver burden and will influence service use. The study has implications for service development as the lack of personalization and consideration of culture in current service provision is a major concern for the caregivers in this study. We would also suggest that motivations and willingness to provide care should be considered by those professionals working to reduce caregiver distress.

Chapter 5

Ethnicity, Familism and Willingness to Care: Important influences on Caregiver Mood?

The material presented in this chapter is currently in review as:

Parveen, S & Morrison, V. Ethnicity, familism, and willingness to care: Important influences on caregiver mood? *Social Science and Medicine.*

Abstract

The study aimed to determine if ethnic differences exist in different parts of Lazarus's Transactional Model of Stress and Coping (coping, social support and caregiving stressors) and whether differences in familism and willingness to care further influence caregiver mood. A total of 235 primary family caregivers were recruited for the questionnaire study; of which 162 were White-British and 73 were British South-Asian. British South-Asian caregivers had significantly higher levels of familism than White-British caregivers, and British South-Asian caregivers used significantly more behavioural disengagement and religious coping than White-British caregivers who were more likely to make use of substances and humour as coping methods (controlling for an age effect). British South-Asian caregivers also reported having significantly less support than White-British caregivers. Familism was significantly related to White-British caregiver depression. Whilst levels of willingness to care did not differ between the two caregiver groups, opposing relationships were seen in the association between willingness to care and caregiver anxiety. Regression analyses, carried out with the two groups separately found that self blame was a significant positive concurrent predictor of South-Asian anxiety and depression. High use of substances, low use of humour and low mean satisfaction with support were strong concurrent predictors of White-British depression. These findings offer support to the Transactional model of stress in terms of what is associated with two potential outcomes of stress (anxiety and depression), and have implications for development of culturally specific interventions aimed at reducing caregiver distress.

Introduction

The term caregiver is generally used to describe an individual who provides support including physical, emotional and/or personal support (beyond what is typical for their relationship) for a family member or friend who is experiencing problems due to physical, emotional or cognitive impairments, often without financial compensation (Bridges, 1995). There are approximately six million caregivers in the UK, which accounts for 10% of the total population (Carers UK, 2009) and it has been reported that 21% of caregivers provide 50 hours or more of this unpaid care per week (UK Census 2001). Caregivers are of great socioeconomic value in the UK and save the National Health Service (NHS) approximately £87 billion per year. It is estimated that 285, 000 caregivers are from Black or minority ethnic groups (Carers UK, 2007) with the largest ethnic minority group being of South-Asian (Bangladeshi, Indian and Pakistani) origin in the UK. British Bangladeshi and British Pakistani caregivers are thought to be three times more likely to be providing care for a family member than their White-British counterparts (Carers UK, 2007).

Research exploring caregiver distress has mainly employed the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984; Lazarus, 1991; Lazarus, 2000) as a theoretical framework. In this model, stress is defined as a psychological transaction between the stimulus event or characteristics, for example in this context, the onset and severity of the care recipient’s cognitive, behavioural or physical impairments, and the cognitive and emotional characteristics of a caregiver. The model highlights the transaction between cognitive appraisals and reappraisals of the situation and the individual’s experience of various emotions. Each individual will evaluate a stimulus event and its context along with their ability to cope and the resources they have to deal with the situation. Stress or distress will occur when there is a perceived mismatch between the demands of the situation and the coping resources available to deal with the situation (Lazarus, 2000).

There is considerable cross-sectional evidence supportive of this model (essentially a framework to aid understanding of the stress process) showing that caregiver appraisals, coping and use of the resource of social support are significantly associated with caregiver depression **(**Hayley, Levine, Brown & Bartolucci, 1987; Bakas & Burgener, 2002), and these associations have also been supported by longitudinal research (e.g. Goode, Hayley, Roth & Ford, 1998 and Pakenham, 2001).

Aranda & Knight (1997) extended the Transactional Model of Stress and Coping to develop a Socio-cultural Model of Stress which integrates ethnicity and culture within the existing Lazarus framework. Aranda and Knight focus on “ethnicity as culture” and propose that ethnicity is associated with specific cultural differences which will directly affect caregiver appraisals, coping and use of social support. Ethnicity is essentially a psychological sense of belonging to a particular group based on perceived common ancestry, shared historical memories, and elements of a common culture and a sense of group solidarity (Hutchinson & Smith, 1996). Culture is very closely related to ethnicity and is defined as a shared set of values and assumptions based on common history, language and religion thus allowing a community to function together (Henry & Schott, 1999). The model has received support from various studies examining ethnic differences (Knight & Sayegh, 2010; Lai, 2007; Losada, Shurgot, Knight et al, 2006).

Past research on ethnic differences in the caregiver role has mainly focused on African American, Hispanic American and East Asian (Korean, Chinese) caregivers. In a review by Parveen & Morrison (in review) focusing on ethnic differences in caregiver distress, only 17 studies were identified which specifically focused on Asian caregivers from which three studies examined distress in South-Asian caregivers. The absence of research within the British South-Asian caregiver population may be due to language barriers and the belief that British South-Asian caregivers “look after their own” and have an extended family as a support network (Atkin & Rollings, 1992) and are thus less likely to require services.

As well as a lack of research on caregiver distress there has been little if any research that has examined the coping behaviours of British South-Asian caregivers, although there has been a growing amount of research focusing on British South-Asian support networks. Katbamna, Ahmad, Bhakta, Baker & Parker (2004) did not find support for the assumption that British South-Asian families have large family support networks. In fact, in a focus group study of 105 caregivers, they found that caregivers had very limited support from the nuclear and extended family. Fear of disapproval from the wider community further limited the caregiver in accessing other sources of support. In regards to formal support, it has been found that British South-Asian caregivers are often unaware of available services and what they are entitled to by means of formal services (Hepworth, 2005). Asian caregivers have also been found to have problems accessing appropriate services (Bowes & Wilkinson, 2003) and to have experienced a poor relationship with services dues to communication barriers (Mir & Tovey, 2003).

The cultural value of familism is of particular interest in the context of ethnic caregiving experience as it is likely that a strong family orientation will affect the caregiver stress process. Familism is defined as “strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity and solidarity among members of the same family” (Sabogal, Marin, Otero-Sabogal, Marin & Perez-Stable, 1987, 397-398). Familism is noted as being important in caregiver coping and stress responses amongst East Asian caregivers (Knight & Sayegh, 2010). In our recent study it was also found that British South-Asian caregivers also had significantly higher levels of familism than White-British caregivers. It was also found that familism was negatively associated with substance use and positively related to South-Asian caregiver religious coping (but not White-British). White-British familism was positively related to active coping and use of instrumental support (Parveen & Morrison, 2009). Research examining the influence of familism on distress has produced inconclusive findings. For example Lai (2007) and Gupta & Pillai (2002) found familism to be negatively related to caregiver burden but Zhan (2006) and Gupta (2009) found familism to be positively associated with caregiver burden and depression.

Using the Socio-cultural Model of Stress and Coping by Aranda & Knight (1997) as a conceptual frame work, the current study aimed to examine if ethnic differences exist in caregiver familism, willingness to care, coping, social support and caregiver distress, using a sample of British South-Asian and White-British caregivers. The study also focuses on the differential influence of the above independent variables on the distress of the two ethnic groups. It is hypothesised that (1) British South-Asian caregivers will have higher levels of familism. (2) British South-Asian caregivers will have higher levels of willingness to care and low use of support. (3) Familism and willingness to care will be positively related to distress (anxiety and depression). (4) British South-Asian caregivers will experience higher distress due to high familism and lower levels of support.

Method

Participants

Only caregivers who were over the age of 18 years and provided a minimum of seven hours per week of care were eligible for participation in the study. A total sample of 235 caregivers was obtained of which were 162 White-British (58 male and 104 female) and 73 were South-Asian (6 male and 67 female). South-Asian caregivers were more likely to be daughters (28.8%), daughter-in-laws (17.8%) and wives (17.8%). White-British caregivers were more likely to be wives (45.1%), followed by husbands (28.4%) and daughters (13%). Further demographic detail can be found in Table 1.

Table 1. Demographic data for ethnic groups

		Ethnicity		
Demographic	Subgroup	British South-Asian (*n* = 73)	White-British (*n* = 162)	Total
Gender	Male	6 (8.2%)	58 (35.8%)	64
	Female	67 (91.8%)	104 (64.2%)	171
Diagnosis	Cancer	24 (32.9%)	4 (2.5%)	28
	Stroke	15 (20.5%)	20 (12.3%)	35
	Dementia	16 (21.9%)	49 (30.2%)	65
	Parkinson's disease	2 (2.7%)	33 (20.4%)	35
	Multiple sclerosis	0	45 (27.8%)	45
	Multiple of above	2 (2.7%)	3 (1.9%)	5
	Other	14 (19.2%)	8 (4.9%)	22
Marital Status	Single	16 (21.9%)	5 (3.1%)	21
	Married	51 (69.9%)	140 (86.4%)	191
	Divorced	1 (1.4%)	10 (6.2%)	11
	Widow	1 (1.4%)	4 (2.5%)	5
	Missing	4 (5.5%)	3 (1.9%)	7
Occupation	Housewife	35 (47.9%)	0	35
	Full time caregiver	10 (13.7%)	16 (10.1%)	26
	Employed	23 (31.5%)	42 (26.4%)	65
	Retired	2 (2.7%)	96 (60.4%)	98
	Unemployed	0	5 (3.1%)	5
	Student	2 (2.7%)	0	2
	Missing	1 (1.4%)	3 (1.9%)	4
Relationship to care recipient	Husband	2 (2.7%)	46 (28.4%)	48
	Wife	13 (17.8%)	73 (45.1%)	86
	Partner	0	3 (1.9%)	3
	Daughter	21 (28.8%)	21 (13.%)	42
	Daughter in law	13 (17.8%)	1 (0.6%)	14
	Son	4 (5.5%)	4 (2.5%)	8
	Parent	5 (6.8%)	8 (4.9%)	11
	Sibling	5 (6.8%)	2 (1.2%)	7
	Grand daughter	7(9.6%)	0	7
	Friend	1 (1.4%)	2 (1.2%)	3
	Missing	3 (2.7%)	3 (1.9%)	6

Measures[3]

The demographic section of the questionnaire contained questions regarding caregiver ethnicity, gender, age, care recipient diagnosis, marital status, occupation, relationship to care recipient, hours per week spent caregiving and number of years in caregiver role.

The Heller Familism Scale (1976) was used to measure familism. This scale consists of 15 items rated on a five point likert scale and contains items such as "Married children should live close to their parents so that they can help each other". A high score (max score = 60) on this scale indicates high levels of familism. The measure demonstrated good internal consistency with a Cronbach's alpha of 0.85.

The Brief COPE (Carver, 1997) was used to assess use of coping strategies. This measure contains 14 subscales (active coping, use of instrumental support, planning, positive reframing, humour, self distraction, religious coping, acceptance, denial, substance use, use of emotional support, venting, behaviour-disengagement and self-blame) which contain two items each (28 items in total). Each item is rated based on how often the method is employed using a four point Likert scale. As there are only two items per subscale, inter item correlations were used to assess scale reliability. In this study the inter-item correlations ranged from 0.43 (self distraction) to 0.90 (religion).

The Saranson Social Support Questionnaire (Sarason, Sarason, Shearin, Pierce, 1987) was used to assess the amount of and satisfaction with support. Caregivers were required to list all the social support they have (with the option of "no one" also included) and then rate on a six point scale their level of satisfaction with each support source (1 = Very dissatisfied to 6 = Very satisfied). Two scores

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[3] Measures can be found in Appendix 5 page 408.

were obtained from this measure: the total number of supports received and the mean satisfaction with the overall support. This measure demonstrated good internal consistency for total support (0.75) and satisfaction with support (0.88).

The Willingness to Care Scale (WCS) developed by Abell (2001) was used to assess caregiver's willingness to provide care. The measure consists of three subscales of 10 emotional tasks, 10 instrumental tasks and 10 nursing tasks that are typically carried out by caregivers. An example of an item from the measure would be "help some one eat a meal". Caregivers were required to rate each item on a five point likert scale regarding how willing they were to complete each task (1 = completely unwilling to 5 = completely willing). The internal consistency (Cronbach's alpha) for the emotional scale was a good 0.93, for the instrumental scale a moderate 0.65 was achieved and for the nursing scale was also good 0.93.

Caregiver mood was assessed using the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) which consists of two subscales: depression and anxiety, each one containing 7 items which are rated on a 4 point scale ranging from 0-3. A possible maximum score of 21 can be obtained on each subscale and individuals with a score ranging from 0-7 are considered to be "normal", scores from 8-10 are "borderline" and scores above 11 indicate "caseness". Previously the two scales have demonstrated good internal reliability however in the current study the anxiety subscale achieved only moderate levels (Cronbach's reliability alpha of 0.63 and 0.65 for depression).

Procedure

Ethical approval was received from the departmental ethics committee before the commencement of data collection. Various representative caregiver support groups across the U.K were sent packs containing information about the study. Fifteen interested groups (of which five represented specifically British South-Asian caregivers) invited the researcher to meet the caregivers in person and discuss the study in further detail. Caregivers who wished to participate in the study were given a questionnaire pack containing a study information sheet, consent form, a questionnaire, information regarding caregiver services and a free-post envelope. All caregivers had the option of completing the questionnaire at home or with the aid of the researcher. Fifteen South-Asian caregivers required the translation help of the researcher to complete the questionnaire. A further three caregiver groups posted the questionnaire packs directly to the caregivers on their mailing list. Short articles about the research study were also placed on caregiver websites and newsletters. Once caregivers returned their completed questionnaires, they received debrief information and further information about caregiver services. A response rate of 90% was achieved for the British South-Asian sample and approximately 31% for the White-British sample.

Data analysis

Using SPSSv17, non parametric tests were conducted to examine demographic group (gender, care recipient diagnosis, and relationship with care recipient) differences in anxiety and depression. Independent t tests and equivalent non parametric tests were used to examine ethnic differences in independent variables (IVs). ANCOVA tests were used to control for the effect of age to ensure that the differences in independent variables was due to ethnicity. Pearson’s correlation analysis was conducted to explore the relationship between IVs and anxiety and depression for each ethnic group. Partial correlations were also conducted to control for the effect of age. Hierarchical regression analysis was performed to examine the amount of variance in anxiety and depression was explained by IVs for each ethnic group. Only those relationships that reached statistical significance during correlation analysis were entered into the regression model. Dummy variables were created for categorical IVs such as gender before being entered into the regression model.

Results

T-tests were conducted to establish whether British South-Asian and White-British caregivers differed in age, number of hours of caregiving per week and number of years in caregiver role. With regards to age British South-Asian caregivers (M = 40.91, SD = 16.5) were significantly younger than White-British (M = 63.78, SD = 8.51) caregivers (t (225) = -10.65, $p < .001$). There was no significant difference between British South-Asian caregiver hours spent caregiving (M = 101.66, SD = 69.43) and White-British hours spent caregiving (M = 108, SD = 66.32). There was also no significant difference in number of years in caregiver role between British South-Asian (M = 8.27, SD = 8.12) and White-British (M = 8.51, SD = 7.72) caregivers.

Demographic differences in distress

Gender differences in distress within the South-Asian sample could not be examined as there were only 6 male caregivers. There were no significant diagnosis group differences in distress for South Asian caregivers. The relationship variable was re-categorised into 3 groups: spouse (n = 15), adult child (including children in law; n = 38) and other (including parents, siblings; n = 18) and a Kruskall-Wallis test was used to examine group differences. Spouse caregivers (Mean rank = 21.67) were found to be significantly less anxious than adult children (Mean rank = 40.58) and other caregivers (Mean rank = 38.28; H = 12.51, p = .002). Age was found to have a significant relationship with anxiety (r = -.28, p = .02) as did the number of years in care role ($r = -.29$, $p = .01$). The number of hours per week of caregiving was not significantly related to anxiety.

White-British female caregivers ($M = 10.54$, $SD = 5.31$) were significantly more anxious than White-British male caregivers ($M = 8.55$, $SD = 3.78$; $t = -2.48$, $p = .01$). A significant effect of diagnosis group was found whereby the dementia group (Mean rank = 91.95) had significantly higher anxiety than the Parkinson’s disease (Mean rank = 67.15), multiple sclerosis (Mean rank = 74.57) and other group (Mean rank = 50.50; $H = 12.67$, $p = .03$). No significant differences in anxiety were found for the relationship groups. Caregiver age, the number of hours and year in care role were also not significantly related to caregiver anxiety.

There were no significant differences in depression between diagnosis groups within the South-Asian sample. Spouse caregivers (Mean rank = 26.14) were found to have significantly lower levels of depression than the adult children (Mean rank = 38.59) and the other group (Mean rank = 36.25) within the South-Asian sample ($H = 8.48$, $p = .01$). Age was found to have a significant relationship with depression ($r = -.26$, $p = .03$) but the number of hours and year in care role were not significantly related to caregiver depression.

There were no gender differences in depression for the White-British group. The dementia group (Mean rank = 95.79) significantly had higher levels of depression than the cancer (Mean rank = 80.00), Parkinson’s disease (Mean rank = 61.82), multiple sclerosis (Mean rank = 76.40) and other group (Mean rank = 50.62; $H = 17.72$, $p = .003$). There were no significant differences in depression between the relationship groups. The number of hours per week of caregiving was significantly related to depression ($r = .16$, $p = .05$). White-British caregiver age and number of years in care role were not significantly related to caregiver depression.

Ethnic differences in IVs and distress

As can be seen from Table 2, once the effect of age was controlled using ANCOVA tests, South-Asian caregivers continued to have significantly higher levels of familism compared to White-British caregivers ($p < .001$). No significant differences in willingness to care were found. With regards to coping strategies, White-British caregivers used significantly more humour ($p < .01$) and substances ($p <.05$). South-Asian caregivers significantly used more behavioural disengagement ($p < .001$) and religious coping ($p < .001$).

White British caregivers had significantly more support than South-Asian caregivers ($p < .001$) but there was no significant difference in mean satisfaction with support. Four 2 (Ethnicity) by 2 (yes/no) Chi square analysis were conducted to examine differences in the use of family, friends and formal services as support used by British South-Asian and White-British caregivers. White-British caregivers (8.2%) were less likely to report they had no support at all compared to British South-Asian caregivers (24.7%) ($x^2 = 10.36$, $p < .001$); there was no significant difference in the use of family support (British South-Asian 74%, White-British 73.6%, $x^2 = .004$, $p = .95$); White-British caregivers (52.2%) were more likely to use friends as support than British South-Asian (21.9%) caregivers ($x^2 = 17.54$, $p < .001$) and White-British caregivers were also more likely to use formal services (52.2%) compared to British South-Asian (9.6%) caregivers ($x^2 = 39.27$, $p <.001$).

In relation to distress, South-Asian caregivers had significantly higher levels of depression than White-British caregivers ($p < .05$) but not anxiety (although both groups scored in the clinical borderline category).

Table 2: Descriptive data for ethnic group, t test analysis and ANCOVA analysis controlling for the effect of age

		British South-Asian		White-British		T tests (df = 1, 233)		ANCOVA analysis			
Scale	Subscale	*Mean*	*SD*	*Mean*	*SD*	*t/u*	*p* value	Ethnicity *F*	*p* value	Age *F*	*p* value
Familism		44.84	13.60	24.09	11.76	11.88	0.001***	95.58	0.001***	0.55	0.55
Willingness	Emotional	43.90	6.43	44.90	7.99	-0.82	0.41	1.39	0.24	0.76	0.39
to care	Instrumental	43.79	10.54	44.32	7.01	-0.34	0.73	0.99	0.32	0.99	0.32
	Nursing	40.89	8.69	42.53	9.67	-1.01	0.32	0.94	0.33	0.62	0.43
brief COPE	Self distraction	4.60	1.83	4.38	1.83	0.88	0.38	0.03	0.87	0.91	0.34
	Active coping	5.36	1.81	5.15	1.87	0.77	0.44	1.01	0.32	0.93	0.34
	Denial	3.52	1.78	2.94	1.64	2.43	0.02*	2.29	0.13	0.21	0.65
	Substance use	2.40	1.22	2.78	1.54	-2.00	0.05*	3.67	0.05*	0.42	0.52
	Emotional support	4.42	1.83	4.41	1.69	0.05	0.96	0.27	0.60	0.87	0.35
	Instrumental support	4.49	1.76	5.13	1.79	-2.53	0.01**	0.001	0.97	7.09	0.001***
	Venting	4.40	1.94	3.67	1.66	2.77	0.01**	1.50	0.22	1.10	0.30
	Positive reframing	4.75	1.79	4.33	1.81	1.65	0.10	3.87	0.05*	1.32	0.25
	Self blame	3.84	1.91	3.31	1.47	2.09	0.04*	0.01	0.93	8.59	0.004**
	Planning	4.89	1.72	4.96	1.83	-0.29	0.78	0.02	0.90	0.19	0.66
	Behaviour disengagement	3.71	1.88	2.62	1.26	4.51	0.001***	16.52	0.001***	0.04	0.85
	Humour	2.81	1.56	3.35	1.71	-2.29	0.02*	8.24	0.004**	2.34	0.13
	Acceptance	5.93	1.88	6.20	1.87	-1.01	0.32	0.09	0.76	3.74	0.05*
	Religious coping	5.85	2.31	3.58	2.22	7.15	0.001***	49.91	0.001***	7.67	0.01**
Social	Total Support	1.92	1.50	3.22	1.47	-6.21	0.001***	24.41	0.001***	0.09	0.76
Support	Mean satisfaction	4.02	1.98	4.96	1.13	-4.60	0.001***	0.29	0.59	24.51	0.001***
HADS	Anxiety	9.85	4.19	8.03	3.60	3.40	0.001***	2.28	0.13	3.54	0.06
	Depression	7.75	4.47	5.71	3.50	3.76	0.001***	4.28	0.04*	1.56	0.21

British South-Asian Anxiety:

Partial correlation analysis controlling for the effects of age (see Table 3) found that familism was not significantly related to South-Asian caregiver anxiety. Willingness to provide instrumental and nursing care were positively related to anxiety but only nursing willingness to care remained significant once the effect of age was controlled. Denial, substance use, emotional support, venting and self blame were all significantly positively related to anxiety. Perhaps surprisingly, no significant relationship between social support and anxiety was found.

Table 3. Correlations and partial correlation analysis examining relationships between IVs and **anxiety** for ethnic groups

	British South-Asian			White-British		
			Age controlled			Age controlled
Variable	*r*	*n*	*r*	*r*	*n*	*r*
Familism	-0.01	73	-0.04	0.12	159	0.09
Emotional willingness	0.19	63	0.15	-0.21*	92	-0.03
Instrumental willingness	0.31*	57	0.25	-0.22*	90	-0.09
Nursing willingness	0.30*	57	0.34**	-0.24*	75	-0.11
Self distraction	-0.12	73	-0.08	0.30***	160	0.30***
Active coping	-0.12	73	-0.08	0.06	160	0.06
Denial	0.43***	73	0.41***	0.27***	160	0.27***
Substance use	0.26*	72	0.26*	0.22**	160	0.22**
Emotional support	0.20	73	0.24*	0.07	160	0.07
Instrumental support	0.08	73	0.12	0.12	160	0.13
Venting	0.29**	73	0.30**	0.34***	160	0.34***
Positive reframing	-0.14	73	-0.07	-0.04	160	-0.04
Self blame	0.47***	73	0.42***	0.18*	160	0.18*
Planning	0.08	73	0.10	0.06	160	0.06
Behaviour disengagement	0.07	73	0.11	0.33***	160	0.33***
Humour	-0.06	73	-0.02	-0.06	160	-0.06
Acceptance	-0.02	73	0.05	-0.11	160	-0.11
Religious coping	-0.21	73	-0.17	0.06	160	0.06
Total Support	0.07	73	0.09	-0.01	157	-0.02
Mean satisfaction	0.05	73	0.16	-0.19*	157	-0.19*

Note

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

As can be seen from table 4, hierarchical multiple regression found that demographic factors (age, years in role and caregiver-care recipient relationship were entered at step 1) accounted for 14% of the variance in South-Asian anxiety. Instrumental and nursing willingness to care accounted for a further 6% of the variance in anxiety. Coping (denial, substance use, emotional support, venting and self blame) added a final and significant 25% to the model with the final model accounting for a significant 45% of the variance in South-Asian anxiety. An examination of the beta values suggests that self blame was the strongest positive concurrent predictor of anxiety.

Table 4. Summary of hierarchical regression for British South-Asian anxiety.

	Model 1			Model 2			Model 3		
Predictor	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Age	-0.05	0.05	-0.18	-0.07	0.05	-0.27	-0.06	0.04	-0.2
Years in care role	-0.13	0.09	-0.22	-0.05	0.10	-0.08	0.04	0.09	0.07
Relationship	-0.01	0.004	-0.18	-0.002	0.004	-0.06	0.0001	0.004	-0.01
Instrumental willingness				0.02	0.08	0.05	0.06	0.07	0.14
Nursing willingness				0.13	0.10	0.25	0.09	0.09	0.17
Denial							0.59	0.36	0.23
Substance use							-0.04	0.51	-0.01
Emotional support							0.50	0.34	0.19
Venting							-0.16	0.37	-0.07
Self blame							0.91	0.39	0.37*
r^2 Change		0.14			0.06			0.25	
F Change		2.62			1.65			3.74**	

Note

* *p* < .05 ** *p* < .01

White-British Anxiety:

As can be seen from Table 3, familism was not significantly related to White-British anxiety. In contrast to the South-Asian group, willingness to care had a significant negative relationship with caregiver anxiety. Self distraction, denial, substance use, venting, self blame and behavioural disengagement were all positively related to anxiety. Mean satisfaction with social support was found to be significantly negatively related to anxiety.

In the final regression model (see table 5), demographics (gender and care recipient diagnosis) accounted for a non significant 7% of the variance in White-British anxiety. Willingness to care added a non significant 0.4% to the model. Coping (self distraction, denial, substance use, venting, self blame and behavioural disengagement) accounted for a larger but not significant variance of 15% and mean satisfaction with social support added a final 4% to the model. The final model accounted for 26% of the variance in White-British anxiety.

Table 5. Summary of hierarchical regression for White-British anxiety.

	Model 1			Model 2			Model 3			Model 4		
Predictor	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Gender	1.59	1.34	0.16	1.49	1.44	0.15	1.47	1.47	0.14	1.40	1.45	0.14
Diagnosis	-0.67	0.51	-0.17	-0.67	0.55	0.17	-0.43	0.57	-0.10	-0.60	0.58	-0.15
Emotional willingness				-0.004	0.12	-0.01	0.03	0.12	0.05	0.03	0.12	0.04
Instrumental willingness				0.02	0.17	0.04	-0.07	0.17	-0.09	-0.05	0.17	-0.08
Nursing willingness				-0.04	0.12	-0.08	0.06	0.13	0.12	0.04	0.13	0.09
Self distraction							0.14	0.41	0.05	0.04	0.41	0.02
Denial							0.56	0.46	0.19	0.41	0.47	0.14
Substance use							0.17	0.44	0.05	0.26	0.43	0.08
Venting							0.50	0.46	0.17	0.47	0.45	0.16
Self blame							-0.12	0.54	-0.04	-0.07	0.53	-0.02
Behaviour disengagement							0.82	0.55	0.21	0.72	0.55	0.18
Mean support satisfaction										-0.88	0.59	-0.20
r^2 Change		0.07			0.004			0.15			0.04	
F Change		1.99			0.08			1.50			2.19	

British South-Asian Depression:

As can be seen from Table 6, familism and willingness to care were not related to South-Asian caregiver depression. Active coping was negatively associated with depression and denial, substance use and self blame were all positively related to depression. Social support was not found to be significantly related to depression.

Table 6. Correlation and partial correlation analysis examining the relationship between IVs and **depression** for ethnic groups

	British South-Asian			White-British		
			Age controlled			Age controlled
Variable	*r*	*n*	*r*	*r*	*n*	*r*
Familism	-0.02	72	0.01	0.18*	159	0.07
Emotional willingness	0.07	62	0.06	-0.01	92	0.05
Instrumental willingness	0.23	56	0.13	-0.04	71	0.04
Nursing willingness	0.07	57	0.14	-0.12	75	-0.01
Self distraction	-0.21	72	-0.17	0.16*	161	0.17*
Active coping	-0.29*	72	-0.26*	0.11	161	0.11
Denial	0.36**	72	0.33**	0.28***	161	0.29***
Substance use	0.24*	71	0.24*	0.37***	161	0.38***
Emotional support	0.01	72	0.05	0.05	161	0.05
Instrumental support	-0.08	72	-0.04	0.14	161	0.14
Venting	0.09	72	0.09	0.24**	161	0.24**
Positive reframing	-0.18	72	-0.10	-0.12	161	-0.11
Self blame	0.45***	72	0.39***	0.21**	161	0.21**
Planning	-0.002	72	0.03	0.03	161	0.03
Behaviour disengagement	-0.05	72	-0.01	0.27***	161	0.28***
Humour	-0.08	72	-0.03	-0.26***	161	-0.26***
Acceptance	-0.09	72	-0.02	-0.16*	161	-0.17*
Religious coping	-0.11	72	-0.06	-0.03	161	-0.04
Total Support	-0.13	72	-0.12	-0.11	158	-0.10
Mean satisfaction	-0.19	72	-0.10	-0.20**	158	-0.22**

Note

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

As can be seen from table 7, hierarchical regression found that demographics (age and relationship with care recipient) accounted for a significant 14% of the variance in South-Asian depression. Coping (active coping, denial substance use and self blame) added a final significant 22% to the model. The final model accounted for 36% of the variance in South-Asian depression and as with South-Asian anxiety; self blame was the strongest, positive concurrent predictor of depression.

Table 7. Summary of hierarchical regression for British South-Asian depression.

	Model 1			Model 2		
Predictor	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Age	-0.09	0.04	-0.29**	-0.04	0.03	-0.13
Relationship	-0.01	0.003	-0.27*	-0.01	0.003	-0.20
Active coping				-0.49	0.29	-0.18
Denial				0.47	0.33	0.17
Substance use				0.45	0.45	0.11
Self blame				0.73	0.34	0.28*
r^2 Change		0.14			0.22	
F Change		5.28**			5.36***	

Note

* *p* < .05 ** *p* < .01 ****p* < .001

White-British depression:

Familism was found to have a significant positive relationship with depression for White-British caregivers but once the effect of age was controlled, the relationship became non significant. Willingness to care was not significantly related to depression. Self distraction, denial, substance use, venting, self blame and behavioural disengagement were all positively related to depression. Acceptance and use of humour were negatively related to depression. Total amount of support was not significantly related to depression but mean satisfaction with support had a negative relationship with depression.

Hierarchical regression analysis (see table 8) found that demographics (care recipient diagnosis and hours per week caregiving) accounted for a significant 6% of the variance in White-British depression. Familism accounted for only 0.03% of the variance. Coping (self distraction, denial, substance use, venting, self blame, behaviour disengagement, acceptance and humour) accounted for a significant 15% of the variance in depression and social support added a final significant 8% to the model. The final model accounted for 29% of the variance in White-British depression, with use of substances being a strong positive predictor and use of humour as well as mean satisfaction with social support being strong negative predictors of depression.

Table 8. Summary of hierarchical regression for White-British depression.

	Model 1			Model 2			Model 3			Model 4		
Predictor	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Diagnosis	-0.68	0.29	-0.19*	-0.67	0.29	-0.19*	-0.55	0.29	-0.16	-0.74	0.28	-0.21**
Hours per week	0.01	0.01	0.13	0.01	0.01	0.13	0.01	0.01	0.14	0.01	0.01	0.17*
Familism				0.02	0.03	0.05	-0.004	0.03	-0.01	0.004	0.03	0.01
Self distraction							0.01	0.22	0.003	-0.10	0.21	-0.04
Denial							0.21	0.23	0.08	0.05	0.22	0.01
Substance use							0.55	0.24	0.19*	0.66	0.23	0.23**
Venting							0.31	0.25	0.12	0.30	0.24	0.11
Self blame							0.10	0.27	0.03	0.12	0.25	0.04
Behaviour disengagement							0.53	0.31	0.15	0.41	0.29	0.11
Humour							-0.43	0.21	-0.16*	-0.46	0.20	-0.17*
Acceptance							-0.11	0.20	-0.05	-0.09	0.19	-0.04
Mean support satisfaction										-1.19	0.31	-0.30**
r^2 Change		0.06			0.003			0.15			0.08	
F Change		4.67**			0.44			3.15**			14.72***	

Note

* *p* < .05 ** *p* < .01 ****p* < .001

Discussion

As hypothesised the British South-Asian caregivers had significantly higher levels of familism than White American caregivers, which is inline with our previous findings (Parveen & Morrison, 2009). Parveen, Morrison & Robinson (in press) as well as Katbamna & Bhakta (1998) also report from qualitative findings that the main motivation for providing care is a sense of family obligation.

Despite differences in familism, there was no significant ethnic difference in levels of willingness to care in the current study. This may be due to a number of reasons, including the fact that obligation to provide care (familism) may not necessarily equate to willingness to provide care. That is, a caregiver may feel highly obligated but not necessarily feel willing to provide care. Although this relationship has not been examined in quantitative research, a focus group study by Parveen et al (in press), also found that British Indian and British Pakistani caregivers were motivated to provide care by a sense of cultural obligation but were not always willing to provide care (that is they felt they had no choice but to provide care and weren’t always willing). However, both South-Asian and White-British caregivers were generally willing to continue providing care.

Several differences with regards to coping emerged between the two ethnic groups, but many of these were confounded by the influence of age. South-Asian caregivers were significantly younger than White-British caregivers. Differences in use of instrumental support and self blame were found to be due to age as opposed to ethnicity. Use of instrumental support was positively associated with age whereas self blame was negatively related to age. Perhaps as older caregivers are more likely to experience their own health problems they make more use of instrumental support.

Once age was appropriately controlled, South-Asian caregivers continued to significantly make more use of behavioural disengagement and religious coping than White-British caregivers, who were more likely to use substances and humour. These results are in concurrence with the limited previous work in this area. For example, Parveen, Morrison & Robinson (In press) also found that South-Asian caregivers were very reliant on religious coping. Although caregivers used some form of behavioural disengagement and venting, use of substances was more common in White-British caregivers. Hussain & Cochrane (2003) also found in a qualitative study that religiosity, talking, crying and self harm was commonly used coping methods among British South-Asian depressed women. Perhaps the reliance on religion and prayer among British South-Asian caregivers is due to lack of support, as certainly our data show that British South-Asian caregivers had significantly lower support than White-British caregivers.

British South-Asian caregivers report significantly less support and were less satisfied with their support than White-British caregivers. This supports other findings that British South-Asian caregivers lack support from the family and formal services (Hepworth, 2005; Katbamna et al, 2004; Mir & Tovey, 2003). Surprisingly it emerged that there was no significant difference in the use of family support between the two ethnic groups, yet it is often assumed that British South-Asian families have large extended support networks (Atkin & Rollings, 1992). Our findings may be due to change in family structure caused by recent economic pressures for example movement within families to seek employment (Mann, 2009). As expected and previously reported (Katbamna et al 2004 & Parveen et al, in press) British South-Asian caregiver were less likely to use friends and formal services as support.

As hypothesised, British South-Asian caregivers were significantly more anxious and depressed than White-British caregivers. However this was influenced by age, which we therefore controlled for. On doing this British South-Asians remained significantly more depressed than White-British caregivers. It should be noted that both groups were in the borderline category for anxiety “caseness”. Although there is a lack of comparable studies the findings are inline with research using Eastern Asian and White American caregivers, which found that Asian caregivers were significantly more distressed than the comparator group (Chun, Knight, & Youn, 2007; Mackenzie, Perry, Lockhart, Cottee, Cloud, & Mann, 2007; Lee & Farran, 2004). A possible explanation for this difference in distress may be ethnic differences in illness perceptions. Past research has found that threat appraisals are related to poorer outcomes and these effects are maintained longitudinally (Pakenham, 2001). Further research is required regarding ethnic differences in caregiver illness perceptions.

In accordance with the third hypothesis, familism was not related to British South-Asian distress but did have a significant positive relationship with White-British caregiver depression which was influenced by age in that familism was positive related to depression for older White-British caregivers. Despite a number of previous studies finding a relationship between familism and distress, our non-findings, at least for the Asian sample, are in accordance with Chun et al (2007) who also found no effect of familism on distress in Korean, Korean-American and White-American caregivers. Our results suggest instead that ethnicity influences use of specific coping strategies which in turn influences distress.

The final hypothesis suggesting that British South-Asian caregivers will experience more distress due to familism and low levels of social support is not supported. Coping appears to have a more important relationship with ethnic group distress. Self blame was a strong concurrent positive predictor of South-Asian anxiety and depression. Interestingly, use of emotional support was also a positive predictor of South-Asian anxiety. Due to the cross-sectional data, it is difficult to predict if use of emotional support caused anxiety or whether increasing anxiety led to the use of emotional support. Behavioural disengagement and mean satisfaction with social support appeared to be stronger concurrent predictors of White-British anxiety, whereas use of substances was a stronger positive predictor of and use of humour and satisfaction with support were negative predictors of White-British depression. Familism and willingness to care were not found to be significant predictors of distress in either group. This may be due to familism being related to general caregiver burden as opposed to psychological distress. An opposing relationship between willingness to care and distress was found for the two ethnic groups, with highly willing South-Asian caregivers being more anxious and highly willing White-British caregivers experiencing lower anxiety.

Whilst considering the implications of the findings for culturally appropriate interventions or services, some limitations need to be addressed. Although the study expands on the existing evidence base by using a quantitative methodology and well validated, theoretically derived instruments wherever possible, the cross-sectional design limits causal inferences from being made at this time. An ongoing longitudinal study will examine the consistency of ethnic differences and how the caregiver experience changes over time. Another methodological issue includes the low scale reliability of the instrumental willingness to care scale with the item “willing to help pay for recipient’s medicine”. This item may be irrelevant for British caregivers as many receive free prescriptions from the National Health Service, particularly within Wales, where 38% of our sample reside where prescription charges have been abolished. Surprisingly the Hospital Anxiety and Depression Scale also demonstrated low reliability compared to previous studies, with one item in the anxiety scale, “I get sort of a frightened feeling as if something bad is going to happen” causing problems for British South-Asian caregivers. The item “I feel as if I am slowed down” in the depression scale caused problems for the White-British caregivers. This may be due to the White-British sample being older in age and therefore the feeling of being slowed down may be considered normal by the sample causing a ceiling effect. Another possible explanation for the low reliability of the scales may be due to the measures being informally translated to caregivers during the data collection process as opposed to using validated translated measures.

The study also made use of a convenience sample recruited from support groups, which may have biased the results. Caregivers already in touch with services may have higher distress levels than the general caregiver population. The two ethnic groups also had a contrasting demographic profile with differences in role relationships and diagnosis. To accommodate this we controlled for confounding variables during regression analysis and these factors appeared to have little effect. Also, the British South-Asian caregivers that participated in the study were young and may have been more acculturated than the general British South-Asian population. Thus despite having high familism values, they may not have actually practiced them. It would be of interest to examine general motivations to care as well as focusing on specific familism values. Although the effect of age was carefully controlled in analysis to prevent confounding, the younger age of the British South-Asian caregiver sample is actually representative of the British South-Asian caregiver population (UK Census, 2001). Although the findings may not entirely be due to ethnic differences (ethnicity and age being partly confounded), the contribution of our findings to the understanding of ethnic caregiver experience, and the implications of the findings for services remain significant.

The findings are also supportive of the Transactional Model of Stress (Lazarus & Folkman, 1984) in that coping and social support were stronger concurrent predictors of distress than familism; however further research is required to establish the influence of willingness to care in the caregiving experience, particularly due to its importance in predicting British South-Asian anxiety. There has been very limited research using the South-Asian caregiver population. In a systematic review of Asian caregiver distress literature by Parveen & Morrison (in review) only three studies were identified that made use of a South-Asian population (two were American Indian). The majority of current South-Asian caregiver literature has focused on caregiver use of support, using small samples and qualitative designs. The current study expands on previous research by using a theoretical framework dominant in health psychology research and using a quantitative methodology (which also enables the validation of previous qualitative findings reported by Parveen, Morrison and Robinson, in press).

As well as adding to the evidence base, the study has a number of practical implications. The current study highlights the importance of considering use of coping strategies in minority groups and its associations with caregiver’s outcomes. The findings of the study suggest that reducing self blame, denial and behavioural disengagement may reduce distress in caregivers, and there is evidence of the efficacy of coping skills training in caregivers as well as patients (McMillan, Small, Schonwetter, Tittle, Moody & Haley, 2005). Willingness to care also appears to have an influence on British South-Asian caregiver anxiety. By ensuring caregivers are not overly willing, that is that they do not have unrealistic expectations about what instrumental and nursing tasks they should be doing, the level of distress could be reduced.

Chapter 6

Predicting Caregiver Anxiety and Depression

The material presented in this chapter is currently in review as:

Parveen, S & Morrison, V. Predicting Caregiver Anxiety and Depression. *Psychology and Health.*

Abstract

The current study aimed to examine whether changes in familism values, illness perceptions, caregiver stressors (number of care tasks performed), coping and use of support were related to caregiver anxiety and depression. 123 primary informal caregivers completed a questionnaire at three time points: Baseline, three months from baseline and nine months from baseline. It was found that perceptions of illness consequences, use of substances and total use of social support increased over time, whereas use of positive reframing coping and familism decreased over time. Using regression residual scores it was found that increased perceptions of emotional representations, gender and care recipient diagnosis were predictive of anxiety nine months from baseline. Decreased perceptions of personal control and religious coping, and increasing perceptions of emotional representations were predictive of depression nine months from baseline. The findings add to the understanding of changes in the caregiver experience and have potential implications for the development of interventions and caregiver support services.

Introduction

The term caregiver is used to describe an individual who provides physical and/or emotional support for a family member or friend who is experiencing difficulties due to physical, emotional and/or cognitive impairments. The support they provide is generally beyond what is considered the norm for their relationship and they often do this without financial compensation (Bridges, 1995). There are currently over six million caregivers in the U.K. which accounts for 10% of the adult population and it is predicted that every year another 301, 000 individuals will adopt the role of caregiver and that three in five people will be involved in the care role at some point in their lifespan (Carers UK, 2001, 2009). In terms of the amount of care provided, a recent survey (Carers UK, 2009) found that 1.9 million of caregivers provide 20 hours of care per week and a further 1.25 million provide care for 50 or more hours per week. The majority (58%) of caregivers were female and the peak age for providing care was 50-59 years. It is estimated that the care provided by family members and friends at home saves the National Health Service (NHS) approximately £87 billion per year (Carers UK, 2009). Due to the increasing socio economic value of caregivers there has been increasing interest in caregiver physical and psychological health.

A psychological model that has commonly been applied to the study of caregiver psychological health is the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). This model posits that stress results from an imbalance between an individual and their environment whereby personal appraisals of an event or situation, elicit coping and use of support resources and that these responses will mediate the occurrence of a stress response. More specifically, stress will occur when there is a perceived discrepancy between the (perceived or actual) demands of the situation and the (perceived or actual) resources available to deal with the stressor (Lazarus, 1999). In the care situation, potential stressors may include the severity of the care recipient’s impairments, the presence of behavioural problems and limited function or self care activity. The caregiver’s appraisal of these potential stressors will elicit coping methods such as problem solving and the availability and use of social support may aid the caregiver to manage the stressor more effectively (Haley, Levine, Brown & Bartolucci, 1987).

The Transactional Model of Stress and Coping has been used to identify various individual risk factors associated with poor psychological health in caregivers. For example various studies have examined the influence of ethnicity (Parveen & Morrison, in press); gender (Pinquart & Sorensen, 2006); age (Pariante, Carpiniello, Orru et al, 1997); caregiver personality (Gallant & Connell, 2003) and care recipient diagnosis (Kim & Schulz, 2008). The model has received support from, several cross-sectional studies, for example, Haley et al (1987) found in a study of 54 caregivers of individuals with a dementia diagnosis that appraisals, coping and social support were all related to caregiver depression even when the severity of the caregiver’s stressors were statistically controlled. More recently Hanks, Rapport & Vangel (2007) examined the role of coping, family functioning, perceived social support, and the care recipient’s functional status in relation to caregiver appraisals of burden and mastery. Amongst this sample of 60 family caregivers of individuals with a traumatic brain injury, emotional coping styles, behavioural control issues (in regards to family functioning) and perceived social support were all found to be highly associated with caregiver burden. Social support was also strongly positively associated with caregiver mastery (self appraised ability to deal with care demands). The importance of coping styles in relation to caregiver appraisals were highlighted as the results suggest that caregivers who relied on task oriented coping (as opposed to emotion focused coping) had higher caregiver satisfaction. Although this study was cross-sectional which limits conclusions regarding direction of effects, by measuring dispositional coping style as opposed to situation specific coping strategies this limitation is perhaps reduced as theoretically dispositions precede situational appraisals and responses, however longitudinal evidence would be advantageous.

One longitudinal study which confirms the predictive role of appraisals is Goode, Haley, Roth & Ford’s (1998) study of 122 caregivers of Alzheimer Disease patients. These authors measured changes in caregiver stressors (e.g. care recipient’s need for assistance), appraisals, coping strategy, social support and mental and physical health outcomes over a period of 12 months. Their findings suggest that increased caregiver stressors were not predictive of outcomes over time however benign appraisals, use of approach coping and high levels of social support were associated with more positive caregiver outcomes. Similarly, amongst 89 caregivers of individuals with a multiple sclerosis diagnosis; caregiver gender, low threat appraisals, low reliance on emotional coping, and high levels of social support were all predictive of lower depression over 12 months (Pakenham, 2001).

In addition to the above studies (which focus solely on variables in the Transactional model), Nijboer, Triemstra, Tempelarrr, Sanderman & Van den Boss (1999) in a six month longitudinal study of 148 caregivers of patients with newly diagnosed colorectal carcinoma, found that higher levels of depression were associated with low income, living alone with the patient, a poor relationship with the patient, high patient dependency and high involvement in care tasks. Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle et al (2004) also report similar findings from a sample of 89 caregivers of women with an advanced breast cancer diagnosis in that caregiver depression increased as the care recipient’s functional status decreased. They further highlight that although the patient’s physical and emotional factors are predictive of caregiver distress, caregiver perceived burden is actually the strongest predictor of caregiver anxiety and depression over time.

Therefore the current literature has shown that care recipient functional status, caregiver appraisals (benign vs. threat), caregiver coping (problem solving vs. emotional focused) and use of social support are associated with caregiver distress, thus supporting the Transactional model of stress. However there may be a need to extend this model to include wider influences such as the cultural value familism. Familism has been defined as strong feelings of loyalty, reciprocity and solidarity among family members (Losada, Robinson & Knight, 2006). We have shown previously that familism is related to demographic factors (ethnicity and age) and specific coping methods such as active coping, use of humour and religious coping (Parveen & Morrison, 2009). In a further cross-sectional study of 235 caregivers, familism was related to the use of support and the specific coping methods of religious coping, use of humour and substance use. Willingness to care was also found to explain 6% of variance in caregiver anxiety (Parveen & Morrison, in review).

Thus the current study seeks to extend current understanding by focusing on changes in the caregiver process as the theoretical model used is dynamic. We will also examine whether caregiver values such as familism are related to changes in caregiver outcomes. The current study will make use of a longitudinal design to examine whether changes in familism, illness perceptions, coping and social support are predictive of absolute caregiver anxiety and depression at the end of nine months.

Method

Sample

A total of 123 family caregivers participated in this study of which 41 were male and 82 were female. 96 of the sample described their ethnic background as White-British and the remaining 27 caregivers identified themselves as British South-Asian (Bangladeshi, Indian and Pakistani). The mean age of the sample was 61.16 years (*SD* = 13.72) with an age range of 18-84 years. 88.6% of the sample was married and only 4.9% were single. The majority of participants were spouses (70%) and daughters/daughters in law (17.9%) caring for individuals with a range of conditions: Parkinson’s disease (31%); multiple sclerosis (26.8%); dementia (20.3%); stroke (7.3%), and cancer (4.1%). Caregivers had on average been providing care for 9.91 years. Further demographic details can be found in Table 1.

Table 1. Demographic data.

Demographic variable	Status	*n*	%
Gender	Male	41	33.3
	Female	82	66.7
Ethnicity	White English	75	61
	White Scottish	5	4.1
	White Welsh	16	13
	Asian Bangladeshi	4	3.3
	Asian Indian	10	8
	Asian Pakistani	13	10.6
Marital status	Single	6	4.9
	Married	109	88.6
	Divorced	4	3.3
	Widow	3	2.4
	Missing	1	0.8
Occupation	Employed	17	13.8
	House wife	24	19.5
	Retired	63	51.2
	Unemployed	15	12.2
	Missing	4	3.3
Relationship	Spouse	85	70
	Daughter	17	13.8
	Daughter-in-law	5	4.1
	Parent	9	7.3
	Sibling	1	0.8
	Son	3	2.4
	Grandchild	1	0.8
	Missing	1	0.8
Care recipient diagnosis	Dementia	25	20.3
	Stroke	9	7.3
	Cancer	5	4.1
	Parkinson's disease	38	31
	Multiple sclerosis	33	26.8
	Other	13	10.5

Measures[4]

The first part of the questionnaire consisted of general demographic questions to identify caregiver ethnicity, gender, age, marital status, occupation, care recipient diagnosis, number of hours per week care-giving and number of years in care role.

The number of emotional, instrumental and nursing tasks performed by the caregiver was measured using the Willingness to Care Scale (Abell, 2001). The scale was developed by Abell (2001) for the purpose of assessing the willingness and ability to care of caregivers providing support for an individual with an AIDS diagnosis. The measure contains a list of typical care tasks (10 emotional, 10 instrumental and 10 nursing) and caregivers are requested to rate on a 5 point likert scale how willing and how able they are to perform each task. In the current study caregivers were simply required to identify the number of tasks they performed from each list.

The Heller Familism Scale (1976) was used to measure caregiver familism. The measure contains 15 items measured on a 5 point likert scale (max score = 60). An example of an item from the measure would be “Children owe it to their parents to put family interests above their own personal interests”. The scale demonstrated good internal reliability ($\alpha = 0.92$).

Caregiver illness perceptions were examined using the brief Illness Perception Questionnaire (brief IPQ) by Broadbent, Petrie, Main & Weinman (2006). The measure consists of 9 items which measure on an 11 point likert scale (0 to 10): consequence, timeline, personal control, treatment control, identity, concern, coherence, emotional representation and causal beliefs. Reliability can not be ascertained as each component is assessed by a single item; however its predecessor

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[4] The measures used in the questionnaire can be found in appendix 5 page 408.

the IPQ-R has proven a reliable tool in a wide range of populations (Hagger & Orbell, 2003).

Caregiver coping was measured using the brief COPE (Carver, 1997), developed from the well validated COPE. The measure contains 28 items which form 14 subscales (2 items per scale). The 14 scales measure use of specific coping strategies: self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religious coping and self blame. The maximum score for each scale is 8. As each scale contains only 2 items, inter item correlations were used to test reliability and these ranged from 0.41 (acceptance) to 0.90 (religious coping) and thus demonstrate good reliability.

The Social Support Questionnaire (Saranson, 1983) was used to measure caregiver use of social support. The questionnaire requires the caregivers to list the amount of support persons they have and rate how satisfied they are with each support (on a 6 point likert scale). Two scores are obtained from the measure: total number of supports and mean satisfaction with support. Both scales demonstrated good reliability in the current study with total support achieving an alpha of 0.72 and mean satisfaction $\alpha = 0.84$.

Caregiver anxiety and depression was measured using the Hospital Anxiety and Depression Scale (HADS) by (Zigmond and Snaith, 1983). There are two subscales (anxiety and depression) which contain 7 items each measured on a 4 point likert scale (max score = 21). An example of an anxiety item would be “I get sudden feelings of panic” and a depression item would be “I have lost interest in my appearance.” Scores between 0-7 on either subscale are categorized as normal, 8-10 as borderline and 11+ as caseness. Both subscales demonstrated good reliability with anxiety achieving an alpha of 0.87 and depression $\alpha = 0.83$.

Procedure

Prior to data commencement, ethical approval was obtained from the School of Psychology Research Ethics Committee. Various caregiver support groups (including Carers Wales, Alzheimer's Society, Stroke Association, Parkinson's disease Society and the Multiple Sclerosis Society) across England, Wales and Scotland were contacted. Groups that were interested in participating in the study were sent questionnaire packs (containing information sheets, consent forms, the questionnaire and information regarding caregiver support services) to pass onto eligible caregivers. Other caregivers were recruited through advertisements in relevant newsletters, and via poster displays in public places. Caregivers were asked to complete the questionnaire at home in their own time with the exception of 13 British South-Asian caregivers who required the translation aid of the researcher. All caregivers were required to be 18 years or over and be providing care for an ill family member or friend in a non professional capacity. The caregivers were also required to provide care for a minimum of 7 hours per week. No other exclusion criteria were applied.

Caregivers were required to complete all measures at three time points Baseline (Time 1), 3 months from baseline (Time 2) and 9 months from baseline (Time 3). 154 caregivers were recruited at Time 1 (a response rate of 31%) of which 130 individuals completed questionnaire at both subsequent time points, however these were different individuals and overall 123 caregivers completed all three questionnaires. Common reasons for drop out included: caregiver was too busy; caregiver was experiencing ill health, placement of care recipient in a nursing home or death of care receipt. Analysis was conducted to examine whether caregivers that dropped out from study differed from those who remained. No significant differences were found in age, anxiety or depression. Once caregivers returned their third completed questionnaire, they received debrief information and a list of support services available in their area.

Data analysis

Using SPSS v17, independent sample t tests and one way ANOVA tests were conducted to measure ethnic, gender and diagnosis group differences in anxiety and depression. Repeated measures ANOVAs were used to examine whether variables changed significantly over time. Residual change was calculated for period 1 that is baseline (T1) to three months (T2). A residual score above 0 reflects a higher IV score than would be expected given previous levels; a negative residual score reflects IV scores that are lower than would be predicted. Residual change scores were correlated with absolute anxiety and depression at time 3 separately. Hierarchical regressions were conducted to test if changes in IVs were predictive of final anxiety and depression. Only those correlations that reached significance were used in the hierarchical regressions models, although age was included in the first step of the regression due to the potential confounding effect. Dummy variables were created for categorical IVs such as gender before being entered into the regression model.

Results

Independent samples t tests were conducted to examine if anxiety and depression differed by ethnic, gender or diagnosis group. As can be seen in Table 2, British South-Asian caregivers were found to have significantly higher anxiety than White-British caregivers at all 3 time points. Within measures ANOVAS found that anxiety did not significantly change over time for British South-Asian caregivers (F =

(2, 25) 1.35, *p* = .28) nor the White-British caregivers (*F* (2, 93) = 0.89, *p* = .41). British South-Asian caregivers had significantly higher depression levels than White-British caregivers at Time 2 and 3. Whereas South-Asian depression did not significantly change over time (*F* (2, 24) = 2.20, *p* = .13), White-British caregiver depression increased over time (*F* (2, 93) = 3.47, *p* = .04).

Female caregivers were found to be significantly more anxious than male caregivers at all 3 time points (Table 2). Anxiety was found to remain relatively stable for both male (*F* (2, 38) = 1.61, *p* = .21) and female (*F* (2, 80) = 0.99, *p* = .38) caregivers. Female caregivers had significantly higher levels of depression than male caregivers at time 3. Female depression scores were found to significantly increase over time (*F* (2, 79) = 7.30, *p* = .001) but male depression scores did not significantly change (*F* (2, 38) = 0.78, *p* = .93). British South-Asian caregivers (*M* = 51.22, *SD* = 15.99) were significantly younger than the White British caregivers (*M* = 63.98, *SD* = 11.63; *t* = 3.86 (1, 120), *p* = .001) and female caregivers (*M* = 58.27, *SD* = 13.79) were significantly younger than male caregivers (*M* = 67.08, *SD* = 11.66; *t* = 3.48 (1, 120), *p* = .001), thus age will also be considered as potential confounding factor and will be controlled for during hierarchical regression analysis.

One way ANOVAs were conducted to examine differences in anxiety and depression for diagnosis groups (see Table 2). Due to multiple comparisons, the alpha level was adjusted to *p* < .01. At Time 3 the dementia group had significantly higher depression scores than the Parkinsons disease group (*p* < .01).

Pearson’s correlation analysis was conducted to examine the relationship between continuous independent variables (the number of hours per week caregiving and number of years in care role) with anxiety and depression. No statistically significant relationship was found.

Table 2. Changes in anxiety and depression for ethnic, gender and diagnosis groups.

Demographic group		Anxiety			Depression		
		Time 1 *M* *(SD)*	Time 2 *M* *(SD)*	Time 3 *M* *(SD)*	Time 1 *M* *(SD)*	Time 2 *M* *(SD)*	Time 3 *M* *(SD)*
Ethnicity	South Asian (27)	10.93 (4.20)	11.11 (4.25)	11.85 (4.19)	8.31 (4.89)	9.41 (4.53)	9.59 (5.06)
	White British (96)	8.95 (4.03)	9.33 (4.13)	8.92 (4.40)	6.69 (3.66)	7.29 (4.34)	7.58 (4.21)
	T test	2.18*	1.97*	3.09**	1.84	2.22*	2.10*
Gender	Male (41)	8.08 (3.46)	8.34 (3.63)	7.51 (4.35)	6.40 (3.28)	6.85 (4.76)	6.85 (4.77)
	Female (82)	10.02 (4.30)	10.41 (4.31)	10.59 (4.26)	7.36 (4.28)	8.21 (4.54)	8.61 (4.21)
	T test	-2.50**	-2.64**	-3.75***	-1.25	-1.60	-2.09*
Diagnosis	Cancer (5)	11.00 (2.92)	8.80 (3.90)	10.80 (3.27)	9.00 (4.24)	9.20 (2.49)	9.20 (3.11)
	Stroke (9)	11.78 (4.97)	10.67 (3.00)	12.67 (3.20)	8.79 (4.18)	8.33 (5.02)	9.22 (4.71)
	Dementia (25)	10.58 (3.94)	11.76 (4.49)	11.44 (4.71)	8.71 (4.48)	6.95 (3.65)	10.68 (5.12)
	Parkinson’s Disease (38)	8.76 (3.92)	8.95 (4.23)	8.66 (4.71)	6.24 (3.56)	6.94 (3.65)	6.68 (3.71)
	Multiple Sclerosis (33)	8.97 (4.54)	9.45 (4.27)	8.42 (4.40)	6.97 (3.96)	7.27 (4.54)	7.21 (4.34)
	Other (13)	7.77 (2.80)	8.46 (3.26)	8.85 (3.13)	4.69 (2.59)	6.08 (3.57)	7.62 (3.91)
	ANOVA *(F)*	1.86	1.90	2.77*	2.76*	2.21	3.15**

Note

* $p < .05$ ** $p < .01$

Change in caregiver factors and distress

Repeated measures ANOVA tests were conducted to examine whether the IVs as well as anxiety and depression changed over time. As can be seen in Table 3, familism which was initially moderate, was found to significantly decrease over time in particular between T1-T2 (p = .001). Caregiver illness perceptions remained stable over time with the exception of the perceived consequence scale which significantly increased over time (p = .03). The number of emotional tasks performed by caregiver was initially high and further significantly increased over time (p = .03) as did the number of nursing tasks (p = .03). Caregiver coping also did not significantly change over time with the exception of decreased use of positive reframing (p = .04) which was moderate to begin with and the use of substances (p = .004) rising from initially low levels. The total amount of support used by caregivers, was initially low but increased significantly over time (p = .01) although the mean satisfaction with the support remained stable and high over time. Caregiver anxiety did not significantly change over time but depression increased significantly (p = .01). Although there was no significant change in anxiety, the mean scores at all three time points suggest that the caregivers are in the borderline “caseness” category (NFER-Nelson, 1995). By time 3 (9 months from baseline), caregiver depression scores were also in the borderline category.

Table 3. Scale descriptives and ANOVA analysis to test change over time.

Scale	Variable Subscale	Time 1 *M*	Time 1 *SD*	Time 2 *M*	Time 2 *SD*	Time 3 *M*	Time 3 *SD*	*t/F*	*df*	*p*
Familism		29.13	14.87	27.87	15.18	26.21	15.11	8.19	120	0.001***
IPQ Brief	Consequence	8.42	1.70	8.78	1.53	8.72	1.53	3.67	120	0.03*
	Time line	9.26	1.84	9.55	1.36	9.34	1.77	1.40	119	0.25
	Personal control	2.43	2.86	2.38	2.70	2.41	2.66	0.01	119	0.99
	Treatment control	4.47	3.33	4.74	3.26	4.83	2.99	0.78	119	0.46
	Identity	8.31	2.00	8.57	1.92	8.37	2.11	0.84	119	0.43
	Concern	8.96	1.53	9.05	1.83	8.97	1.93	0.21	121	0.81
	Coherence	8.25	2.05	8.41	1.72	8.50	1.62	0.99	120	0.37
	Emotional representation	7.35	2.56	7.31	2.81	7.54	2.40	0.92	120	0.40
Number of tasks	Emotional	6.72	3.13	6.85	3.16	7.29	2.75	3.64	107	0.03*
	Instrumental	7.86	1.67	7.88	2.09	8.10	1.87	1.16	103	0.32
	Nursing	4.57	3.40	5.12	3.57	4.72	3.23	3.59	102	0.03*
brief COPE	Self distraction	4.33	1.91	4.19	1.92	4.30	1.86	0.44	121	0.64
	Active coping	5.33	1.93	5.27	1.82	5.21	1.83	0.23	121	0.8
	Denial	2.73	1.37	2.93	1.68	2.94	1.57	1.44	121	0.27
	Substance use	2.48	1.18	2.57	1.30	2.67	2.14	5.68	120	0.004**
	Emotional support	4.46	1.83	4.47	2.47	4.46	1.73	0.004	121	0.10
	Instrumental support	5.04	1.77	4.71	1.93	4.78	1.91	2.38	121	0.10
	Behavioural disengagement	2.79	1.47	2.87	2.27	2.52	1.18	2.50	121	0.09
	Venting	3.86	1.78	3.80	1.83	3.61	1.63	1.86	121	0.16
	Positive reframing	4.56	1.94	4.20	1.92	4.50	1.69	3.34	121	0.04*
	Planning	5.10	1.84	4.94	1.93	4.98	1.86	0.42	121	0.66

Scale	Variable Subscale	Time 1 *M*	 *SD*	Time 2 *M*	 *SD*	Time 3 *M*	 *SD*	*t/F*	*df*	*p*
brief COPE	Humour	3.09	1.57	3.14	1.66	3.26	1.68	0.74	121	0.48
	Acceptance	6.34	1.85	6.49	1.70	6.51	1.53	0.46	121	0.64
	Religious coping	4.34	2.57	4.42	1.83	4.30	2.52	0.69	121	0.50
	Self blame	3.09	1.38	3.17	1.42	3.26	1.52	0.92	121	0.40
Social support	Total support	3.03	1.39	3.31	1.46	3.41	1.62	5.55	118	0.01**
	Mean satisfaction	4.93	1.26	4.86	1.34	4.74	1.36	2.03	116	0.14
HADS	Anxiety	9.39	4.13	9.72	4.20	9.56	4.51	0.44	120	0.64
	Depression	7.04	3.99	7.76	4.45	8.02	4.46	5.35	119	0.01**

Note

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

Predicting anxiety

IVs were converted into residual scores (T1-T2) and were then correlated with absolute anxiety and depression at time 3. Only relationships reaching statistical significance were used in regression analysis.

Table 4. IV residual change correlations with anxiety and depression at time 3.

IV (Period 1)	Anxiety	Depression
Familism	0.0001	-0.001
IPQ Consequence	0.21*	0.17
IPQ Timeline	-0.001	-0.05
IPQ Personal Control	-0.16	-0.26**
IPQ Treatment control	-0.03	-0.01
IPQ Identity	0.02	0.04
IPQ Concern	0.25**	0.14
IPQ Coherence	0.17	0.02
IPQ Emotional representation	0.27**	0.21*
Number of emotional tasks	0.16	0.04
Number of instrumental tasks	0.25**	0.23*
Number of nursing tasks	0.10	0.13
Self distraction	0.11	0.01
Active coping	0.14	0.04
Denial	0.17	0.20*
Substance use	0.13	0.14
Emotional support	-0.02	-0.02
Instrumental support	0.10	0.11
Behavioral disengagement	0.10	0.16
Venting	0.17	0.12
Positive reframing	0.05	-0.13
Planning	0.19*	0.14
Humour	0.04	-0.06
Acceptance	0.05	-0.04
Religious coping	-0.05	-0.19*
Self blame	0.23**	0.28**
Total support	0.09	0.03
Mean satisfaction	-0.06	-0.12

Note

* $p < .05$ ** $p < .01$

As can be seen from Table 4, early changes (period 1, that is between T1-T2) in terms of increased perceptions of illness consequences, increased concern, increased emotional representations, increased number of instrumental tasks, increased use of planning and self blame were all significantly associated with high anxiety at time 3 (9 months from baseline). As can be seen from Table 5 hierarchical regression analysis found that demographics (ethnicity, gender, age and diagnosis) accounted for a significant 19% of the variance in anxiety at time 3. Changes in anxiety during period 1 accounted for a further significant 14% of the variance. Illness perceptions of consequences, concern and emotional representations added a significant 6% to the model and an early increase in instrumental tasks only accounted for a non significant 1% of the variance in anxiety at time 3. Coping (planning and self blame) added a final non significant 1% and the final model accounted for a significant 41% of the variance in time 3 anxiety, with gender (female), diagnosis (dementia) and increased emotional representations being the strongest predictors in the model.

Table 5. Period 1 IVs predicting absolute anxiety at Time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-2.59	1.08	-0.24*	-2.37	0.99	-0.22*	-1.84	0.98	-0.17	-1.76	0.98	-0.16	-1.57	1.00	-0.15
Gender	2.31	0.92	0.24*	1.72	0.85	0.18*	2.26	0.85	0.24*	2.27	0.85	0.24*	2.37	0.86	0.25**
Age	0.03	0.03	0.09	0.02	0.03	0.06	0.02	0.03	0.07	0.02	0.03	0.06	0.02	0.03	0.06
Diagnosis	-0.86	0.33	-0.24*	-0.93	0.31	-0.26**	-0.94	0.30	-0.26**	-0.87	0.30	-0.24*	-0.80	0.32	-0.22*
Anxiety				1.73	0.38	0.38***	1.31	0.40	0.29***	1.19	0.41	0.26**	1.13	0.41	0.25**
IPQ Consequence							0.60	0.40	0.13	0.63	0.38	0.14	0.53	0.39	0.12
IPQ Concern							0.42	0.43	0.09	0.34	0.43	0.07	0.30	0.44	0.07
IPQ Emotional representations							0.68	0.43	0.15	0.75	0.43	0.17	0.73	0.43	0.18*
Instrumental tasks										0.43	0.38	0.10	0.42	0.39	0.09
Planning													0.30	0.40	0.07
Self blame													0.31	0.39	0.07
r^2 Change		0.19			0.14			0.06			0.01			0.01	
F Change		6.05***			20.88***			3.13*			1.30			0.69	

Note

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

Predicting depression

As can be seen in table 4, early increases in emotional representations, number of instrumental tasks, denial and self blame were positively associated with depression at time 3; and a decrease in perceptions of personal control and religious coping were associated with higher depression at time 3. In the regression model (see Table 6), demographic variables accounted for a significant 10% of the variance in depression at time 3. Early changes in depression accounted for a further significant 9% of the variance. Changes in illness perceptions (personal control and emotional representations) added a significant 8% to the model whereas changes in the number of instrumental tasks accounted for a non significant 2% of the variance in the model. Coping (denial, religious coping and self blame) added a final significant 8% to the model, with the final model accounting for a significant 36% of the variance in depression at time 3. Decreased perceptions of personal control and use of religious coping and increased perception of emotional representations were the strongest predictors of the variance in depression at time 3. [5]

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[5] Data pertaining to late changes in IVs (Period 2) was also analysed but due to statistical limitations it is not included in the paper but can be found in the appendix. Please see page 434.

Table 6. Period 1 IVs predicting absolute depression at Time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-1.99	1.13	-0.19*	-1.62	1.09	-0.15	-1.51	1.06	-0.14	-1.44	1.06	-0.13	-0.98	1.03	-0.09
Gender	1.16	0.96	0.12	0.84	0.93	0.09	0.76	0.91	0.08	0.69	0.91	0.07	0.96	0.88	0.10
Age	0.03	0.04	0.08	0.02	0.03	0.08	0.03	0.03	0.10	0.03	0.03	0.09	0.02	0.03	0.07
Diagnosis	-0.74	0.35	-0.21*	-0.75	0.33	-0.21*	-0.74	0.32	-0.21*	-0.66	0.32	-0.18*	-0.64	0.31	-0.18*
Depression				1.38	0.42	0.30***	1.10	0.41	0.24**	0.95	0.42	0.21*	0.77	0.41	0.17
IPQ Personal control							-1.15	0.41	-0.25**	-1.19	0.41	-0.27**	-1.08	0.39	-0.24**
IPQ Emotional representations							0.93	0.41	0.21*	0.96	0.41	0.21*	1.01	0.39	0.22**
Instrumental tasks										0.62	0.40	0.14	0.51	0.38	0.12
Denial													0.67	0.39	0.15
Religious coping													-0.89	0.38	-0.20*
Self blame													0.59	0.39	0.13
r^2 Change		0.10			0.09			0.08			0.02			0.08	
F Change		2.68*			10.94***			5.54**			2.42			3.84**	

Note

* *p* < .05 ** *p* < .01 ****p* < .001

Discussion

The results of the study generally support the hypotheses made in relation to the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) in that changes in illness perceptions, coping and satisfaction with support were found to be associated with anxiety and depression. Familism was found to decrease over time and was not related to caregiver anxiety or depression. As familism is considered a cultural value (Killian & Ganong, 2002), it is perhaps not surprising that familism levels changed over time as culture is amenable to change (Hutchinson & Smith, 1996). There is however a lack of longitudinal evidence to corroborate whether or not familism is a stable factor in the caregiver role.

Various cross-sectional studies have focused on familism within Asian caregivers and have found conflicting evidence regarding familism's relationship with caregiver distress. For example, Lai (2007) in a study of 339 Chinese Canadian caregivers found familism to be a negative predictor of caregiver burden, similar to that reported by Gupta & Pillai (2009) from their study of 118 Indian American caregivers. However Zhan (2006) and Gupta (2002), also using Chinese Canadian and Indian American caregivers, found that familism was positively correlated with caregiver burden and depression. Perhaps familism is not related to caregiver distress but may have some association with other caregiver outcomes such as satisfaction with role and gains.

Caregivers' perceptions of their care recipient's illness remained stable over time, with the exception of perceptions of illness consequence which increased significantly. These findings are surprising as the self regulation theory (Leventhal, Nerenz & Steale, 1984) proposes that illness perceptions will evolve over time based on two processes. Firstly the time since diagnosis will influence the individual's change in perceptions from an acute illness model to a chronic timeline. Secondly illness perceptions are affected by the coping strategies used. This model has recently been tested by Fischer, Scharloo, Abbink, van't Hul, van Ranst, Rudolphus et al (2010) in a longitudinal study of 87 patients diagnosed with chronic obstructive pulmonary disease (COPD). A longer time since diagnosis was found to be associated with a chronic illness model, furthermore perceptions of a longer timeline and consequences increased over time and controllability decreased. In the current study only perceptions of consequences significantly increased, although levels of personal and treatment control were found to be stable, they were very low in our sample of caregivers. The current sample also contained a range of diagnostic groups (including dementia and multiple sclerosis) and the caregivers had been providing care for an average of nine years. Perhaps caregiver perceptions of illness had already shifted to a chronic illness model and representations were now stable. It would be of interest to examine illness perceptions in caregivers new to the role and in a range of diagnostic groups.

Early changes in emotional representations were significant predictors of final anxiety levels. That is caregivers who increasingly perceived that illness affected their care recipient emotionally experienced high levels of anxiety at time 3. A decrease in personal control and an increase in emotional representations were significant predictors of depression. The current findings are supportive of previous longitudinal research, for example Goode et al (1998) & Pakenham (2001) found that although illness perceptions remained stable over time, they were significantly related to changes in depression. Low threat perceptions in particular were strong predictors of a decrease in depression. It is important to note a major difference between the study conducted by Goode et al (1998) and the current study. Goode et al (1998) examined changes in caregiver factors and the influence on *change in depression* during the same period of time whereas we use absolute depression scores at time 3 and early changes in caregiver factors (that is changes in processes between time 1 to time 2) as predictor variables. By using three time points the current study is able to assess the predictive longitudinal value of changes in caregiver processes on distress whereas Goode et al (1998) focus on concurrent changes in caregivers factors and influence on change in distress (despite using a longitudinal design).

In our study, the number of emotional and nursing tasks increased over time, however the number of instrumental tasks carried out and the general number of hours of caregiving per week did not change significantly. Only an increase in instrumental tasks was found to be associated with anxiety and depression, however it was not found to be a strong predictor of distress in the final regression models. This is in contrast with previous literature, e.g. Nijboer et al (1999) found that high involvement in care tasks was predictive of higher levels of depression. However the current study used change variables as opposed to absolute values, therefore although high number of tasks may be associated with high depression, but changes in the number of tasks are not predictive of longitudinal depression.

Contrary to theory and to our expectations caregiver coping did not change significantly over time, with the exception of decreased use of positive reframing over time and increased substance use. Although increases in planning and self blame were related to anxiety they were not found to be significant predictors. However a decrease in religious coping and an increase in self blame were significant predictors of high depression at time 3. The results are consistent with previous findings e.g. Goode et al (1998) who also found that increasing approach coping were associated with decreased depression over time. The current study also found that changes in emotional coping methods (such as denial and self blame) were consistently associated with increased anxiety and depression which is supportive of Hanks et al's (2007) findings.

It is not surprising that increased self blame emerged as a positive predictor of depression. In a qualitative study by Parveen, Morrison & Robinson (in press) it was found that all caregivers used self blame and venting as a coping methods but use of this method often led to feelings of guilt. There is a great amount of literature which has found that "self conscious emotions" such as guilt and shame are evoked during self evaluation and play a significant role in psychological symptoms including anxiety and depression (Tangney, Stuewig & Mashek, 2007). Caregivers in the current study have been found to make use of denial and self blame which have been positive predictors of depression, thus demonstrating clear implications for intervention development.

Surprisingly change in total support use and mean satisfaction with support during period 1 was not significantly associated with anxiety or depression. In previous longitudinal research (Goode et al, 1998 & Pakenham, 2001) changes in social support (in particular mean satisfaction) has also been associated with decreased depression over time as well as in cross-sectional research (Hanks et al 2007 & Parveen & Morrison, in review).

It is not surprising that different variables were associated with anxiety and depression for example changes in denial and religious coping were significantly associated with anxiety but not depression. Although often associated it is generally accepted that anxiety and depression are separate constructs (Dobson, 1985) and therefore should be studied independently. As Lazarus and Smith (1993) have theorised and several studies have explored these emotions as a result of different appraisals and core relational themes for example anxiety may arise from appraisals of threat to future happiness whereas depression is thought to occur when the individual perceives an important loss. Although both states have emotional, cognitive, behavioural and physiological components, the general nature of depression is of withdrawal and diminished activity. The results of the current study support this theory and suggest that interventions aiming to reduce distress in caregivers should focus on anxiety and depression as separate outcomes.

The findings of the current study are generally supportive of the dynamic hypotheses of the Transactional Model of Stress. Specific appraisals (personal control and emotional representation), changes in number and types of care tasks and changes in coping were generally associated with longitudinal caregiver anxiety and depression. Change in familism was not related to anxiety and depression (although absolute familism may be associated levels of distress). However it is important to note the following limitations within the study. The study contains a moderate final sample size (*n* = 123) and experienced a not unexpected (low) response rate (31%), however 80% of those caregivers who participated at baseline remained in the study to complete all three time points. The sample size and attrition rate does appear to be similar to much of the published longitudinal caregiver outcome research (e.g. Goode et al 1998; Pakenham, 2001 & Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti et al, 2005); and therefore we believe the current findings have a contribution to make, particularly because they add to a limited body of literature that has assessed change in caregiver factors. Although ethnic group differences could not be fully examined due to the small South-Asian sample nor diagnoses group differences, the sample is however representative of the caregiver population as caregivers from various geographic regions, ethnic groups, ages and illness groups were included. It is important to note that an artificial baseline was used as opposed to recruiting caregivers who had newly adopted the role. This limits the findings somewhat as the early changes discussed may not actually be early in the care role. Also the findings need to be replicated in a larger sample as we were unable to examine processes of late changes in caregiver factors due to sample limitations.

The current study has several important strengths and implications. Primarily the longitudinal design permitted the investigation of change in anxiety and depression over three time points and acknowledges the dynamic nature of potential predictors. The study also identifies potential vulnerable caregivers that may experience high anxiety and depression. The final model suggests that gender and diagnosis were strong predictors of anxiety, with female caregivers and dementia caregivers experiencing high levels of anxiety. Group analysis established that British South-Asian caregivers also experienced increasing anxiety and depression when compared to White-British caregivers; suggesting that young Asian females may be more vulnerable to distress over time and require additional support. This suggests that this population should be a key target in intervention and service provision.

Finally the examination of change in the caregiver role (values, perceptions, resources) and their influence on caregiver distress provides the basis for intervention development. Changes in emotional representations were strong positive predictors of anxiety and depression and changes in personal control and religious coping were additional negative predictors of depression. The findings therefore add to the understanding of the changes in the caregiver experience and have important implications for the development of psycho-educational interventions that focus on changing illness perceptions and implementing effective coping strategies training. Sorensen, Pinquart, Habil & Duberstein (2002) found in a meta-analysis of caregiver intervention studies that psycho-educational interventions were more consistently associated with improved outcomes cross-sectionally and longitudinally. There are also implications for the early provision caregivers support services of a more practical or instrumental kind with the findings implying that early increases instrumental tasks were predictive of high anxiety and depression.

Chapter 7a

Predicting Caregiver Gains

The material presented in this chapter is currently in review as:

Parveen, S & Morrison, V. Predicting Caregiver Gains. *British Journal of Health Psychology*.

Abstract

The aim of this study was to examine if changes in motivations to care, familism, appraisals, coping and social support were related to caregiver gains. 123 caregivers completed a questionnaire at three time points: baseline, three months and nine months from baseline. Caregiver gains were found to remain stable over time. Group differences in ethnicity, gender and diagnosis were also examined with ethnicity emerging as a significant predictor of caregiver gains. Independent variables were converted into residual change scores and processes of change were examined for two periods: early changes (time 1-time 2) and late changes (time 2-time 3) and their influence on absolute caregiver gains at time 3. Hierarchical regression analysis found that early changes in familism, illness coherence and coping (particularly self distraction and denial) and number of hours caregiving per week were predictive of gains at time 3. Later change in use of emotional support was a strong predictor of caregiver gains. The study has implications for the development of time specific interventions to increase caregiver gains and also for service development.

Introduction

The rapidly aging population and increasing demand for patient support has led to the UK developing a community based care policy (Brereton, 2002). 80% of the care required to support patients at home is now provided by family caregivers. The term caregiver is used to describe an individual who provides emotional and physical support to an individual who is experiencing difficulties due to physical, cognitive or emotional impairments, often without financial compensation (Bridges, 1995). It is estimated there are currently six million caregivers in the UK (with 301, 000 individuals adopting the role every year) saving the National Health Service approximately £87 billion per year (Carers UK, 2009).

Due to the great socioeconomic value of caregivers, there has been increasing interest from health care professionals and governing bodies to maintain the physical and psychological health of caregivers. A common conceptual model that has been applied to the study of the caregiver experience is the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). The model posits that stress will occur when there is a perceived discrepancy between the demands of the care situation and the resources the caregiver has or perceives available to deal with the situation (e.g. social support). Stress is thus defined as a psychological transaction between the environment/event and the cognitive and emotional characteristics of the caregiver. The caregiver’s appraisals of the situation, coping methods (problem focused or emotion focused) and use of support will influence the caregiver’s ability to manage the stressor (Haley, Levine, Brown & Bartolucci, 1987) and thus any outcomes experienced for example physical and psychological wellbeing.

The majority of studies have focused on the negative aspects of caregiving with poorer physical health (Kiecolt-Glaser, Dura, Speiche, Trask & Glase, 1991;

Vitaliano, Zhang & Scanlan, 2003) and psychological health (burden, anxiety and depression) being well documented (Haley et al, 1987; Goode, Hayley, Roth & Ford, 1998; Pakenham, 2001 & Grunfeld, Coyle, Whelon et al, 2004). The role of positive aspects of caregiving has received limited attention in comparison yet it has been shown that the role of caregiver can result in a number of positive gains such as personal satisfaction and growth as well an improved relationship with the care recipient.

Parveen, Morrison & Robinson (in press) found in a qualitative study of 30 family caregivers that caregivers not only discussed the burdens associated with the caregiver role but were also keen to discuss what they had gained from the role. British South-Asian caregivers perceived the main positive aspect of the care role to be gaining blessings from God as well as the care recipient for fulfilling their duties to care. White-British caregivers believed that their positive experiences came from learning new skills within the care role. Cohen, Colantonio & Vernich (2002) also examined positive experiences in the care role amongst a sample of 289 caregivers of the elderly. 73% of their sample could identify at least one positive aspect of the role and 6.9% identified more than one aspect, and positive aspects were found to be related to significantly decreased depression.

Perhaps before research had really began to address positive aspects of caregiving, Kramer (1997) had defined caregiver gains as the extent to which the care role is appraised to enhance the caregiver’s life. Caregiver gains were proposed to include a direct positive affective or practical return as a result of the care role which may be satisfaction or rewards. Research that has aimed to examine the positive aspects of caregiving has mainly focused on the absence of negative effects such as the absence of depressive symptoms (Beach, Schulz, Yee & Jackson, 2000). However

Rapp & Chao (2000) state that the benefits or gains resulting from the care role are conceptually distinct from the negative affect of providing care and therefore caregiver gains should be examined separately.

Research examining caregiver gains has also tended to use the Transactional Model of Stress as a conceptual model, as is the case in caregiver stress studies. For example Kramer’s (1997) study of 74 male spouse caregivers found that use of problem focused coping and satisfaction with support was positively associated with gains but the use of emotion focused coping was associated with increased strain. Rapp & Chao (2000) examined the role of appraisals in perceived caregiver gains in a sample of 63 caregivers of individuals with a dementia diagnosis. Care recipient emotional and behavioural problems were not significantly negatively related to caregiver gains. Positive appraisals of role were found to significantly relate to stress but neither negative nor positive appraisals were associated with positive affect. More recently Kim, Schulz & Carver (2007) examined benefit finding in a large sample of 896 caregivers of cancer patients who had been providing care for an average of 19 months. High levels of religious coping, greater satisfaction with social support and lower education level were significantly related to high levels of benefit finding. Interestingly benefit finding was not significantly related to depression.

Previous research on caregiver gains has mainly been based on cross-sectional data, however one exception is a study by Bacon, Milne, Sheikh & Freeston (2009) which examined care gains over a period of six weeks, using four case studies of caregivers providing care for an individual who had experienced a stroke. An increase in caregiver gains was seen over time and challenge appraisals were significantly positively related to caregiver gains. In contrast caregivers using problem focused coping experienced more gains than those using emotion focused coping.

Studies of caregiver gains have not to date considered the influence of motivations to care and familism on gains, both of which have been examined in studies of negative affect in caregivers. For example Lyonette & Yardley (2003) found in a sample of 204 female caregivers that extrinsic motivations to care (guilt and perceived expectation) were significant predictors of stress. However intrinsic motivations to care (caring nature and living up to one’s principles) was a significant predictor of caregiver satisfaction with role. Familism (defined as strong feelings of loyalty, reciprocity and solidarity among family members) is considered as the root of caregiving (Ramos, 2004). Research focusing on familism and its relationship with negative affect (burden and depression) has produced mixed results. Lai (2007) and Gupta & Pillai (2009) found that familism was a negative predictor of burden in a sample of Chinese Canadian and Indian American caregivers. In contrast, Zhan (2006) and Gupta (2007) have found familism to be a positive predictor of burden and depression in Chinese Canadian and Indian American caregivers.

The present study will build on existing research by examining how different components of the Transactional Model of Stress (care stressors, illness perceptions, coping and social support) are related to caregiver perceived gains using a longitudinal design. In addition the influence of motivations to care and familism will be examined. As the conceptual model used is dynamic in nature, the current study will focus on changes in the independent variables (e.g. coping) and the association with caregiver absolute gains. The following research questions will be addressed:

1. Are caregiver perceived gains stable over time?
2. Do changes in early caregiver factors predict final caregiver gains, or are late changes in caregiver factors stronger predictors?

Method

Sample

A total sample of 154 caregivers was recruited at Time 1 of which 123 completed questionnaires at all three time points. Common reasons for drop out included: illness (either caregiver or care recipient), placement of care recipient in a nursing home or death of care recipient. Analysis was conducted to examine if those caregivers who dropped out of the study differed from those who remained in the study by age, hours of care or outcomes. No significant differences were found. 82 of the caregivers in the final sample were female and 41 were male. 96 of the caregivers identified themselves as White-British and 27 were of British South-Asian (Bangladeshi, Indian and Pakistani) ethnicity. The caregiver age ranged from 18 to 84 years with a mean age of 61.16 years (*SD* = 13.72). With regards to care recipient diagnosis group the largest groups was Parkinson’s disease (*n* = 38), followed by multiple sclerosis (*n* = 33), dementia (*n* = 25), other (*n* = 13), stroke (*n* = 9) and cancer (*n* = 5). The caregivers had been providing care for an average of 9.91 years (*SD* = 13.70). Full demographic details have been described in an additional paper[6].

Measures[7]

The first section of the questionnaire addressed demographic details such as caregiver ethnicity, gender, age, marital status, employment, relationship to care recipient, care recipient diagnosis, hours per week of caregiving and the number of years in the care role.

Caregiver stressors were measured using part of the Willingness to Care Scale (Abell, 1999). The measure contains a list of 10 typical emotional, 10 instrumental

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[6] Full demographic details can be found in Chapter 6

[7] The measures used in the questionnaire can be found in Appendix 5, page 408

and 10 nursing care related tasks. Caregivers were required to state how many of the tasks from each list they performed per week.

Motivations to care were measured at time 2 and three using the Motivations in Elder Caring (MECS) by Lyonette & Yardley (2003). The measure contains 13 items of which 7 items measure extrinsic motivations (EMECS) and 6 items measure intrinsic motivations (IMECS). The items were modified whereby the term elderly person was replaced with care recipient. The items are measured on a 5 point likert scale and demonstrated good reliability with the EMECS achieving an alpha of 0.81 and IMECS $\alpha = 0.74$.

Caregiver familism was measured using the Heller Familism Scale (1976). The measure consists of 15 items (e.g. “married children should live close to their parents so that they can help each other”) measured on a 5 point likert scale (max score = 60). The measure achieved an alpha of 0.92 and therefore demonstrates good internal reliability.

Illness perceptions were assessed using the brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006). The measure contains the following subscales: consequence, timeline, personal control, treatment control, identity, concern, coherence and emotional representation. The subscales are measured on an 11 point likert scale (max score = 10 per scale).

The brief COPE by Carver (1997) was used to assess caregiver coping. The measure contains 28 items which compose the following subscales: self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religious coping and self blame. As each subscale only contains 2 items, inter item correlations were used to assess the reliability. The inter item correlations ranged from 0.41 (acceptance) to 0.90 (religious coping).

Caregiver use of social support was assessed using the Social Support Questionnaire (Saranson, 1983). Caregivers are required to list the amount of support persons they have and how satisfied they are with each person listed using a 6 point likert scale (1 to 6). Two scales are derived from this measure: total support ($\alpha = 0.72$) and mean satisfaction with support ($\alpha = 0.84$).

The caregiver gains were measured using the GAINS developed by Pearlin (1988). The GAINS contains 10 items which are measured on a 4 point likert scale (max score = 30). An example of an item would be “As a result of providing care, to what extent did you learn to do new things?” This is a well validated measure and in the current study also demonstrated good reliability ($\alpha = 0.89$). (We also assessed caregiver mood that is anxiety and depression as well as caregiver quality of life and papers describing the predictors of these are currently in review).

Procedure

As the procedure of the study has been described in-depth elsewhere[8], only a brief summary will be provided. Ethical approval for the study was obtained from the departmental ethics committee. Caregivers were recruited from support groups across the UK as well as adverts through newsletter and posters. Interested caregivers were sent a questionnaire pack containing information about the study, consent forms, a questionnaire and information regarding care services. The caregivers were asked to complete the questionnaire at home in their own time, however 13 of the British South-Asian caregivers required the translation aid of the researcher. Only caregivers over the age of 18 years who provided over 7 hours of care per week were included in

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[8] See Chapter 6

the study. Caregivers completed all measures at three time points: baseline (T1), three months from baseline (T2) and nine months from baseline (T3) with the exception of the motivations to care measure which was not implemented until time 2. All caregivers received full debrief information and a list of support services in their area.

Data analysis

Independent samples T tests were conducted to examine gender and ethnic differences and one way ANOVA was used to examine care recipient diagnosis group differences in caregiver gains. Bivariate analysis examined the relationship between continuous demographic variables (caregiver age, number of hours per week and years in caregiver role) and caregiver gains. Repeated measures ANOVAs were conducted to examine if predictor variables and caregiver gains changed significantly over time. The independent variables were converted into residual change scores for two periods of time, early changes (T1-T2) and late changes (T2-T3). Pearson’s correlation analysis was conducted to test the relationship between the change IVs and absolute (not change) caregiver gains at time 3. Only those variables that were significantly associated with gains at time 3 were entered into the regression model due to sample size limitations. Dummy variables were created for categorical IVs such as gender before being entered into the regression model. Two separate hierarchical regressions were conducted for early change and late change predictors.

Results

Independent samples T tests were conducted to examine ethnic differences in caregiver gains. At all 3 time points South-Asian caregivers reported significantly more gains than White-British caregivers (T1 SA *M* = 24.00 *SD* = 5.59, WB *M* = 17.82 *SD* = 7.37, *t* (1, 118) = 4.64, *p* = .001; T2 SA *M* = 23.59, *SD* = 6.35, WB *M* = 17.88 *SD* = 7.16, *t* (1, 121) = 3.75, *p* = .001; T3 SA *M* = 24.58 *SD* = 6.35, WB *M* =

17.84 *SD* = 6.53, *t* = (1, 115) 6.47, *p* = .001). However, repeated measures ANOVA revealed that there was no significant change in gains over time for either group that is each group was internally consistent. T tests and one way ANOVAs did not find any significant differences for gender or diagnosis groups. Neither caregiver age nor number of years in care role was significantly related to caregiver gains at any time point. However the number of hours of caregiving per week were significantly related to caregiver gains at time 3 (*r* = 0.27, *p* < .01).

Repeated measures ANOVAs were conducted to examine if there was a significant change over time for all variables. (Full descriptive results of changes over time are presented in a separate paper, a brief summary is provided below). Motivations to care remained stable over time but familism significantly decreased (*t* (1, 120) = 8.19, *p* = .001). The number of emotional (*F* (2, 107) = 3.64, *p* = .03) and nursing tasks performed by caregivers (*F* (2, 107) = 3.59, *p* = .03) increased significantly over time, but the number of instrumental tasks did not significantly change. The number of hours per week of caregiving did not significantly change over time. Illness perceptions remained stable over time with the exception of the consequence subscale which increased significantly over time (*F* (2, 120) = 3.67, *p* = .03). With regards to coping, substance use increased over time (*F* (2, 120) = 5.68, *p* = .004) and positive reframing decreased significantly (*F* (2, 120) = 3.34, *p* = .04). Total support available to caregivers increased over time (*F* 2, 118) = 5.55, *p* = .01) but satisfaction with support did not change significantly. Caregiver gains did not change significantly between T1 (*M* = 19.16, *SD* = 7.46) and T2 (*M* = 19.14, *SD* = 7.36) or T3 (*M* = 19.33, *SD* = 6.67; *F* (2, 112) = 0.13, *p* = .88).

Early changes in caregiver factors as predictors of Time 3 gains:

Pearson’s correlation analysis was conducted to examine the relationship between the early changes in caregiver factors and time 3 absolute gains. Only those relationships reaching statistical significance were selected for the regression analysis. As can be seen from table 1, an increase in familism during period 1 was related to high perceived gains at time 3 as was an increase in illness coherence. An increase in use of self distraction, denial, instrumental support, positive reframing, acceptance and religious coping were also associated with high caregiver gains at time 3.

Table 1. Pearson’s correlations between period 1 IVs (early change) and caregiver gains at time 3.

Period 1 IVs	Time 3 Gains
Familism	0.21*
IPQ Consequence	0.02
IPQ Timeline	-0.14
IPQ Personal control	0.09
IPQ Treatment control	0.18
IPQ Identity	0.06
IPQ Concern	0.12
IPQ Coherence	0.29**
IPQ Emotional representations	0.17
Emotional tasks	0.11
Instrumental tasks	0.09
Nursing tasks	0.05
Self distraction	0.24**
Active coping	0.14
Denial	0.31***
Substance use	-0.04
Emotional support	0.18
Instrumental support	0.20*
Behavioural disengagement	0.09
Venting	0.10
Positive reframing	0.20*
Planning	0.14
Humour	0.18
Acceptance	0.18*
Religious coping	0.22*
Self blame	-0.003
Total support	-0.11
Mean satisfaction	-0.01

Note

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

Hierarchical regression analysis (see table 2) found that demographic factors (ethnicity and number of hours per week of caregiving) accounted for a highly significant 22% of the variance in caregiver gains. As would be expected increased caregiver gains during period 1 were significant predictors of caregiver gains at time 3 and accounted for 5% of the variance. Although correlated, familism did not remain significant in the regression model, but an increase in illness coherence accounted for a significant 3% of the variance in gains. Coping (self distraction, denial, instrumental support, positive reframing, acceptance and religious coping) added a final significant 12% to the model with the final model accounting for 42% of the variance in caregiver gains at time 3. An examination of the beta values suggests that ethnicity (being South-Asian), high number of hours in caregiver role, increased use of self distraction and denial were the strongest predictors of caregiver gains.

Table 2. Hierarchical regression using period 1 IVs to predict perceived caregiver gains at time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-6.21	1.38	-0.39***	-5.59	1.36	-0.35***	-5.41	1.46	-0.34***	-5.16	1.44	-0.32***	-3.72	1.42	-0.23**
Hours per week	0.02	0.01	0.20*	0.02	0.01	0.18*	0.02	0.01	0.18*	0.02	0.01	0.17*	0.02	0.01	0.18*
Gains				1.58	0.58	0.23**	1.55	0.59	0.22**	1.18	0.60	0.17*	1.02	0.57	0.15
Familism							0.21	0.60	0.03	0.35	0.60	0.05	0.46	0.57	0.07
IPQ Coherence										1.23	0.58	0.18*	1.22	0.57	0.18*
Self distraction													1.11	0.57	0.17*
Denial													1.27	0.55	0.19*
Instrumental support													0.55	0.58	0.08
Positive reframing													0.31	0.56	0.05
Acceptance													0.04	0.58	0.01
Religious coping													0.94	0.55	0.14
r^2 Change		0.22			0.05			0.001			0.03			0.12	
F Change		15.07***			7.37**			0.13			4.57*			3.29**	

Note

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

Late changes in caregiver factors as predictors of Time 3 gains:

As can be seen from table 3, an increase in perceptions of personal control and illness coherence during period 2 (late changes) were significantly associated with caregiver absolute gains at time 3. An increase in the use of emotional support and positive reframing were also found to be significantly associated with time 3 gains.

Table 3. Pearson's correlations between period 2 IVs (late change) and caregiver gains at time 3.

Period 2 IVs	Time 3 Gains
Extrinsic motivations	0.06
Intrinsic motivations	0.13
Familism	0.08
IPQ Consequence	0.03
IPQ Timeline	-0.09
IPQ Personal control	0.19*
IPQ Treatment control	0.05
IPQ Identity	-0.01
IPQ Concern	0.13
IPQ Coherence	0.21*
IPQ Emotional representations	-0.04
Emotional tasks	0.14
Instrumental tasks	0.09
Nursing tasks	0.02
Self distraction	0.05
Active coping	0.03
Denial	-0.14
Substance use	-0.13
Emotional support	0.22*
Instrumental support	0.10
Behavioural disengagement	-0.02
Venting	-0.13
Positive reframing	0.20*
Planning	-0.05
Humour	0.06
Acceptance	0.05
Religious coping	-0.01
Self blame	-0.17
Total support	-0.05
Mean satisfaction	-0.03

Note

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

Hierarchical regression analysis (see table 4) found that demographic factors (ethnicity and number of hours caregiving per week) accounted for a significant 22% of the variance in caregivers gains. An increase in caregiver gains during period 1 added a significant 5% to the model. Increased personal control and illness coherence added a non significant 1% to the model. Increased use of emotional support and positive reframing during period 2 added a final significant 7% to the model with the final model accounting for a significant 35% of the variance in caregiver gains at time 3. Ethnicity, previous early increase in gains and increase in emotional support were the strongest predictors of time 3 gains.

Table 4. Hierarchical regression using period 2 IVS to predict perceived caregiver gains at time 3.

	Model 1			Model 2			Model 3			Model 4		
Predictor (period 2)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-6.21	1.38	-0.39***	-5.59	1.36	-0.35***	-5.10	1.42	-0.32***	-5.53	1.37	-0.34***
Hours per week	0.02	0.01	0.20*	0.02	0.01	0.18*	0.02	0.01	0.18*	0.01	0.01	0.14
Gains				1.58	0.58	0.23**	1.48	0.59	0.22**	1.51	0.57	0.22**
IPQ Personal control							-0.41	0.58	-0.06	-0.21	0.57	-0.03
IPQ Coherence							-0.59	0.58	-0.09	-0.60	0.55	-0.09
Emotional support										1.34	0.56	0.20*
Positive reframing										0.94	0.55	0.14
r^2 Change		0.22			0.05			0.01			0.07	
F Change		15.07			7.37			0.89			5.55	

Note

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

Discussion

Using the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) as a conceptual model we aimed to examine if changes in caregiver factors (number of hours, tasks, illness perceptions, coping and social support) were predictive of absolute caregiver gains. Using a longitudinal design we were able to examine the influence of early processes of change (time 1-time 2) and late changes (time 2-time 3) on final caregiver gains at time 3. In addition to the variables within the Transactional model, we also studied if changes in family values (familism) and motivations to care influenced caregiver gains. Caregiver gains were found to remain stable over the nine months in which this study was conducted.

Late changes in motivations to care were not found to be associated with caregiver gains. There has been very little research pertaining to motivations to care and outcomes, however Lyonette & Yardley (2003) found in a cross-sectional study that intrinsic motivations to care (as absolute variables not change) were positively related to caregiver satisfaction. Perhaps those individuals who are intrinsically motivated are more willing to provide care and therefore derive more satisfaction from the role thus reporting more gains. It is possible that early changes in motivations to care would have a more significant relationship with caregiver gains as is the case in familism.

Familism was found to significantly decrease over time but changes in familism had a significant positive relationship with caregiver gains. Caregivers whose early family levels increased perceived more gains at time 3 (although this relationship did not remain significant in the final regression model). Late changes in familism were not related to caregiver gains. Perhaps early family values may be important for caregivers to derive satisfaction from the role but later other factors such as effective coping may be more significant in predicting caregiver gains. Previous literature focusing on familism has mainly examined the relationship between familism and negative outcomes (burden and depression) with mixed results being reported whereby some find familism to have a positive relationship with burden and depression (Zhan, 2006) and others have found it to be a negative correlate of burden (Lai, 2007). The mixed findings of previous studies may be due to the focus on the negative aspects of the role such as burden and depression, perhaps familism has a more significant relationship with the positive aspects of caregiving. Indeed the current findings are supportive of this as an early increase in familism was significantly associated with caregiver gains prospectively.

The influence of illness perception on positive caregiver outcomes has received limited attention. In the current study changes in early and late perceptions of illness coherence were significant predictors of caregiver gains. Caregivers who increasingly perceived they understood the care recipient’s illness reported more gains. Later changes in perceived personal control were also found to be related to caregiver gains with caregivers reporting increased control also perceiving more gains although the explained variance was minimal and not significant. The data in the current study suggests that changes in illness perceptions (with the exception of illness coherence) have a limited role in predicting caregiver gains.

The lack of significant relationships between illness perceptions and gains has also been reported by previous research. For example Bacon et al (2009) in a qualitative study of four caregivers of stroke patients found that only perceptions of challenge were significantly associated with a positive care experience. Rapp & Chao (2000) found that neither positive nor negative appraisals were concurrently related to positive affect, although positive appraisals were found to play a significant role in buffering stress. The inconsistent findings suggest that illness perceptions may play a stronger role in patient outcome studies as opposed to caregiver outcomes. Also it has been found that illness perceptions are better able to predict negative caregiver outcomes than positive gains. A number of cross-sectional and longitudinal studies have found that illness perceptions and appraisals play a significant role in caregiver distress (Haley et al, 1987; Goode et al, 1998 & Pakenham, 2001).

Interestingly the changes in the number of tasks (emotional, instrumental and nursing) were not significantly related to caregiver gains. However the number of hours caregiving per week was positively associated with caregiver gains. Caregivers who reported more hours of care per week perceived more gains prospectively. Perhaps the caregivers who spent more hours in the care role had more opportunities to experience the gains associated with the role. It is difficult to compare these findings with previous research as various measures of caregiver stressors have been used and not all studies distinguish between the different types of caregiving.

Changes in caregiver coping were found to be important predictors of caregiver gains. Early increased use of self distraction, denial, instrumental support, positive reframing, acceptance and religious coping were associated with more perceived gains at time 3. It is interesting that two opposing coping strategies that is denial and acceptance were associated with gains, however only self distraction and denial were found to be significant predictors of gains. Later changes in coping found to affect gains included increased use of positive reframing and emotional support, with more use of emotional support being a significant predictor of gains.

The combination of problem and emotion focused coping methods supports Lazarus' (1991) assertions that coping is a process therefore there is no universally effective or ineffective coping strategy. For example early change in denial in the current study was found to be a significant positive predictor of longitudinal gains but later use of emotional support was a significant predictor. This suggests that perhaps earlier use of denial maybe more effective for caregivers to reduce distress but later use of support is more effective. In contrast previous cross-sectional research reports that problem focused coping is related to caregiver gains whereas emotional focused coping was related to strain (Kramer, 1997 & Bacon et al, 2009).

Kim et al (2007) also found that religious coping in particular was associated with greater benefit finding. The current findings support Kim et al (2007) as early increased use of religious coping was found to be significantly related to caregiver gains. Although ethnic differences in religious coping were not explored in the current study, previous studies by Parveen & Morrison (2009) and Parveen, Morrison & Robinson (in press) have found that South-Asian caregiver use religious coping significantly more than White-British caregivers and in the current study were found to significantly report more gains.

Surprisingly, although change in emotional support was a significant predictor of caregiver gains, changes in total and mean satisfaction were not found to have a significant relationship with gains. This is an interesting finding given previous research has found that high levels of social support are related to lower burden and depression (Goode et al, 1998; Pakenham, 2001 & Grunfeld et al, 2004). This finding further highlights the theory that positive affect is conceptually distinct from negative affect (Rapp & Chao, 2000) and therefore factors that reduce burden and depression in caregivers may not necessarily increase caregiver gains.

In summary, the data from the current study suggests that a high number of hours, early perceptions of increasing illness coherence and increasing use of self distraction and denial are predictive of caregiver gains. Later increased use of emotional support is a significant predictor of caregiver gains. Ethnicity also appears to be a strong predictor with British South-Asian caregiver perceiving more gains than White-British caregivers. The current study has a number of strengths and clinical implications. The main strength of the current study is the longitudinal design as much of previous research has been cross-sectional. The Transactional model of stress and coping that many studies make use of as a conceptual model, highlights that stress is a dynamic process therefore a longitudinal design is surely the better test of the model. Although the sample of the study may not be large, it is representative of the caregiver population in the U.K. Caregivers from various geographical locations, diagnosis groups, ethnic and gender groups were recruited and the age of caregivers ranged from 18 to 84 years.

The main implications of the findings are related to the development of time specific interventions, for example early perceptions of illness coherence appear to be important alongside a combination of problem focused (active coping) and emotion focused coping (seeking emotion support). Caregiver should be provided with an educational intervention whereby they are provided with more information regarding the care recipient’s diagnosis. Later as caregivers become more involved within the role, the provision of emotional support perhaps through personally tailored counselling sessions would be beneficial.

Whilst considering the implications of the findings for developing interventions or services, some limitations need to be addressed. The study contains a relatively modest sample size and achieved a response rate of 31%, however only just over 20% of caregivers dropped out of the study. Nevertheless the sample size and attrition rate appears to be similar to other caregiver outcome longitudinal studies (Goode et al, 1998; Pakenham, 2001 & Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti et al, 2005). Also the small South-Asian group size compared to the White-British group limits group comparison analysis. Caregivers were primarily recruited from caregiver support groups which may have influenced the findings (although this now appears to be the norm in caregiver research). The study is further limited as an artificial baseline was created, that is caregivers were not recruited from role adoption over a period of nine months, therefore the “early changes” discussed may not actually be early within the care role. Although it would be of interest for future research to recruit caregivers early on in the care role, this would severely limit the sample size. Despite the limitations of the current study, the findings add to the body of research focusing on positive affect in the caregiver experience and have implications for the development of services and interventions.

Chapter 7b

Caregiver Gains: Mediational Analyses

(Supplementary paper for Chapter 7A, focusing on a mediation hypothesis)

Abstract

The aim of this study was to examine if motivations to care, familism, appraisals, coping and social support were related to caregiver gains and whether such variables change over time. The study further tests whether illness perceptions and coping mediate the relationship between motivations to care and familism and caregiver gains using a longitudinal design. 123 caregivers completed a questionnaire at three time points: baseline, three months and nine months from baseline. The questionnaire assessed motivations to care, familism, caregiver stressors (number of care related tasks), illness perceptions, coping, social support and caregiver gains. Caregiver gains were found to remain stable over time. The concurrent baseline analysis revealed that ethnicity, familism number of nursing tasks, personal control and religious coping were significantly associated with gains at baseline. Longitudinal analysis revealed that familism and religious coping were strong predictors with the final model accounting for 30% of the variance in time 2 gains. Religious coping continued to be a strong predictor of T3 gains and the final model accounted for 42% of the variance in time 3 gains. Religious coping and positive reframing mediated the relationship between familism and gains. The study has implications for the development of time specific interventions to increase caregiver gains and also for service development.

Introduction

The rapidly aging population and increasing demand for patient support has led to the UK developing a community based care policy (Brereton, 2002). 80% of the care required to support patients at home is now provided by family caregivers. The term caregiver is used to describe an individual who provides emotional and physical support for an individual who is experiencing difficulties due to physical, cognitive or emotional impairments, often without financial compensation (Bridges, 1995). It is estimated there are currently six million caregivers in the UK (with 301, 000 individuals adopting the role every year) saving the National Health Service approximately £87 billion per year (Carers UK, 2009).

Due to the great socioeconomic value of caregivers, there has been increasing interest from the government and health care professionals to maintain the physical and psychological health of caregivers. The majority of studies have focused on the negative aspects of caregiving with poorer physical health (Kiecolt-Glaser, Dura, Speiche, Trask & Glase, 1991; Vitaliano, Zhang & Scanlan, 2003) and psychological health (burden, anxiety and depression) being well documented (Haley et al, 1987; Goode, Hayley, Roth & Ford, 1998; Pakenham, 2001 & Grunfeld, Coyle, Whelon, Clinch, Reyno, Earle et al, 2004).

A common conceptual model that has been applied to the study of the caregiver experience is the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), which posits that stress will occur when there is a perceived discrepancy between the demands of the (care) situation and the resources the individual (caregiver) has or perceives available to deal with the situation (e.g. social support). Stress is thus defined as a psychological transaction between the environment/event and the cognitive and emotional characteristics of the caregiver.

The caregiver’s appraisals of the situation, coping methods (problem focused or emotion focused) and use of support will influence the caregiver’s ability to manage the stressor (Haley, Levine, Brown & Bartolucci, 1987) and thus any outcomes experienced for example physical and psychological wellbeing.

The role of positive aspects of caregiving has received limited attention in comparison yet it has been shown that the role of caregiver can result in a number of positive gains such as personal satisfaction and growth as well as an improved relationship with the care recipient. Parveen, Morrison & Robinson (in press) found in a qualitative study of 30 family caregivers, that caregivers not only discussed the burdens associated with the caregiver role but were also keen to discuss what they had gained from the role. British South-Asian caregivers perceived the main positive aspect of the care role to be gaining blessings from God, as well as from the care recipient for fulfilling their duties to care. White-British caregivers believed that positive experiences came from learning new skills within the care role. Cohen, Colantonio & Vernich (2002) also examined positive experiences in the care role amongst a sample of 289 caregivers of the elderly. 73% of their sample could identify at least one positive aspect of the role and 6.9% identified more than one aspect. Positive aspects were found to be concurrently related to significantly decreased depression.

Different terminologies have been used to describe the positive changes during the caregiving experience including, benefit finding, personal growth, post-traumatic growth and gains. In the current paper, the term caregiver gain has been adopted which Kramer (1997) defines as the extent to which the care role is appraised to enhance the caregiver’s life. Caregiver gains were proposed to include a direct positive affective or practical return as a result of the care role which may be subjective feelings of satisfaction or rewards. Research that has sought to examine the positive aspects of caregiving has mainly focused on the absence of negative effects such as the absence of depressive symptoms (Beach, Schulz, Yee & Jackson, 2000). However Rapp & Chao (2000) state that the benefits or gains resulting from the care role are conceptually and empirically distinct from the negative affect of providing care and therefore caregiver gains should be examined separately. This has been supported by Pakenham (2005) who examined benefit finding in a longitudinal study of 404 patients with a multiple sclerosis diagnosis. Benefit finding was found to be related to positive affect and life satisfaction but had a weak association with negative affect.

There has been some debate concerning the nature of gains with some studies focusing on benefit finding and gains as a coping process (Pakenham, 2005) or as an outcome (Kramer, 1997 and Kim, Schulz & Carver, 2007). Rapp & Chao (2000) have focused on caregiver gains as a form of positive appraisal and strain as negative appraisal. In a study of 63 caregivers of individuals with a dementia diagnosis; positive appraisals (gains) were found to significantly relate to negative affect but neither negative nor positive appraisals were associated with positive affect. Kramer's (1997) study of 74 male spouse caregivers found that use of problem focused coping and satisfaction with support was positively associated with gains but the use of emotion focused coping was associated with increased strain. More recently Kim et al (2007) examined benefit finding in a large sample of 896 caregivers of cancer patients who had been providing care for an average of 19 months. High levels of religious coping, greater satisfaction with social support and lower education level were significantly concurrently related to high levels of benefit finding. In the case of caregiving (which is considered an ongoing stressor), caregiver perceived gains can be considered as a coping strategy or as an outcome, in the current study, caregiver gains will be treated as an outcome variable.

Most of the previous research on caregiver gain (including the above studies) has mainly been based on cross-sectional data; however one exception is a study by Bacon, Milne, Sheikh & Freeston (2009) which examined care gains over a period of six weeks, using four case studies of caregivers providing care for an individual who had experienced a stroke. An increase in caregiver gains was seen over time and challenge appraisals were significantly positively related to caregiver gains. Caregivers using problem focused coping experienced more gains than those using emotion focused coping.

Studies of caregiver gains have not to date considered the influence of motivations to care and familism on gains, both of which have been examined in studies of negative affect in caregivers. For example Lyonette & Yardley (2003) found in a sample of 204 female caregivers that extrinsic motivations to care (guilt and perceived expectation) were significantly related to stress. However intrinsic motivations to care (caring nature and living up to one’s principles) were associated with caregiver satisfaction with role. Familism (defined as strong feelings of loyalty, reciprocity and solidarity among family members) is considered as the root of caregiving (Ramos, 2004), however research examining familism and its relationship with negative affect (burden and depression) has produced mixed results. Lai (2007) and Gupta & Pillai (2009) found that familism was a negative predictor of burden in amongst Chinese Canadian and Indian American caregivers. In contrast, Zhan (2006) and Gupta (2002) have found familism to be a positive predictor of burden and depression in similar populations. This suggests that the direction of association is unclear and given that these are cross-sectional studies, further longitudinal exploration is warranted.

The present study will build on existing research by examining how different components of the Transactional Model of Stress (care stressors, illness perceptions, coping and social support) are related to caregiver perceived gains using a longitudinal design. In addition the influence of motivations to care and familism will be examined. The study will examine the relationship of the above factors over three time points (baseline, three months from baseline and nine months from baseline). Due to limited existing literature on caregiver gains, the study will explore concurrent caregiver perceived gains as well as longitudinal change. The following research questions will be addressed:

1. Are caregiver perceived gains stable over time?
2. What factors are associated with caregiver perceived gains and is this relationship consistent over time?
3. Do illness perceptions and coping mediate the relationship between motivations to care, familism and perceived gains?

Method

Sample

A total sample of 154 caregivers was recruited at Time 1 of which 123 completed questionnaires at all three time points. Common reasons for drop out included: illness (either caregiver or care recipient), placement of care recipient in a nursing home or death of care recipient. Analysis was conducted to examine if those caregivers who dropped out of the study differed from those who remained in the study by age, hours of care or outcomes. No significant differences were found. 82 of the caregivers in the final sample were female and 41 were male. 96 of the caregivers identified themselves as White-British and 27 were of British South-Asian (Bangladeshi, Indian and Pakistani) ethnicity. The caregiver age ranged from 18 to 84 years with a mean age of 61.16 years (*SD* = 13.72). With regards to care recipient diagnosis group the largest groups was Parkinson's disease (*n* = 38), followed by multiple sclerosis (*n* = 33), dementia (*n* = 25), other (*n* = 13), stroke (*n* = 9) and cancer (*n* = 5). The caregivers had been providing care for an average of 9.91 years (*SD* = 13.70). Full demographic details have been described in an additional paper[9].

Measures[10]

The first section of the questionnaire addressed demographic details such as caregiver ethnicity, gender, age, marital status, employment, relationship to care recipient, care recipient diagnosis, hours per week of caregiving and the number of years in the care role.

Caregiver stressors were measured using part of the Willingness to Care Scale (Abell, 1999). The measure contains a list of 10 typical emotional, 10 instrumental and 10 nursing care related tasks. Caregivers were required to state how many of the tasks from each list they performed per week.

Motivations to care were measured using the Motivations in Elder Caring (MECS) by Lyonette & Yardley (2003). The measure contains 13 items of which 7 items measure extrinsic motivations (EMECS) and 6 items measure intrinsic motivations (IMECS). The items were modified whereby the term elderly person was replaced with care recipient. The items are measured on a 5 point likert scale and demonstrated good reliability with the EMECS achieving an alpha of 0.81 and IMECS $\alpha = 0.74$.

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[9] Full demographic details can be found in Chapter 6

[10] The measures used in the questionnaire can be found in Appendix 5, page 408.

Caregiver familism was measured using the Heller Familism Scale (1976). The measure consists of 15 items (e.g. “married children should live close to their parents so that they can help each other”) measured on a 5 point likert scale (max score = 60). The measure achieved an alpha of 0.92 and therefore demonstrates good internal reliability.

Illness perceptions were assessed using the brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006). The measure contains the following subscales: consequence, timeline, personal control, treatment control, identity, concern, coherence and emotional representation. The subscales are measured on an 11 point likert scale (max score = 10 per scale).

The brief COPE by Carver (1997) was used to assess caregiver coping. The measure contains 28 items which compose the following subscales: self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religious coping and self blame. As each subscale only contains 2 items, inter item correlations were used to assess the reliability. The inter item correlations ranged from 0.41 (acceptance) to 0.90 (religious coping).

Caregiver use of social support was assessed using the Social Support Questionnaire (Saranson, 1983). Caregivers are required to list the amount of support persons they have and how satisfied they are with each person listed using a 6 point likert scale (1 to 6). Two scales are derived from this measure: total support ($\alpha = 0.72$) and mean satisfaction with support ($\alpha = 0.84$).

The caregiver gains were measured using the GAINS developed by Pearlin (1988). The GAINS contains 10 items which are measured on a 4 point likert scale (max score = 30). An example of an item would be “As a result of providing care, to what extent did you learn to do new things?” This is a well validated measure and in the current study also demonstrated good reliability (α = 0.89). (We also assessed caregiver mood that is anxiety and depression as well as caregiver quality of life and papers describing the predictors of these are currently in review).

Procedure

As the procedure of the study has been described in-depth elsewhere[11], only a brief summary will be provided. Ethical approval for the study was obtained from the departmental ethics committee. Caregivers were recruited from support groups across the UK as well as adverts through newsletter and posters. Interested caregivers were sent a questionnaire pack containing information about the study, consent forms, a questionnaire and information regarding care services. The caregivers were asked to complete the questionnaire at home in their own time, however 13 of the British South-Asian caregivers required the translation aid of the researcher. Only caregivers over the age of 18 years who provided over 7 hours of care per week were included in the study. Caregivers completed a questionnaire at three time points: baseline (T1), three months from baseline (T2) and nine months from baseline (T3). All caregivers received full debrief information and a list of support services in their area.

Data analysis

Repeated measures ANOVAs were conducted to examine if predictor variables and caregiver gains changed significantly over time. Pearson’s correlation analysis was conducted to test the relationship between the IVs (T1, T2) and caregiver gains at all three time points. Only those variables that were significantly associated with gains were entered into the regression model due to sample size limitations. Partial correlation analysis was used to control for previous levels of gains in the

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[11] See Chapter 6

longitudinal analysis. Only variables that remained significantly related to subsequent gains when previous levels of gains had been controlled were used in the longitudinal regression models. Ethnicity, age and hours caregiving were added to the first step of the hierarchical regression models followed by IVs that were found to be significantly related to gains. Dummy variables were created for categorical IVs such as ethnicity before being entered into the regression model. Mediation analysis following guidelines by Baron and Kenny (1986) was conducted using T1 IVs, T2 mediators and T3 gains.

Results

Independent samples T tests were conducted to examine ethnic differences in caregiver gains. At all 3 time points South-Asian caregivers reported significantly more gains than White-British caregivers (T1 SA M = 24.00 SD = 5.59, WB M = 17.82 SD = 7.37, t (1, 118) = 4.64, p = .001; T2 SA M = 23.59, SD = 6.35, WB M = 17.88 SD = 7.16, t (1, 121) = 3.75, p = .001; T3 SA M = 24.58 SD = 6.35, WB M = 17.84 SD = 6.53, t (1, 115) = 6.47, p = .001). However, repeated measures ANOVA revealed that there was no significant change in gains over time for either group that is each group was internally consistent. T tests and one way ANOVAs did not find any significant differences for gender or diagnosis groups. Neither caregiver age nor number of years in care role was significantly related to caregiver gains at any time point. However the number of hours of caregiving per week were significantly related at T2 (r = 0.22, $p < .05$) and at T3 (r = 0.27, $p < .05$).

Repeated measures ANOVAs were conducted to examine if there was a significant change over time for all variables. (Full descriptive results of changes over time are presented in a separate paper, a brief summary is provided below). Motivations to care remained stable over time but familism significantly decreased (t

(1, 120) = 8.19, *p* = .001). The number of emotional (*F* (2, 107) = 3.64, *p* = .03) and nursing tasks performed by caregivers (*F* (2, 107) = 3.59, *p* = .03) increased significantly over time, but the number of instrumental tasks did not significantly change. The number of hours per week of caregiving did not significantly change over time. Illness perceptions remained stable over time with the exception of the consequence subscale which increased significantly over time (*F* (2, 120) = 3.67, *p* = .03). With regards to coping, substance use increased over time (*F* (2, 120) = 5.68, *p* = .004) and positive reframing decreased significantly (*F* (2, 120) = 3.34, *p* = .04). Total support available to caregivers increased over time (*F* 2, 118) = 5.55, *p* = .01) but satisfaction with support did not change significantly. Caregiver gains did not change significantly between T1 (*M* = 19.16, *SD* = 7.46) and T2 (*M* = 19.14, *SD* = 7.36) or T3 (*M* = 19.33, *SD* = 6.67; *F* (2, 112) = 0.13, *p* = .88).

Concurrent predictors of gains at T1:

Pearson's correlation tests were conducted to examine the relationships between variables at T1 (See Table 1). Familism was positively correlated with gains (*p* < .001), as were the number of emotional tasks (*p* < .05) and nursing tasks (*p* < .01) carried out. With regards to illness perceptions, only the personal control subscale was significantly (and positively) related to gains (*p* < .05). Quite a few coping strategies were associated with the number of reported gains. Active coping (*p* < .01), use of emotional support (*p* < .001), behavioural disengagement (*p* < .01), positive reframing (*p* < .001), acceptance (*p* < .001) and religious coping (*p* < .001) were found to have positive significant relationships with gains and finally, the use of substances had a negative relationship with gains (*p* < .05).

Table 1. Pearson's and partial correlations between IVs (at Time 1 and Time 2) and caregiver gains

Time 1 IVs	Time 1 Gains	Time 2 Gains[1]	Time 3 Gains[2]
Familism	0.45***	0.44*** (0.20*)	0.48*** (0.18*)
Number of emotional tasks	0.21*	0.04 (-0.15)	0.10 (-0.05)
Number of instrumental tasks	0.14	-0.04 (-0.19*)	0.11 (0.07)
Number of nursing tasks	0.25**	0.06 (-0.17)	0.23* (0.13)
IPQ Consequence	0.09	0.15 (0.12)	0.18* (0.15)
IPQ Timeline	-0.08	-0.17 (-0.16)	-0.10 (0.003)
IPQ Personal control	0.21*	0.12 (-0.05)	0.10 (-0.08)
IPQ Treatment control	0.12	0.08 (-0.02)	0.10 (0.01)
IPQ Identity	0.01	0.02 (0.02)	0.01 (-0.004)
IPQ Concern	0.07	0.15 (0.14)	0.19* (0.17)
IPQ Coherence	0.06	0.02 (-0.02)	0.02 (-0.04)
IPQ Emotional representations	0.09	0.02 (-0.05)	0.02 (-0.04)
Self distraction	-0.13	-0.11 (-0.02)	0.01 (0.20*)
Active coping	0.28**	0.26** (0.08)	0.21* (-0.04)
Denial	-0.002	-0.01 (-0.01)	0.01 (0.03)
Substance use	-0.18*	-0.15 (-0.03)	-0.19* (-0.08)
Emotional support	0.23***	0.20* (0.05)	0.18* (-0.01)
Instrumental support	0.12	0.09 (0.01)	0.15 (0.10)
Behavioural disengagement	0.25**	0.13 (-0.06)	0.18* (0.01)
Venting	0.01	0.10 (0.13)	0.05 (0.03)
Positive reframing	0.42***	0.32*** (0.04)	0.39*** (0.11)
Planning	0.17	0.12 (0.001)	0.12 (-0.03)
Humour	-0.13	-0.10 (-0.02)	-0.09 (-0.02)
Acceptance	0.23***	0.09 (-0.10)	0.11 (-0.07)
Religious coping	0.53***	0.51*** (0.22**)	0.54*** (0.19*)
Self blame	-0.01	0.01 (0.02)	-0.03 (-0.05)
Total support	0.07	-0.10 (-0.22*)	-0.02 (-0.04)
Mean satisfaction	0.14	0.06 (-0.05)	0.10 (0.002)

Time 2 IVs	Time 2 Gains[1]	Time 3 Gains[2]
Extrinsic motivations	0.17 (0.10)	0.23** (0.16)
Intrinsic motivations	0.26** (0.06)	0.27** (0.03)
Familism	0.47*** (0.23**)	0.52*** (0.23**)
Number of emotional tasks	0.14 (-0.03)	0.17 (-0.003)
Number of instrumental tasks	0.06 (-0.01)	0.15 (0.13)
Number of nursing tasks	0.15 (0.06)	0.29** (0.26**)
IPQ Consequence	0.08 (0.05)	0.14 (0.13)
IPQ Timeline	-0.10 (0.02)	-0.16 (-0.17)
IPQ Personal control	0.13 (0.09)	0.15 (0.09)
IPQ Treatment control	0.19* (0.12)	0.21* (0.10)
IPQ Identity	0.07 (0.13)	0.04 (0.06)
IPQ Concern	0.17 (0.19*)	0.19* (0.18*)
IPQ Coherence	0.36*** (0.28**)	0.26** (0.04)
IPQ Emotional representations	0.13 (0.07)	0.16 (0.09)
Self distraction	0.02 (-0.03)	0.21* (0.28**)
Active coping	0.33*** (0.22*)	0.23* (-0.02)
Denial	0.17 (0.09)	0.27** (0.22*)
Substance use	-0.15 (-0.003)	-0.18* (-0.04)
Emotional support	0.14 (0.04)	0.24** (0.17)
Instrumental support	0.25** (0.09)	0.25** (0.04)
Behavioural disengagement	0.04 (-0.04)	0.14 (0.12)
Venting	0.09 (0.12)	0.11 (0.13)
Positive reframing	0.35*** (0.10)	0.40*** (0.13)
Planning	0.22* (0.17)	0.17 (0.06)
Humour	0.12 (0.12)	0.09 (0.05)
Acceptance	0.18* (0.07)	0.20* (0.06)
Religious coping	0.49*** (0.19*)	0.57*** (0.25**)
Self blame	0.04 (0.09)	-0.02 (-0.04)
Total support	0.01 (-0.02)	-0.08 (-0.16)
Mean satisfaction	0.07 (-0.03)	0.05 (-0.06)

Note

[1] In brackets controlling for Time1 gains using partial correlations

[2] In brackets controlling for Time1 and Time 2 gains using partial correlations

* *p* < .05 ** *p* < .01 *** *p* < .001

Hierarchical regression analysis (see Table 2) revealed that caregiver ethnicity and age accounted for 12% of the variance in gains at T1 (although age was not significantly associated with reported gains during correlation analysis, it was included in the regression as a possible confounding variable with ethnicity). Familism added a further significant 8% to the model, whereas the number of emotional and nursing tasks only accounted for non significant 3% of variance in gains. Perceptions of personal control however added a significant 6% to the model. Active coping, substance use, use of emotional support, behavioural disengagement, positive reframing, acceptance and religious coping added the final 17% to the model. The final model accounts for 46% of the variance in gains. The examination of the final beta values suggests that religious coping, nursing tasks and familism were the strongest positive predictors of gains in the model.

Table 2. Hierarchical regression predicting caregiver gains at Time 1.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (Time 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-6.61	1.76	-0.37***	-1.13	2.38	-0.06	-0.83	2.36	-0.05	-1.06	2.28	-0.06	3.07	2.33	0.17
Age	0.04	0.05	0.07	0.02	0.05	0.04	0.01	0.05	0.01	0.02	0.05	0.03	-0.02	0.05	-0.04
Familism				0.21	0.06	0.41***	0.19	0.06	0.38***	0.18	0.06	0.37***	0.1	0.06	0.19
IPQ Personal control							0.53	0.22	0.20*	0.65	0.23	0.25	0.66	0.21	0.25**
Emotional tasks										-0.04	0.23	-0.02	-0.10	0.21	-0.04
Nursing tasks										0.55	0.22	0.24*	0.52	0.20	0.22*
Active coping													0.52	0.36	0.13
Substance use													-1.07	0.53	-0.17
Emotional support													0.28	0.37	0.07
Behavioural disengagement													0.40	0.44	0.08
Positive reframing													0.39	0.37	0.10
Acceptance													-0.04	0.36	-0.01
Religious coping													1.01	0.34	0.35**
r^2 Change		0.12			0.08			0.04			0.05			0.17	
F Change		7.39***			10.76***			5.66*			3.47*			4.30***	

Note

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

Longitudinal predictors of gains:

Time 2 (three months from baseline)

Partial correlations analysis was used to examine the relationship between T1 predictor variables and T2 gains whilst controlling for T1 gains. Demographics factors including ethnicity, age and hours caregiving were included in the first step of the hierarchical regression. As can be seen from Table 1, familism continued to be positively associated with gains ($p < .01$). Emotional and nursing tasks were no longer significantly associated with gains but the number of instrumental tasks performed by caregivers was found to have a negative relationship with gains ($p < .05$). Illness perceptions were not significantly related to gains at T2. With regards to coping, only religious coping remained positively associated with gains ($p < .01$). Although the total amount of support used by caregivers at T1 was not significantly related to gains concurrently, it had a significant negative relationship with gains at T2 ($p < .05$).

In the final regression model (see Table 3), ethnicity, age and number of hours accounted for 12% of the variance in caregiver gains. Familism accounted for a significant 8%. The number of instrumental tasks accounted for non significant 1% but religious coping added a further significant 9% to the predictive model. Total support did not add significantly to the model. The final beta values suggest that religious coping and familism are the strongest predictors of caregiver gains in a longitudinal model. The final model accounts for 30% of the variance in gains at three months from baseline.

Table 3. Hierarchical regression predicting caregiver gains at Time 2.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (Time 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-5.99	1.83	-0.34***	-0.73	2.39	-0.04	-1.06	2.41	-0.06	1.87	2.41	0.11	1.93	2.58	0.11
Age	0.04	0.06	0.08	0.03	0.05	0.06	0.03	0.05	0.06	0.001	0.05	0.001	0.0001	0.05	0.0001
Hours per week	0.01	0.01	0.08	0.003	0.01	0.02	0.003	0.01	0.03	0.01	0.01	0.05	0.01	0.01	0.05
Familism				0.21	0.06	0.42***	0.21	0.06	0.42***	0.12	0.07	0.25	0.12	0.07	0.25
Instrumental tasks							-0.34	0.34	-0.09	-0.43	0.33	-0.11	-0.42	0.33	-0.11
Religious coping										1.21	0.33	0.42***	1.22	0.33	0.43***
Total support													-0.03	0.49	-0.01
r^2 Change		0.12			0.08			0.01			0.09			0.0001	
F Change		4.65**			10.50**			0.98			13.53***			0.004	

Note

** $p < .01$ *** $p < .001$

Time 3 (nine months from baseline)

As can be seen in Table 1, T1 and T2 IVs were correlated with T3 gains whilst controlling for T1 and T2 gains that is the DV is a measure of change in gains reported by T3. T1 familism continues to be significantly related to gains ($p < .05$). The number of nursing tasks performed at T2 are positively related to gains at T3 ($p < .01$) as are perceptions of illness concern ($p < .05$). Self distraction (T1) and religious coping (T1 and T2) are significantly related to gains at T3. Denial at T2 also has a positive relationship with gains ($p < .05$). In the final model (see Table 4), ethnicity, age and hours accounted for 22% of variance in caregiver gains at nine months from baseline. Familism significantly added 5% to the model and number of nursing accounted for a further significant 4%. Caregiver concern does not add significantly to the model but coping (self distraction, religious coping and denial) added a significant 11% to the model. The final model accounted for 42% of the variance in caregiver gains at nine months from baseline with religious coping being the strongest positive predictor.

Table 4. Hierarchical regression predicting caregiver gains at Time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-6.75	1.56	-0.42***	-3.18	2.07	-0.20*	-3.25	2.07	-0.20*	-2.88	2.01	-0.18*	-0.47	1.99	-0.03
Age	0.04	0.05	0.08	0.03	0.05	0.07	0.04	0.05	0.08	0.02	0.05	0.05	0.002	0.04	0.004
Hours per week	0.02	0.01	0.18*	0.01	0.01	0.14	0.01	0.01	0.14	0.01	0.01	0.08	0.01	0.01	0.11
Familism (T1)				0.14	0.06	0.31**	0.14	0.06	0.31**	0.14	0.05	0.30**	0.06	0.05	0.14
IPQ Concern (T2)							0.22	0.20	0.10	0.39	0.20	0.17	0.34	0.19	0.15
Nursing tasks (T2)										0.48	0.17	0.25**	0.38	0.17	0.20*
Self distraction (T1)													-0.46	0.28	-0.13
Religious Coping (T1)													1.02	0.28	0.39***
Denial (T2)													0.58	0.33	0.15
r^2 Change		0.22			0.05			0.01			0.05			0.10	
F Change		9.86***			6.39**			1.29			7.93**			6.00***	

Note

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

Potential mediating factors of predictor variables and gains at T3

Mediation analysis was conducted to test whether illness perceptions and coping at T2 mediated the relationship between T1 familism and care tasks and caregiver gains at T3. Analysis was conducted following the guidelines suggested by Baron & Kenny (1986). In order to test for mediation, three conditions have to be met: the IV has to be significantly related to the potential mediator, the mediator has to be significantly related to the DV and finally the IV also has to significantly be associated with the DV. Once these conditions are met, three separate regressions are run whereby the mediator is regressed on the IV (equation 1), the DV is regressed on the IV (equation 2) and the DV is regressed on the IV and the mediator (equation 3). In order for mediation to be established, the beta values obtained from equation 3 must me smaller than those from equation 2. The Sobel Z test was used to test the statistical significance in the reduction of the beta values. As can be seen in Table 5, the analysis found that positive reframing (at T2) significantly, but only partially mediated the relationship between familism at T1 and gains at T3. Beta values were reduced from 0.48 to 0.42 ($Z = 2.42$, $SE = 0.01$, $p = .02$). Religious coping (T2) was found to be a more significant mediator between familism at T1 and gains at T3, as beta values were reduced from 0.48 to 0.21 ($Z = 4.24$, $SE = 0.03$, $p = .001$).

Table 5. Longitudinal mediation analysis testing the relationship between time 1 IVs and Time 3 gains using time 2 mediators.

	Predictors	*Beta*	*SE*	*t* test	Equation statistics **(Sobel Z Test)**
Step 1	Familism	0.05	0.01	0.54	*F* = 0.29, r^2 = .002, *p* = .59
Step 2	Familism	0.48	0.04	5.84***	*F* = 34.15, r^2 = .23, *p* = .001
Step 3	Familism	0.48	0.04	5.89***	*F* = 22.61, r^2 = .28, *p* = .001
	IPQ Coherence	0.24	0.31	2.96**	**_Z_ = 0.95, _SE_ = 0.01, _p_ = .34**
Step 1	Familism	0.20	0.01	2.20*	*F* = 4.84, r^2 = .04, *p* = .03
Step 2	Familism	0.48	0.04	5.84***	*F* = 34.15, r^2 = .23, *p* = .001
Step 3	Familism	0.42	0.04	5.31***	*F* = 27.77, r^2 = .33, *p* = .001
	Positive reframing	0.32	0.27	4.09***	**_Z_ = 2.42, _SE_ = 0.01, _p_ = .02***
Step 1	Familism	0.61	0.01	8.36***	*F* = 69.84, r^2 = .37, *p* = .001
Step 2	Familism	0.48	0.04	5.84***	*F* = 34.15, r^2 = .23, *p* = .001
Step 3	Familism	0.21	0.04	2.24*	*F* = 31.02, r^2 = .35, *p* = .001
	Religious coping	0.44	0.25	4.66***	**_Z_ = 4.24, _SE_ = 0.03, _p_ = .001*****
Step 1	Familism	0.18	0.01	1.98*	*F* = 3.90, r^2 = .03, *p* = .05
Step 2	Familism	0.48	0.04	5.84***	*F* = 34.15, r^2 = .23, *p* = .001
Step 3	Familism	0.46	0.04	5.51***	*F* = 18.54, r^2 = .25, *p* = .001
	Self distraction	0.13	0.29	1.58	**_Z_ = 1.23, _SE_ = 0.01, _p_ = .22**
Step 1	Nursing tasks	0.23	0.05	2.46*	*F* = 6.07, r^2 = .05, *p* = .02
Step 2	Nursing tasks	0.23	0.20	2.45*	*F* = 6.01, r^2 = .05, *p* = .02
Step 3	Nursing tasks	0.18	0.20	1.92	*F* = 5.67, r^2 = .10, *p* = .01
	IPQ Coherence	0.22	0.37	2.26*	**_Z_ = 1.65, _SE_ = 0.06, _p_ = .10**
Step 1	Nursing tasks	0.22	0.05	2.41*	*F* = 5.80, r^2 = .05, *p* = .02
Step 2	Nursing tasks	0.23	0.20	2.45*	*F* = 6.01, r^2 = .05, *p* = .02
Step 3	Nursing tasks	0.19	0.20	1.99*	*F* = 4.87, r^2 = .09, *p* = .01
	Active coping	0.18	0.35	1.89	**_Z_ = 1.54, _SE_ = 0.06, _p_ = .12**
Step 1	Nursing tasks	0.21	0.06	2.25*	*F* = 5.04, r^2 = .04, *p* = .03
Step 2	Nursing tasks	0.23	0.20	2.45*	*F* = 6.01, r^2 = .05, *p* = .02
Step 3	Nursing tasks	0.19	0.20	1.98*	*F* = 5.49, r^2 = .10, *p* = .01
	Instrumental support	0.21	0.33	2.18*	**_Z_ = 1.54, _SE_ = 0.06, _p_ = .12**
Step 1	IPQ1 Consequence	0.28	0.10	3.16**	*F* = 10.01, r^2 = .08, *p* = .002
Step 2	IPQ1 Consequence	0.18	0.36	1.99*	*F* = 3.94, r^2 = .03, *p* = .05
Step 3	IPQ1 Consequence	0.14	0.37	1.48	*F* = 3.27, r^2 = .06, *p* = .04
	IPQ6 Concern	0.15	0.35	1.59	**_Z_ = 1.39, _SE_ = 0.12, _p_ = .16**
Step 1	IPQ1 Consequence	0.21	0.10	2.34*	*F* = 5.48, r^2 = .04, *p* = .02
Step 2	IPQ1 Consequence	0.18	0.36	1.99*	*F* = 3.94, r^2 = .03, *p* = .05
Step 3	IPQ1 Consequence	0.14	0.36	1.53	*F* = 4.25, r^2 = .07, *p* = .02
	Active coping	0.20	0.34	2.11*	**_Z_ = 1.53, _SE_ = 0.10, _p_ = .13**
Step 1	IPQ6 Concern	0.25	0.11	2.85*	*F* = 8.10, r^2 = .06, *p* = .01
Step 2	IPQ6 Concern	0.19	0.40	2.09*	*F* = 4.35, r^2 = .04, *p* = .04
Step 3	IPQ6 Concern	0.14	0.40	1.48	*F* = 4.89, r^2 = .08, *p* = .01
	Instrumental support	0.21	0.32	2.30*	**_Z_ = 1.81, _SE_ = 0.13, _p_ = .07**

Discussion

The goals of this study were to examine if caregiver gains remained stable over time, what factors were concurrently associated with gains and which predicted gains longitudinally. Finally we tested what factors mediate the relationship between predictor variables and gains. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) was used as a conceptual model to guide our analysis and interpretation.

Caregiving motivations were found to remain stable over time and the reported motivations to care also did not change significantly over time. Extrinsic motivations such as fulfilling duty were not related to concurrent gains or prospective gains. Intrinsic motivations such as feeling it is part of your nature to care for others were associated with concurrent gains at T2 and prospectively with gains reported at T3. However this latter relationship was reduced to non significance once prior gain was controlled suggesting that intrinsic motivations to care do not explain the change in reported gains. There has been very little research pertaining to motivations to care and outcomes, however Lyonette & Yardley (2003) found in a cross-sectional study that intrinsic motivations to care were positively related to caregiver satisfaction. Perhaps those individuals who are intrinsically motivated are more willing to provide care and therefore derive more satisfaction from the role thus reporting more gains.

Familism was found to significantly decrease over time and in the cross-sectional data was positively associated with caregiver gains, that is, caregivers with high familism report more gains. Both our cross-sectional and longitudinal analyses found familism to be a strong predictor of gains. Previous literature focusing on familism has mainly examined the relationship between familism and negative outcomes (burden and depression) with mixed results being reported whereby some find familism to have a positive relationship with burden and depression (Zhan, 2006) and others have found it to be a negative correlate of burden (Lai, 2007). The mixed findings of previous studies may be due to the focus on the negative aspects of the role such as burden and depression, perhaps familism has a more significant relationship with the positive aspects of caregiving. Indeed the current findings are supportive of this as familism was a significant predictor of caregiver gains concurrently and prospectively.

Caregiver stressors (i.e. the number of care tasks performed) were concurrently related to caregiver gains (with the exception of instrumental tasks), although in the regression model they did not significantly account for the variance in gains. The number of nursing tasks was a significant positive predictor of gains at T3 that is caregivers reported more gains when they were providing more nursing care. It is of interest that emotional and nursing tasks are positive predictors of gains but instrumental tasks are negative predictors of gains. This may be due instrumental tasks being related to general housework such as cooking and cleaning, therefore may not be perceived as care related gains. It is difficult to compare these findings with previous research as various measures of caregiver stressors have been used and not all studies distinguish between the different types of caregiving. Nevertheless it is perhaps not surprising that the more number of tasks performed by the caregiver (emotional and nursing), the higher the number of reported gains. By spending more time in the role, the caregiver has more opportunity to experience the positive aspects of the role such as satisfaction.

With regards to illness perceptions only the personal control subscale was significantly concurrently associated with gains however its effects did not persist in the longitudinal analysis. In fact only the concern subscale was prospectively associated with gains and even that relationship did not persist in the regression analysis. The inconsistent and lack of significant relationships between illness perceptions and gains has also been reported by previous research. For example Bacon et al (2009) in a study of 4 caregivers of stroke patients found that only perceptions of challenge were significantly associated with a positive care experience. Rapp & Chao (2000) found that neither positive nor negative appraisals were concurrently related to positive affect, although positive appraisals were found to play a significant role in buffering stress. The inconsistent findings suggest that illness perceptions may play a stronger role in patient outcome studies as opposed to caregiver outcomes. Also it has been found that illness perceptions are better able to predict negative caregiver outcomes than positive gains. A number of cross-sectional and longitudinal studies have found that illness perceptions and appraisals play a significant role in caregiver distress (Haley et al, 1987; Goode et al, 1998 & Pakenham, 2001).

Our findings have shown relatively strong effects of coping on the reporting of gains. Active coping, emotional support seeking, behavioural disengagement, positive reframing, acceptance and religious coping were all found to have a significant positive relationship with concurrent gains. Use of substances was negatively related to gains. Self distraction was a negative predictor of gains at T3 but only once previous levels of reported gains had been controlled suggesting that self distraction was related to change in gains reported not the final absolute value of gains. The combination of problem and emotion focused coping methods supports Lazarus' (1991) assertions that coping is a process therefore there is no universally effective or ineffective coping strategy. For example denial in the current study was found to be a significant positive predictor of longitudinal gains (that is change in gains) but was negatively related to gains at baseline. In contrast previous cross-sectional research reports that problem focused coping is related to caregiver gains whereas emotional focused coping was related to strain (Kramer, 1997 & Bacon et al, 2009).

Kim et al (2007) also found that religious coping in particular was associated with greater benefit finding. The current findings support Kim et al (2007) as religious coping was found to be a significant positive predictor of gains at all three time points, accounting for 9% of the variance at T2 and 11% at T3 (along with self distraction and denial). Religious coping and positive reframing were also found to mediate the relationship between familism and gains. Although ethnic differences in religious coping were not explored in the current study, previous studies by Parveen & Morrison (2009) and Parveen, Morrison & Robinson (in press) have found that South-Asian caregiver use religious coping significantly more than White-British caregivers and in the current study were found to significantly report more gains.

Surprisingly neither total support received nor mean satisfaction with support were concurrently related to gains, which contrasts with previous research (Kramer, 1997 & Kim et al 2007). In the longitudinal analysis, had a significant negative relationship with gains at T2 but this only accounted for 1% of the variance. This is an interesting finding given previous research has found that high levels of social support are related to lower burden and depression (Goode et al, 1998; Pakenham, 2001 & Grunfeld et al, 2004). This finding further highlights the theory that positive affect is conceptually distinct from negative affect (Rapp & Chao, 2000) and therefore factors that reduce burden and depression in caregivers may not necessarily increase caregiver gains.

In summary, high familism and religious coping appear to be important predictors of caregiver reported gains. Religious coping appears to mediate the effect of familism on caregiver gains. The current study has a number of strengths and clinical implications. The main strength of the current design is the longitudinal design as much of previous research has been cross-sectional. The Transactional model of stress and coping that many studies make use of as a conceptual model, highlights that stress is a dynamic process therefore a longitudinal design is surely the better test of the model. Although the sample of the study may not be large, it is representative of the caregiver population in the U.K. Caregivers from various geographical locations, diagnosis groups, ethnic and gender groups were recruited and the age of caregivers ranged from 18 to 84 years.

The main implications of the findings are related to the development of time specific interventions, for example illness perceptions of personal control appear to be important to early experience of gains alongside a combination of problem focused (active coping) and emotion focused coping (seeking emotion support). Familism and religious coping appear to be more important in predicting gains over time. Also as caregivers experienced more gains with performing nursing tasks as opposed to instrumental tasks, this suggests that services should focus on providing caregivers with more instrumental support. This would allow the caregivers to spend more time performing tasks that are beneficial to them.

Whilst considering the implications of the findings for developing interventions or services, some limitations need to be addressed. The study contains a relatively modest sample size and achieved a response rate of 31%, however only just over 20% of caregivers dropped out of the study. Nevertheless the sample size and attrition rate appears to be similar to other caregiver outcome longitudinal studies (Goode et al, 1998; Pakenham, 2001 & Molloy, Johnston, Johnston, Morrison, Pollard, Bonetti et al, 2005). Also the small South-Asian group size compared to the

White-British group limits group comparison analysis. Caregivers were primarily recruited from caregiver support groups which may have influenced the findings (although this now appears to be the norm in caregiver research). The study is further limited as an artificial baseline was created, that is caregivers were not recruited from role adoption over a period of nine months. Although it would be of interest for future research to recruit caregivers early on in the care role, this would severely limit the sample size. Despite the limitations of the current study, the findings add to the body of research focusing on positive affect in the caregiver experience and have implications for the development of services and interventions.

Chapter 8

Predicting Caregiver Quality of Life

The material presented in this chapter is currently in review as:

Parveen, S & Morrison, V. Predicting Caregiver Quality of Life. *Psychology and Health.*

Abstract

The current study aimed to examine if changes in familism, illness perceptions, caregiver stressors (number of emotional, instrumental and nursing tasks performed), coping and social support were related to changes in caregiver physical, psychological, social and environmental quality of life. 123 family caregivers completed a questionnaire at three time points: baseline, three months from baseline and nine months from baseline. Independent variables were converted into residual change scores and time 3 absolute quality of life scores were used as outcomes. Demographic factors (ethnicity and care recipient diagnosis) were strong predictors of quality of life in particular physical and environmental quality of life. Early changes in illness perceptions (perceived consequences and emotional representation) and coping (active coping, religious coping and self blame) were predictive of longitudinal quality of life. The findings have implications for the development of interventions to improve quality of life.

Introduction

It is estimated that there are currently over six million caregivers in the UK, a number which is rapidly increasing (Carers UK, 2009). Of the six million caregivers, it is thought that 1.9 million caregivers provide care for 20 hours per week and a further 1.25 million provide care for over 50 hours per week (Carers UK, 2009). The average age of caregivers in the UK is 50 years and the caregiver population is predominantly female (Carers UK, 2009). The General Household Survey (2000) found that 52% of the caregivers were adult children and 18% were spouse caregivers. The assistance provided by caregivers in maintaining patients at home is estimated to save the National Health Service £87 billion per year. A caregiver in this study is described as an individual who provides emotional and/or physical support to a family member or friend who is experiencing difficulties due to physical, emotional and/or cognitive impairments, without financial compensation (Bridges, 1995).

The impact of the care role on the caregiver has been receiving increasing interest from health professionals and researchers. Common models applied to such research has included Karasek’s Demand-Control Model (1979) and the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). The Transactional Model of Stress and Coping in particular has proved to be popular and successful in identifying factors associated with caregiver burden and distress. This model (first adapted by Haley, Levine, Brown & Bartolucci, 1987) to the caregiver experience posits that stress will occur when the caregiver perceives a discrepancy between the demands of the role and the resources they have available to deal with the situation. Specific coping strategies, social support and appraisals mediate the relationship between the stressor and caregiver outcomes (burden or distress).

Offering support to this model, research has found that specific appraisals, coping strategies and use of social support are predictive of caregiver distress. Cross-sectional research (Haley et al, 1987; Brien, 1993; Davis, Hermanson, Koopman, Weibel & Spiegel, 2000), has found that positive (benign and low threat) appraisals, use of problem focused coping and social support were associated with decreased levels of stress and the use of avoidant coping and/or emotion focused coping was related to higher levels of distress. These findings have importantly been supported by longitudinal research which found that benign appraisals, use of approach coping, low reliance on emotion focused coping and high levels of social support was predictive of low depression over 12 months (Goode, Haley, Roth & Ford, 1998; Pakenham, 2001).

More recently, research has focused on the influence of familism (feelings of solidarity and loyalty among family members) on caregiver outcomes in various ethnic groups. It has been consistently demonstrated that Eastern Asian (Chun, Knight & Youn, 2007), South-Asian (Parveen & Morrison, 2009), Hispanic (Losada, Shurgot, Knight et al, 2006) and African American (Shurgot & Knight, 2005) caregivers exhibit higher levels of familism than their Caucasian counterparts. However research examining the relationship between familism and caregiver outcomes has produced conflicting findings. Lai (2007) and Gupta & Pillai (2009) reporting familism to be a negative predictor of burden whereas Zhan (2006) and Gupta (2002) finding familism to be positively associated with burden and depression. More recently Parveen & Morrison (in review) have found in a longitudinal study that familism is a consistent positive predictor of caregiver gains over nine months.

Despite the growing literature on caregiver burden and distress, there has been little research on quality of life as an outcome of caregiving. The concept of quality of life as described by the World Health Organisation (WHO, 1996) suggests that quality of life is an individual's perception of their position based on their culture and is associated with their goals and expectations. The description suggests that quality of life is not simply a health status or mental state but is a subjective evaluation based on a social and environmental context. Although there is an interest among health care professionals regarding quality of life, the majority of research has focused on physical (meta-analysis by Vitaliano, Zhang, Scanlan, 2003) and psychological quality of life. There has been very little research on the other components of quality of life such as social and environmental. Carers UK (2009) found in a recent survey that social isolation was common amongst the caregiver population. Social exclusion was thought to result from the isolating nature of providing care and also from perceived or actual discrimination by service providers. Social isolation has also been found to be associated with poor mental health outcomes in patient populations (Cornwell & Waite, 2009; Hawthorne, 2008 & Friedmann, Thomas, Liu, Morton, Chapa & Gottlieb, 2006).

Studies that have specifically examined the impact of caregiving on quality of life (as opposed to burden and distress) have focused on the following variables: caregiving situation (care recipient's functional status), caregiver factors (age, gender) and environmental factors (social support). Markowitz, Gutterman, Sadik & Papadopoulos (2003) examined health related quality of life in a cross-sectional, but very large sample of 2477 caregivers of an individual with an Alzheimer's disease diagnosis. Poor psychological health in patients, low perceived quality of patient's medication, gender (female) and number of hours caregiving were found to be associated with poorer mental functioning in caregivers but not physical functioning. High levels of social support were related to higher levels of concurrent physical and mental functioning. Martinez-Martin, Benito-Leon, Alonso, Catalan, Pondal, Zamarbide et al (2005) also report similar findings in a much smaller sample of 62 caregivers of Parkinson disease patients; that is the caregiving situation (patient’s functional status) was significantly associated with caregiver health related quality of life. However patient and caregiver demographic factors such as gender and age were not significantly related to health quality of life.

The influence of the caregiving situation, caregiver factors and social support on health related quality of life was further examined in a longitudinal study of 232 caregivers of stroke patients (McCullagh, Brigstocke, Donaldson and Kira, 2005). Increased patient disability, anxiety and depression were found to be associated with poorer quality of life in caregivers over one year. A negative relationship between age (patient and caregiver) and quality of life was also established. Support from social services had, perhaps surprisingly little effect on caregiver quality of life. At three months from baseline (10 days of stroke onset), increased age, male gender and poor patient physical health were important determinants of caregiver quality of life. At 12 months, caregiver depression became an additional correlate of caregiver quality of life.

The current study aims to extend previous research by focusing on caregiver social and environmental in addition to physical and psychological quality of life. Factors previously associated with caregiver burden and distress such as familism, illness perceptions, coping and social support will be examined here in relation to the four domains of quality of life (physical, psychological, social and environmental). In addition variables studied in previous quality of life research are also examined such as caregiver demographic factors (ethnicity, gender and age), and caregiver situation factors (care recipient diagnosis, hours caregiving, years in care role, type and number of care tasks performed per week). A longitudinal design (baseline, three months from baseline and nine months from baseline) is used to examine if early changes in the independent variables are predictive of final quality of life at time 3.

Method

Sample

Full demographic details have been provided elsewhere[12] therefore will only be described briefly here. Caregivers completed all the measures at each time point. 154 caregivers completed a questionnaire at time 1(baseline), 130 at time 2 (3 months from baseline) and 130 at time 3(9 months from baseline). 123 caregivers completed a questionnaire at all three time points and are thus the sample for the current paper.

Of the 123 caregivers, 27 described their ethnicity as British South-Asian and 96 identified themselves as White-British. 82 of the caregivers were female and 41 were male. The average age of the sample was 61.16 years (*SD* = 13.72) and had been providing care for 9.91 years (*SD* = 13.70). Caregivers were providing care for individual with the following diagnoses: Parkinson's disease (*n* = 38), multiple sclerosis (*n* = 33), dementia (*n* = 25), stroke (*n* = 9), cancer (*n* = 5) and other (*n* = 13).

Measures[13]

The questionnaire addressed demographic details such as caregiver ethnicity, gender, age, marital status, employment, relationship to care recipient, care recipient diagnosis, hours per week of caregiving and the number of years in the care role.

The Willingness to Care Scale by Abell (1999) was used to measure caregiver stressors. The measure was originally composed to measure willingness to care in caregivers of individuals with an AIDS diagnosis. The scale in this study was used to measure the number of and types of tasks the caregiver performed in a week. The

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[12] Full demographic details can be found in Chapter 6.

[13] The measures included in the questionnaire can be found in Appendix 5, page 408.

measure consists of three scales: emotional tasks, instrumental tasks and nursing tasks (with 10 items per scale). Caregivers were required to tick each task they performed during the week, this resulted in a final score for the number of tasks they did from each list.

Caregiver familism was measured using the Heller Familism Scale (1976). The measure contains 15 items which are rated on a 5 point likert scale (max score = 60). The measure also demonstrated good internal reliability (α = 0.92).

The brief Illness Perception Questionnaire (brief IPQ) by Broadbent, Petrie, Main & Weinman (2006) was used to assess caregiver illness perceptions. The measure consists of single item scales (rated on an 11 point likert scale, max score = 10 per scale) designed to measure: consequence, timeline, personal control, treatment control, identity, concern, coherence and emotional representation. Although reliability can not be determined for this measure, the revised Illness Perception Questionnaire (IPQ-R) has been established as a reliable measure in previous studies (Hagger & Orbell, 2003).

The brief COPE (Carver, 1997) was used to assess caregiver coping. The measure consists of 14 subscales (each containing 2 items, max score = 8) which include: use of self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religious coping and self blame. Due to each scale only containing 2 items, inter item correlations were calculated to test the reliability of the scales. The inter item correlations ranged from 0.90 (religious coping) to 0.41 (acceptance) and thus demonstrate good reliability.

Caregiver use of social support was measured using the Social Support Questionnaire by Saranson (1983). Caregivers were required to list the amount of support they received and how satisfied they were with each person who supported them on a 6 point likert scale. Two scores are derived from the measure: total support and mean satisfaction with support. Both scales demonstrated good reliability in the current study (total support: α = 0.72 and mean satisfaction: α = 0.84).

The brief quality of life questionnaire by the World Health Organisation (WHO, 2004) was used to assess caregiver quality of life. The measure assesses the four domains of quality of life on a 5 point likert scale. The subscale measuring physical quality of life consists of 7 items (max score = 35) and demonstrated good reliability (α = 0.70). The psychological quality of life subscale contains 6 items (max score = 30) and also demonstrated acceptable reliability (α = 0.60). The social quality of life contains 3 items (max score = 15) and inter item correlation analysis demonstrated good reliability (0.44). The environmental subscale consists of 8 items (max score = 40) and also proved to be a reliable scale (α = 0.77).

Procedure

As the procedure of the study has been described in-depth elsewhere[14], only a brief summary is provided here. Ethical approval for the study was obtained from School of Psychology Research Ethics Committee before data collection commenced. Interested caregiver support groups were sent questionnaire packs (containing a cover letter, information sheet, consent form, a questionnaire and a list of support services) to be handed out to the caregivers. To be eligible for the study caregivers were required to be over the age of 18 years and provide care for a minimum of 7 hours per week. Caregivers completed the questionnaire at home in their own time (with the exception of 13 British South-Asian caregivers who requested the translation aid of the researcher) and returned the questionnaire by free post directly to the first author

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[14] See Chapter 6

(SP). 123 caregivers completed a questionnaire at all three time points and received debrief information. Caregivers who dropped out of the study were compared to those who remained and no significant differences were found in the age, number of hours of caregiving or quality of life.

Data analysis

All data was analysed using SPSSv17. Independent samples t tests were used to compare ethnic and gender group differences in quality of life. One way ANOVAs were calculated to compare quality of life by diagnosis group. Pearson's correlations were conducted to explore the relationship between continuous variables (caregiver age, number of hours caregiving per week and number of years in role) and quality of life scores. Independent variables were converted into residual change scores for period 1 (time 1-time 2) and were correlated with final physical, psychological, social and environmental quality of life at time 3 (nine months from baseline). Separate hierarchical regression analyses were conducted for each quality of life domain. Dummy variables were created for categorical IVs such as ethnicity before being entered into the regression model.

Results

Group differences

As can be seen from Table 1, White-British caregivers had a significantly higher physical quality of life than British South-Asian caregivers at all three time points although physical quality of life did not significantly change over time within either group. No significant ethnic differences were found in psychological or social quality of life at any time point and both domains were stable over time within both groups. White-British caregivers had a significantly higher environmental quality of life than South-Asian caregivers at all three time points. Environmental quality of life did not significantly change over time for White-British caregivers but did for South-Asian caregivers, whereby it was higher at time 2.

There were no significant gender differences in physical, psychological or social quality of life, nor did the three domains significantly change over time for either gender. Although a significant gender difference in environmental quality of life was not found, female environmental quality of life significantly decreased at time 3.

One way ANOVAs were conducted on diagnosis groups and it was found that the groups significantly differed in physical quality of life. Post hoc analysis (due to multiple comparisons, the alpha level was adjusted to $p < .01$) revealed that the multiple sclerosis caregivers had a higher physical quality of life than the other illness caregivers ($p < .01$). At time 3, the MS caregivers had a higher physical quality of life than the dementia and other group ($p < .01$). The only group differences in psychological quality of life was at time 3 whereby the dementia caregivers had lower levels the Parkinson’s disease caregivers ($p < .01$); but there were no group differences in social quality of life. Group differences were found in environmental quality of life with dementia caregivers reporting lower environmental quality of life than the multiple sclerosis caregivers at time 1 ($p < .01$).

Table 1. Descriptive data for demographic groups.

		Ethnicity			Gender			Diagnosis of care recipient						
Quality of life		WB (*n* = 96)	SA (*n* = 27)	T test	Male (*n* = 41)	Female (*n* = 82)	T test	Cancer (*n* = 5)	Stroke (*n* = 9)	Dementia (*n* = 25)	PD (*n* = 38)	MS (*n* = 33)	Other (*n* = 13)	One way ANOVA
Physical	T1 *M*	22.48	19.60		22.70	21.40		19.31	22.27	20.14	22.74	23.16	19.64	
	(*SD*)	(4.67)	(3.64)	-2.96***	(4.05)	(4.83)	1.48	(6.36)	(3.84)	(4.03)	(4.82)	(4.23)	(4.36)	2.55*
	T2 *M*	22.87	19.78		22.81	21.91		18.11	23.54	20.74	23.02	23.84	19.32	
	(*SD*)	(4.33)	(3.93)	-3.29***	(4.09)	(4.57)	1.05	(2.47)	(3.53)	(3.96)	(4.71)	(3.31	(5.36)	4.36***
	T3 *M*	22.56	18.42		22.56	21.18		18.06	22.97	19.53	22.45	23.73	18.64	
	(*SD*)	(4.52)	(4.19)	-4.27***	(5.02)	(4.58)	1.52	(3.16)	(3.35)	(5.42)	(4.45)	(3.84)	(4.45)	4.85***
Within measures ANOVA		1.17	1.93		0.05	0.95		0.31	1.95	1.74	0.18	1.57	0.57	
Psychological	T1 *M*	17.85	18.64		17.17	18.45		22.77	17.07	16.35	19.02	17.11	19.35	
	(*SD*)	(5.52)	(7.25)	0.60	(3.24)	(7.05)	-1.10	(17.11)	(2.86)	(4.30)	(7.35)	(3.63)	(2.58)	1.54
	T2 *M*	17.57	17.97		17.87	17.55		17.80	17.48	16.63	18.06	17.53	18.92	
	(*SD*)	(3.19)	(3.32)	0.57	(2.65)	(3.48)	0.52	(3.40)	(3.22)	(3.31)	(3.17)	(3.48)	(2.12)	1.05
	T3 *M*	17.53	17.17		17.54	17.41		16.33	17.85	15.51	18.22	17.68	18.53	
	(*SD*)	(2.97)	(3.25)	-0.53	(2.84)	(3.13)	0.22	(3.67)	(2.86)	(3.39)	(2.71)	(2.83)	(2.16)	3.34**
Within measures ANOVA		0.50	1.19		1.81	0.53		2.66	0.90	4.21*	0.29	0.91	1.27	

		Ethnicity			Gender			Diagnosis of care recipient						
Quality of life		WB (*n* = 96)	SA (*n* = 27)	T test	Male (*n* = 41)	Female (*n* = 82)	T test	Cancer (*n* = 5)	Stroke (*n* = 9)	Dementia (*n* = 25)	PD (*n* = 38)	MS (*n* = 33)	Other (*n* = 13)	One way ANOVA
Social	T1 *M*	9.10	9.58		8.35	9.64		13.93	7.37	10.67	8.90	8.57	8.44	
	(*SD*)	(7.83)	(7.29)	0.28	(6.08)	(8.40)	-0.87	(16.99)	(3.11)	(10.90)	(6.31)	(6.69)	(2.01)	0.73
	T2 *M*	7.58	8.10		7.59	7.74		7.13	7.48	7.41	8.03	7.44	8.23	
	(*SD*)	(2.04)	(1.54)	1.23	(1.96)	(1.96)	-0.42	(1.64)	(2.82)	(1.42)	(1.98)	(2.13)	(1.79)	0.72
	T3 *M*	7.40	7.88		7.41	7.55		7.13	6.78	7.05	7.93	7.33	8.23	
	(*SD*)	(1.98)	(1.56)	1.16	(1.84)	(1.94)	-0.36	(1.85)	(2.58)	(1.56)	(1.68)	(2.25)	1.40)	1.41
Within measures ANOVA		1.37	1.03		0.81	2.62		0.32	1.93	1.72	0.11	0.77	0.09	
Environmental	T1 *M*	28.64	22.81		28.72	26.65		26.73	26.64	24.01	27.18	30.78	26.01	
	(*SD*)	(7.47)	(4.91)	-3.82***	(8.98)	6.37)	1.47	(3.64)	(4.51)	(4.44)	(4.33)	(11.48)	(5.19)	2.70*
	T2 *M*	27.32	24.34		27.20	26.38		26.45	26.96	24.16	27.68	27.66	25.70	
	(*SD*)	(4.06)	(4.41)	-3.29***	(4.30)	(4.30)	0.98	(4.82)	(3.47)	(4.69)	(3.63)	(4.24)	(4.52)	2.71*
	T3 *M*	27.08	22.88		27.06	25.70		25.48	26.28	24.18	27.06	27.19	24.88	
	(*SD*)	(3.44)	(3.99)	-5.41***	(4.26)	(3.74)	1.81	(3.99)	(3.64)	(4.20)	(3.83)	(3.86)	(3.02)	2.56*
Within measures ANOVA		2.10	4.11*		0.77	3.18*		1.12	1.63	0.26	1.54	1.69	0.68	

Note:

WB = White British. SA = South-Asian. PD = Parkinson's disease. MS = Multiple Sclerosis.

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

Pearson correlation analysis was used to explore the relationship between continuous demographic variables (age, hours and years) with quality of life at time 3. Age was not significantly related to physical, psychological or social quality of life but was significantly associated with environmental quality of life at time 3 ($r = .27$, $p < .01$). However ANCOVA analysis found that once the effect of ethnicity was removed, the relationship between age and environmental quality of life was reduced to non significance ($F = 1.87$, $p = .17$).The number of hours caregiving per week were only significantly related to physical quality of life 2 ($r = -.23$, $p < .01$) as were the number of years in the care role ($r = -.33$, $p < .001$).

Repeated measures ANOVAs were conducted to examine if there was a significant change over time for independent variables and quality of life. (Full descriptive results are presented in a separate paper[15]). As shown in Figure 1, whilst physical and psychological quality of life did not change significantly over time, both social quality of life and environmental quality of life significantly decreased over time (F (2, 118) = 3.46, $p = .04$ and F (2, 118) = 3.09, $p = .05$ respectively). Physical and psychological quality of life scores were found to be moderate but social and environmental quality of life was found to be low in the current sample.

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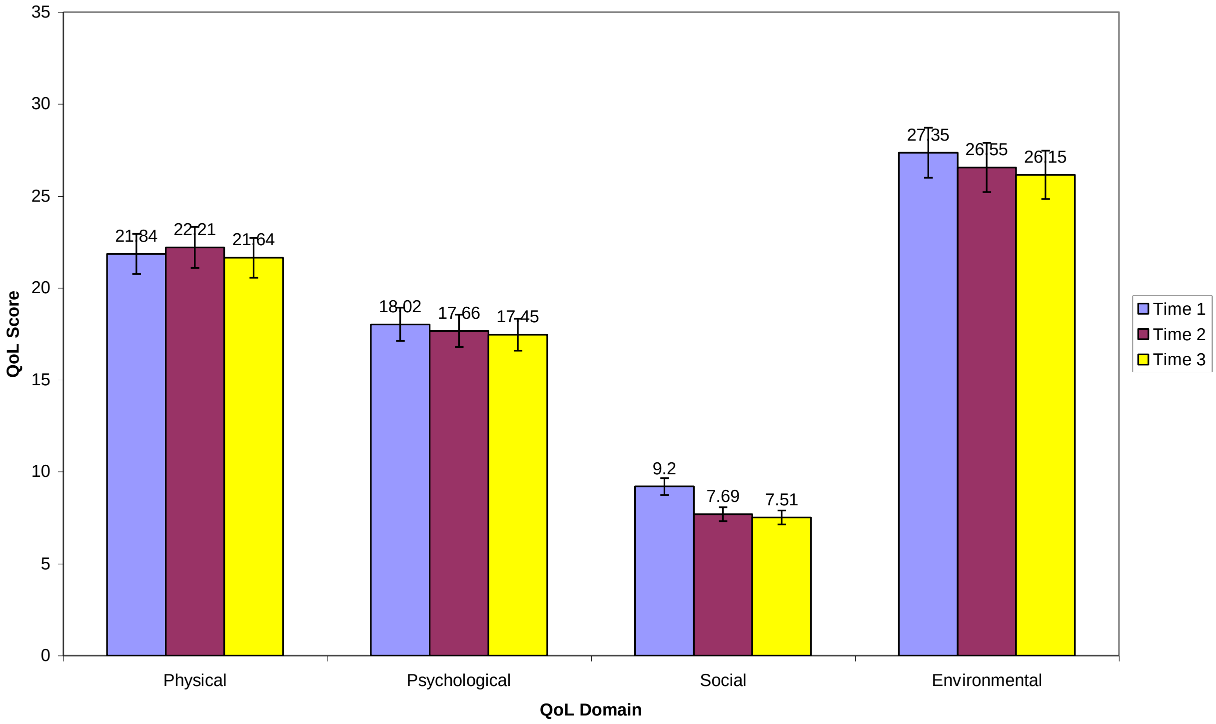
[15] Descriptive results are presented in Chapter 6.

Figure 1. *Mean caregiver quality of life scores over three time points*



Predicting longitudinal physical quality of life

Pearson correlation analysis (presented in Table 2) was used to explore the relationship between residual change in predictor variables during period 1[16] and absolute quality of life at time 3. Only significant relationships were entered into the regression models.

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[16] Data pertaining to late changes in IVs (Period 2) was also analysed but due to statistical limitations it is not included in the paper but can be found in the appendix. Please see page 436.

Table 2. Residual change IV correlations with quality of life at time 3.

IVs (Period 1)	Physical QoL	Psychological QoL	Social QoL	Environmental QoL
Familism	-0.11	0.07	0.06	-0.14
IPQ1 Consequence	-0.12	-0.25**	-0.17	-0.08
IPQ2 Timeline	-0.01	0.01	-0.04	-0.06
IPQ3 Personal control	0.08	0.17	0.07	0.15
IPQ4 Treatment control	-0.13	0.12	0.04	0.07
IPQ5 Identity	-0.05	-0.10	0.06	-0.04
IPQ6 Concern	-0.16	-0.17	-0.01	-0.17
IPQ7 Coherence	-0.16	0.06	0.17	0.03
IPQ8 Emotional representation	-0.18*	-0.14	-0.14	-0.18*
Number of emotional tasks	-0.18	-0.15	-0.05	-0.10
Number of instrumental tasks	-0.18	-0.22*	-0.23*	-0.10
Number of nursing tasks	-0.19	-0.22*	-0.01	-0.06
Self distraction	-0.13	-0.07	-0.05	-0.06
Active coping	-0.20*	-0.01	0.19*	-0.03
Denial	-0.14	-0.25**	-0.14	-0.13
Substance use	0.04	-0.09	-0.19*	-0.01
Emotional support	-0.08	0.02	0.12	0.05
Instrumental support	-0.05	-0.04	0.09	-0.11
Behavioural disengagement	0.07	-0.17	-0.09	-0.10
Venting	-0.16	-0.16	-0.12	-0.03
Positive reframing	-0.14	-0.01	0.10	0.01
Planning	-0.12	-0.16	-0.02	0.02
Humour	-0.13	0.03	0.06	0.10
Acceptance	-0.09	0.05	0.01	0.08
Religious coping	0.18*	0.13	-0.01	0.10
Self blame	-0.06	-0.29**	-0.32***	-0.21*
Total support	-0.04	0.01	0.01	0.10
Mean satisfaction	0.09	0.12	0.19*	0.18*

Note:

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

Early decreases in emotional representations, active coping and an increase in religious coping were found to be significantly related to a higher physical quality of life at time 3. As can be seen from table 3, demographic variables (ethnicity, gender, care recipient diagnosis, hours and years in care role) accounted for a significant 29% of the variance in physical quality of life. Increased physical quality of life during period 1 added a further non significant 0.2% to the model. Decreasing emotional representations during period 1 did not contribute significantly but changes in active coping and religious coping during period 1 accounted for a significant 7% of the variance in physical quality of life at time 3. The final model accounted for a significant 36% of the variance in physical quality of life with ethnicity, diagnosis, high number of years in the care role, increasing use of active coping and decreasing use of religious coping being the strongest predictors of a poorer physical quality of life at time 3. White-British and multiple sclerosis caregivers were found to have the highest physical quality of life.

Table 3. Period 1 IVs predicting Physical QoL at time 3.

	Model 1			Model 2			Model 3			Model 4		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	3.52	0.98	0.31***	3.44	1.00	0.30***	3.37	1.02	0.29***	3.49	0.98	0.31***
Gender	-0.32	0.87	-0.03	-0.33	0.87	-0.03	-0.39	0.89	-0.03	-0.37	0.85	-0.04
Diagnosis	0.91	0.33	0.24**	0.92	0.33	0.24**	0.90	0.34	0.24**	0.89	0.33	0.24**
Hours per week	-0.01	0.01	-0.14	-0.01	0.01	-0.13	-0.01	0.01	-0.12	-0.01	0.01	-0.14
Years in care role	0.23	0.05	-0.38***	-0.23	0.05	-0.38***	-0.23	0.06	-0.37***	-0.23	0.05	-0.37***
Physical qol				-0.24	0.40	-0.05	-0.26	0.41	-0.05	-0.10	0.40	-0.02
IPQ Emotional representations							-0.14	0.42	-0.03	0.03	0.42	0.01
Active coping										-0.84	0.39	-0.18*
Religious coping										1.03	0.38	0.22**
r^2 Change		0.29			0.002			0.001			0.07	
F Change		8.98***			0.35			0.12			5.66**	

Note:

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

Predicting longitudinal psychological quality of life

Early increases in perceptions of illness consequences, the number of instrumental and nursing tasks, as well as increased denial and self blame were significantly associated with a decreasing psychological quality of life at time 3 (see table 2). Hierarchical regression analysis found that demographic variables (ethnicity, gender and diagnosis) accounted for a non significant 4% of the variance in psychological quality of life at time 3. Early increases in psychological quality of life added a highly significant 33% to the model and changes in perceptions of consequences added a further significant 4%. Changes in the number of instrumental and nursing tasks accounted for a non significant 2% of the variance and coping (denial and self blame) added a final non significant 1% to the model. The final model accounted for a significant 44% of the variance in psychological quality of life at time 3. An examination of the beta values reveals that early increasing psychological quality of life and decreasing perceptions of consequences are the strongest predictors of a higher psychological quality of life at time 3.

Table 4. Period 1 IVs predicting Psychological QoL at time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	0.43	0.75	0.06	0.63	0.61	0.09	0.48	0.59	0.07	0.47	0.59	0.07	0.24	0.61	0.03
Gender	0.19	0.66	0.03	0.53	0.54	0.08	0.38	0.53	0.06	0.44	0.53	0.07	0.36	0.53	0.06
Diagnosis	0.50	0.24	0.21*	0.35	0.20	0.15	0.38	0.19	0.16	0.38	0.20	0.16	0.35	0.20	0.15
Psychological qol				1.77	0.25	0.58***	1.71	0.24	0.56***	1.63	0.25	0.53***	1.53	0.25	0.50***
IPQ Consequences							-0.62	0.24	-0.21*	-0.60	0.24	-0.20*	-0.56	0.24	-0.18*
Instrumental tasks										-0.27	0.26	-0.09	-0.25	0.26	-0.08
Nursing tasks										-0.26	0.26	-0.09	-0.20	0.27	-0.07
Denial													-0.23	0.25	-0.08
Self blame													-0.27	0.25	-0.09
r^2 Change		0.04			0.33			0.04			0.02			0.01	
F Change		1.53			51.27***			6.82**			1.76			1.05	

Note:

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

Predicting longitudinal social quality of life

An early increase in the number of instrumental care tasks, substance use and self blame were significantly associated with a decreased social quality of life at time 3. Increased use of active coping and mean satisfaction with social support during period 1 were positively associated with social quality of life at time 3. As can be seen from table 5, demographics (ethnicity, gender and diagnosis) accounted for a non significant 3% of the variance in social quality of life during regression analysis. Increased social quality of life during period 1 accounted for a highly significant 52% of the variance in social quality of life at time 3. Changes in the number of instrumental tasks and coping (active coping, substance use and self blame) added a further non significant 2% and 3% respectively to the model. Changes in mean satisfaction added a final non significant 0.4% to the model with the final model accounting for 60% of the variance in social quality of life at time 3. Early change in social quality of life was the only significant predictor of time 3 social quality of life to emerge.

Table 5. Period 1 IVs predicting Social QoL at time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	-0.43	0.47	-0.10	-0.14	0.32	-0.03	-0.16	0.32	-0.04	-0.30	0.32	-0.07	-0.35	0.33	-0.08
Gender	0.12	0.42	0.03	0.11	0.29	0.03	0.13	0.28	0.03	0.14	0.28	0.03	0.11	0.28	0.03
Diagnosis	0.23	0.15	0.15	0.11	0.10	0.07	0.08	0.10	0.06	0.07	0.10	0.04	0.05	0.11	0.03
Social qol				1.39	0.13	0.73***	1.35	0.13	0.71***	1.28	0.13	0.67***	1.27	0.13	0.67***
Instrumental tasks							-0.24	0.13	-0.13	-0.19	0.13	-0.10	-0.19	0.13	-0.10
Active coping										0.08	0.13	0.04	0.07	0.13	0.04
Substance use										-0.20	0.13	-0.11	-0.20	0.13	-0.10
Self blame										-0.23	0.14	-0.12	-0.20	0.14	-0.11
Satisfaction with support													0.13	0.13	0.07
r^2 Change		0.03			0.52			0.02			0.03			0.004	
F Change		1.17			114.61***			3.71			2.33			1.02	

Note: ****p* < .001

Predicting longitudinal environmental quality of life.

Increased early perception of emotional representations and self blame were significantly negatively associated with environmental quality of life whereas increased mean satisfaction with support was positively associated with environmental quality of life at time 3. Hierarchical regression analysis found that demographic variables (ethnicity, gender, age and diagnosis) accounted for a significant 21% of the variance in environmental quality of life. Early changes in environmental quality of life added a further highly significant 33% to the model. Changes in emotional representations accounted for a non significant 1% of the variance in environmental quality of life. Self blame and mean satisfaction added a non significant 0.1% to the model each with the final model accounting for a significant 55% of the variance in environmental quality of life at time 3. Only two significant predictors of environmental quality of life at time 3 emerged, that is ethnicity (being from a White-British ethnic background) and early increases in environmental quality of life.

Table 6. Period 1 IVs predicting Environmental QoL at time 3.

	Model 1			Model 2			Model 3			Model 4			Model 5		
Predictor (period 1)	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*	*B*	*SE*	*Beta*
Ethnicity	3.85	0.89	0.41***	3.15	0.69	0.33***	2.98	0.70	0.31***	2.92	0.72	0.31***	2.93	0.72	0.31***
Gender	-0.02	0.76	-0.002	-0.23	0.59	-0.03	-0.36	0.59	-0.04	-0.37	0.60	-0.04	-0.36	0.60	-0.04
Age	0.03	0.03	0.10	0.02	0.02	0.07	0.02	0.02	0.07	0.02	0.02	0.07	0.02	0.02	0.07
Diagnosis	0.26	0.28	0.08	0.26	0.21	0.08	0.25	0.21	0.08	0.24	0.21	0.08	0.24	0.22	0.08
Environmental qol				2.29	0.26	0.58***	2.27	0.26	0.57***	2.26	0.26	0.57***	2.26	0.27	0.57***
IPQ Emotional representations							-0.33	0.27	-0.08	-0.33	0.27	-0.08	-0.33	0.27	-0.08
Self blame										-0.15	0.27	-0.04	-0.16	0.27	-0.04
Satisfaction with support													-0.06	0.28	-0.01
r^2 Change		0.21			0.33			0.01			0.001			0.0001	
F Change		7.50			77.2			1.55			0.31			0.04	

Note:

*** $p < .001$

Discussion

The aim of the current study was to examine if early changes in familism values, illness perceptions, coping and social support were associated with longitudinal absolute physical, psychological, environmental and social quality of life of caregivers. As with previous research examining caregiver quality of life, demographic factors (ethnicity, diagnosis and the number of years caregiving) emerged as strong predictors of physical and environmental quality of life.

Significant ethnic differences were found in physical and environmental quality of life at all three time points. White-British caregivers had significantly higher physical and environmental quality of life than South-Asian caregivers. This is an interesting finding as quality of life in the South-Asian caregiver population has received little attention and the domain of environmental Qol, which addresses access to health services, safety of living conditions, availability of transport and information perhaps relate to possible social inequities. It is surprising that South-Asian caregivers perceived a significantly lower physical quality of life than White-British caregivers despite being significantly younger as it would be presumed that older caregivers would experience a decline in physical health (McCullagh et al, 2005). This finding should be interpreted with caution as the South-Asian group only contained 27 caregivers in comparison to 96 White-British caregivers. However previous research has also found that ethnicity is a significant predictor of all four domains of quality of life (Utsey, Chae, Brown & Kelly, 2002).

No significant ethnic difference in psychological quality of life was found which is surprising given previous evidence (see meta-analysis by Pinquart & Sorensen, 2005) where caregiver distress levels differ by ethnic groups, however in this study we adopt a psychological quality of life scale and not a specific assessment of a psychological disorder such as anxiety or depression, as is the case in the majority of the studies included in the meta-analysis, thus ethnic groups may differ in mood states, but not in subjectively evaluated quality of life.

We did consider whether the ethnic group differences found were confounded by the effect of age as White-British caregivers were significantly older than the South-Asian caregivers, however age was not found to be significantly related to change in physical quality of life but was positively associated with change in environmental quality of life, whereby older caregivers experienced a better environmental quality of life. These findings are consistent with Mercier, Peladeau & Tempier (1998) who also found in a sample of 165 people with mental illness that older people had a better quality of life than younger people and were more satisfied with their living conditions. This may be due to the aging process facilitating the social integration process or perhaps lower expectations of older people.

The current study found no significant gender differences in quality of life, which is surprising when compared to findings reported elsewhere. For example, Hagedoorn, Buunk, Kuijer, Wobbes & Sanderman (2000) report data from 173 couples dealing with various forms of cancer and a control group of 80 couples, and find female caregivers to have a lower quality of life than female controls and male caregivers. McCullagh et al (2005) in a sample of caregivers of stroke patients found that male caregivers had a lower quality of life compared to female caregivers. Mercier et al (1998) concludes that studies of the general population samples have found that gender has little influence on quality of life, which is consistent with the current findings. The gender differences in quality of life reported previously may be due to an influence of care recipient diagnosis, for example a caregiver providing care for an individual with cancer will experience different demands compared to those caring for and individual who has had a stroke.

Indeed the most significant demographic predictor of change in quality of life appeared to be the care recipient's diagnosis (particularly in physical quality of life). Caregivers of individuals with a multiple sclerosis diagnosis had the highest physical quality of life in comparison to the other groups; whereas dementia caregivers had low physical, psychological and environmental quality of life. It is not surprising that diagnosis was a strong predictor of quality of life as previous research in caregiver quality of life (Markowitz et al, 2003; Martinez-Martin et al, 2005 & McCullagh et al, 2005) has consistently found that the patients functional status (which included level of physical disability, age and mood) is related to caregiver health related quality of life. Due to the considerable physical and psychological demands of providing care for an individual with dementia, this would suggest that these caregivers would have the lowest quality of life.

Caregiver familism was found to decrease significantly over time in the current study. There is little if any research examining if familism is a stable construct, however as familism is a cultural value, it is possible for it to be amenable to change as culture is a dynamic entity which changes as individuals interact with the environment in new ways (Henry & Schott, 1999). Changes in familism were not however significantly related to quality of life in the current study. There has been very little research (if any) exploring the relationship between familism and caregiver quality of life and previous evidence of an association between familism caregiver burden and distress has produced mixed findings. Familism may not have a direct effect on caregiver outcomes but its influence may be mediated by coping and use of social support; however it was not possible to test for mediation in the current study due to data not meeting statistical requirements.

Changes in the number of emotional, instrumental and nursing tasks were not strong predictors of quality of life, however an increase in instrumental and nursing tasks was related to a poorer psychological quality of life and increased number of instrumental tasks was also significantly associated with a low social quality of life at time 3 (however they were not significant predictors in the final regression model). It is perhaps not surprising that the increased number of instrumental tasks would be related to a low psychological and social quality of life as the increasing demands may lead to the caregiver to perceiving high levels of burden and also a decreasing amount of time available to socialise with other people. Previous research (Markowitz et al, 2003; Martinez-Martin et al, 2005 & McCullagh et al, 2005) has found that amount of caregiving (usually measured as hours) is negatively associated with quality of life. In the current study the number of hours caregiving per week were a negative predictor of only physical quality life.

With regards to illness perceptions, and consistent with what one would hypothesise, decreasing perceptions of emotional representations were related to higher physical and environmental quality of life. That is caregivers who increasingly perceived the care recipient to be more emotionally upset by the illness experienced a lower physical and environmental quality of life longitudinally. This is consistent with earlier discussion regarding the influence of care recipient’s functional status (including care recipient mood) on caregiver quality of life. However it should be noted that only changes in perceptions of illness consequences were significant predictors of psychological quality of life. Decreasing perceptions of illness consequences were found to be related to a higher psychological quality of life. The current findings suggest that early changes in illness perceptions have a limited role in predicting quality of life in caregivers. However previous research which has examined absolute (as opposed to change) scores of illness perceptions have found that illness perceptions are consistently related to quality of life in particular among patient populations (Covic, Seica, Gusbeth-Tatomir, Gavrilovici & Goldsmith, 2004). We chose to examine the influence of changes in illness perceptions on quality of life as the theoretical model used in the current (the Transactional Model of Stress and Coping, Lazarus & Folkaman, 1984) is dynamic and there is also a limited amount of research examining illness perceptions in relation to quality of life in caregiver populations.

Changes in active coping and religious coping were found to be strong predictors but only in relation to physical quality of life. Interestingly a decrease in active coping was predictive of a higher physical quality of life. This may be due to caregivers becoming involved in too many care activities thus leading to burn out. Increased use of religious coping was found to be predictive of a high physical quality of life. Although increases in denial and self blame were found to be negatively related to psychological quality of life they were not significant predictors. An increase in the use of substances and self blame were predictive of decreasing social quality of life and increasing self blame was also a negative predictor of environmental quality of life. Although changes self blame emerged as significantly related to psychological, social and environmental quality of life, it was not a significant predictor in the final models. Active coping is generally considered as an adaptive coping method but the current study found it to be predictive of deteriorating physical quality of life. This supports Lazarus' (2000) claim that no coping strategy is adaptive or maladaptive and different methods can be used interchangeably to deal with a stressor. The influence of religious coping on patient quality of life has been examined previously with results suggesting that use of religious coping was associated with better health quality of life in cancer patients (Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet, & Prigerson, 2007). Religious coping has also been found to be related to caregiver gain (Parveen & Morrison, in review), which would suggest that increased use would lead to an improved quality of life. The current findings are thus consistent with the previous research and further suggest that these effects are maintained longitudinally.

In summary caregiver's illness beliefs (consequences), ethnicity and care recipient diagnosis appear to be consistent predictors of change in quality of life; however the current study has a number of limitations which need to be noted. The study experienced a low response rate (31%) which resulted in a fairly small final sample (*n* = 123), however almost 80% of those caregivers who participated at baseline remained in the study to complete all three time points. Also all of the caregivers were recruited through the use of caregiver support groups which may have biased the results e.g. the caregivers in a support group may have been more distressed than non support group caregivers. Although ethnic and diagnosis group differences in quality of life were found, these findings should be interpreted with caution as the groups differed in size (i.e. only 27 of the caregivers were South-Asian and the cancer group only consisted of 5 caregivers). Furthermore the ethnic groups significantly differed in age (although the difference in care providing hours and years was not significant) which may have influenced the results. The study also requires replication with a larger sample as the current sample did not allow us to examine the influence of late changes in caregiver processes on quality of life. It is also important to note that an artificial baseline was used, that is caregivers were not necessarily new to the role and so called early changes discussed in the study may not actually be early changes in real time. Finally although some variables such as familism were not found to be associated with change in quality of life in the current study, a relationship between absolute familism values and absolute quality of life may exist but was not examined in the current study.

Despite the above limitations, the current study has a number of strengths and implications for intervention development. Previous caregiver research has primarily focused on psychological quality of life or general health related quality of life and assessed independent variables as static phenomenon which is inconsistent with theory as caregiver variables are a shifting experience and thus we selected to study change in predictor variables. The current study further extends on this research and also examines social and environmental quality of life. Despite the small South-Asian group size, the study highlights that important ethnic group differences exist and further research is required in this population. Research focusing on ethnicity and caregiver quality of life is important as it has implications for planning health services and also for identifying reasons for the differences in health among the ethnic groups.

The current study also extends on previous caregiver quality of life by going beyond caregiver situation factors, caregiver demographic factors and environmental factors and exploring the effect of familism, illness perceptions and specific coping strategies on longitudinal quality of life. The focus on change in predictor variables enables the development of time specific interventions aimed to improve caregiver quality of life. The results of the study suggest that early illness perceptions (consequences and emotional representations) were important predictors of later quality of life. Caregivers in the current study had high perceptions of consequences and emotional representations and low treatment control suggesting these would be key illness perceptions to target in early psycho-educational interventions. Furthermore although changes in self blame were not significant predictors of quality of life they were related to psychological, social and environmental quality of life suggesting that this is another variable that caregiver interventions should aim to reduce through education. The current findings also provide a basis for developing intervention programmed aimed at improving specific domains of quality of life.

Chapter 9

Methodological Discussion

Methodological Discussion

The results from the longitudinal questionnaire study are presented as three separate chapters: caregiver anxiety and depression (Chapter 6), caregiver gains (Chapter 7) and caregiver quality of life (Chapter 8). As the study was presented in a series of journal articles, methodological discussion was somewhat limited. The current chapter aims to address the methodological issues which arose during the study in further detail prior to the general discussion of the PhD research which is presented in Chapter 10. The main focus of this discussion will be the (pre data collection) justification of the measures employed in the longitudinal questionnaire study followed by a "post data collection" reflection on the performance of the measures used. Finally a discussion of the data analysis plan will be presented which will include details pertaining to the underlying analytic strategies and the statistical limitations that arose during the analysis stage.

Justification of Measures

Familism:

Ramos (2004) describes familism as the root of caregiving (discussed in Chapter 1) and there are a number of different measures available to explore the various aspects of familism; for example filial piety, felt responsibility and filial obligation. Much of cross-cultural research has been conducted using Hispanic and Eastern Asian caregivers therefore it is not known what specific aspect of familism South-Asian caregivers ascribe to. This suggests that a broad global measure of familism would be appropriate to use with South-Asian caregivers. The two most widely used measures of familism include the Bardis Familism Scale (1959) and the Heller Familism Scale (1976). The Bardis Familism Scale contains 16 items measured on a 5 point likert scale and has proven to be a reliable measure (Chun, Knight &

Youn, 2007; Youn, Knight, Jeong & Benton, 1999). The Heller Familism Scale contains 15 items (very similar to the Bardis Scale) also measured on a 5 point likert scale. The Heller familism scale was originally developed in 1970 and after much cross validation procedures (described in Heller, 1976) a modified version was released in 1976. The Heller Familism Scale has been widely used and proved to be a reliable measure (Killian & Ganong, 2002). The Heller Familism Scale will be used in the longitudinal questionnaire study due to accessibility issues.

Reflection:

The Heller Familism Scale was successfully utilised in the study with only three caregivers unable to complete it fully. The scale demonstrated good internal reliability at all three time points (Time 1 $\alpha = 0.93$, Time 2 $\alpha = 0.93$ and Time 3 $\alpha = 0.92$). Item 15 of the measure “If a person’s father has a medical bill of $1500, which he can not pay, the son is morally obligated to pay the debt” was modified (change of currency) for a UK sample. It was expected that this item may cause problems as the UK has a National Health Service and caregivers would not be expected to pay huge medical bills, however no problems emerged with this item. As with most measures, a validated translated version of this measure was not available in the required languages (Welsh, Urdu, Hindi, and Bengali). Currently the measure is being validated in Spanish and Portuguese.

Knight & Sayegh (2010) highlight that familism is a multidimensional construct and that using local cultural values in caregiver research may be a more useful strategy than taking the global construct familism and applying it across cultures. This raised the questions as to which specific cultural value should be examined within the South-Asian caregiver population (for example filial piety, that is respect for your elders, is a commonly held value amongst Eastern Asian caregivers as is felt responsibility amongst Hispanic caregivers). The research presented in this thesis (specifically Chapter 4) suggests that family obligation may be more relevant to British South-Asian caregivers. As cultural values within the South-Asian caregiver community have not been previously examined, using the global measure of familism was appropriate.

Motivations to care:

During the focus group study (see Chapter 4) it emerged that caregivers were motivated by diverse factors to provide care. As family obligation is only one motivation to provide care, the Heller Familism Scale (1976) would not be an adequate measure of motivations to care and a broader measure would be required. A recent systematic review (1960-2008) by Quinn, Clare & Woods (2010) identified only four studies that examined motivations to care of which two measured filial obligation/expectancy (forms of familism) and the remaining two developed their own scales. Carruth (1996; as cited by Quinn et al 2010) developed a Motivating Factors Index which contained three subscales including: obligatory feelings, family loyalty and avoiding nursing homes. Kabitsi & Powers (2002; as cited by Quinn et al 2010) used the Spousal Motivations to Care Inventory, which consists of 18 items on a likert scale and further open ended questions. Although this measure explores a more diverse range of motivations than the Motivating Factors Index, it is a complex measure and perhaps not suitable for a sample with limited English language ability.

A simpler measure of motivations to care was found known as the Motivations in Elder Caregiving Scale (MECS) developed by Lyonette and Yardley (2003). The measure consists of two subscales exploring extrinsic motivations (The elderly person expected me to care for him/her) and intrinsic motivations to provide care (Caring for the elderly person is a way of living up to my principles). It is suitable for use across diverse caregiving contexts. It has been developed using an inductive interview based approach and has demonstrated good internal reliability (EMECS α = 0.84 and IMECS α = 0.77). Although this is a relatively new measure it appears to be the most appropriate to use with the current sample as it is short (13 items on a 5 point likert scale) and easy to complete in comparison to the Motivating Factors Index and the Spousal Motivations to Care Inventory.

Reflection:

This measure was not incorporated into the questionnaire until Time 2 (there was some overlap between the analysis of the qualitative data and the development of the questionnaire). The measure had to be amended in that that the word “elderly” was replaced with “care recipient”. This is due to the caregivers in the current study providing care for individuals with a range of diagnostic conditions and not simply the elderly. The measure appeared to work well within the study, again demonstrated by the lack of missing data. Both the EMECS (Time 2 α = 0.77 and Time 3 α = 0.81) and IMECS (Time 2 α = 0.87 and Time 3 α = 0.74) demonstrated good internal reliability over time. The MECS is currently only available in the English language and had to be informally translated to caregivers.

Illness perceptions:

Leventhal’s Self Regulation Model (1984) proposes that patient’s perceptions of illness are based on five distinct components (identity, cause, timeline, cure/control, and consequences) which in turn influence coping. The original Illness Perception Questionnaire (IPQ) developed by Weinman, Petrie, Moss-Morris and Horne (1996) is theoretically bound and provides a quantitative assessment of the five components of illness perceptions. The IPQ has been found to be psychometrically sound, and is considered flexible as it can be used with diverse populations.

Later the revised Illness Perceptions Questionnaire (IPQ-R) was developed by Moss-Morris, Weinman, Petrie et al (2002) to further improve the measurement properties of the existing scales specifically the cure/control subscale. The cure/control subscale was found to demonstrate low internal consistency in previous research and was thus split to create two separate subscales. The timeline subscale was also extended and now included items assessing perceptions of a cyclical timeline (which were overlooked in the original IPQ). The Self Regulation Model (Leventhal, 1984) suggests that in response to illness, people develop cognitive and emotional representations which give rise to problem and emotional focused coping. The original IPQ was designed to only assess the cognitive components of illness representations and this was felt to be a limitation in its capacity to describe the patient's response to illness. This led to the addition of an emotional representation subscale in the IPQ-R. Finally to also assess the extent to which the patient's illness representation provided a coherent understanding of the illness led to the development of an illness coherence subscale. The final IPQ-R although found to be a reliable and valid measure (Hagger & Orbell, 2003) was found to be a lengthy and time consuming measure as it includes over 80 items.

The brief IPQ (Broadbent, Petrie, Main & Weinman, 2006) uses a single item scale approach to assess perceptions on a continuous linear scale. The measure consists of nine subscales (consequences, timeline, personal control, treatment control, identity, concern, coherence, emotional representations and cause). The causal subscale requires participants to list the top three factors that they perceive caused the illness (such as environment, genetics, diet). The brief IPQ has been found to have good test re-test reliability and concurrent validity. The brief IPQ will used in the current study as it is short and simple to complete, provides a rapid assessment of illness perceptions and thus suitable for a population with limited English language ability.

Reflection:

The brief IPQ was found to be suitable for the sample used in the current study and again there was very little missing data. The only subscale found to be problematic was the causal subscale. Unlike the other subscales in the measure, this question was open ended and caregivers were required to list the factors they perceived to have caused the care recipient’s illness. Most caregivers did not complete this scale resulting in large amounts of missing data thus the scale was dropped from subsequent analyses.

Recently there has been much debate pertaining to the validity of the brief IPQ. Van Oort, Schroder & French (2011) have suggested that the brief IPQ lacks content validity as the measure was formed by combining items from the IPQ-R into a single item. The aim of content validity is to assess the extent to which the measure examines all aspects of the construct which may not be possible to do with a single summary item. Van Oort et al (2011) also suggest that the measure assesses the strength of the illness representation and not the actual content. They aimed to assess the content validity of the brief IPQ using a cognitive interviewing approach whereby 45 participants “thought aloud” whilst completing the measure. 88 problems were identified during the study with the main problem identified as participants having to reread a question or stumbling whilst reading it. Van Oort et al (2011) suggest that the brief IPQ be developed further and at least five items should be used to assess each scale. Broadbent, Kaptein & Petrie (2011) have criticised the Dutch study and propose that Van Oort et al (2011) used the incorrect instructions whilst administrating the measure and the items were incorrectly translated. Furthermore the participants included in the study did not have an established illness diagnosis.

The IPQ-R would perhaps have been a better measure of illness perceptions, however the brief IPQ worked well in the current study with no caregivers reporting any problems with the measure (with the exception of the causal subscale). The questionnaire used in the current study was 24 pages long and caregivers were required to complete it over three time points thus a lengthier measure of illness perceptions would have been inappropriate for this sample. Although the brief IPQ has been validated in a number of languages, it was not available in the languages required for this sample and was informally translated.

Willingness to care:

A search of the literature revealed that as with motivations to care, there are very few studies that have explored willingness to care in a quantitative manner. A study by McKee, Whittick, Gilhooly et al (1999) aimed to examine willingness to care in 228 family caregivers of elderly individuals (50% of whom had been diagnosed with dementia) using the Gilhooly (1986) Willingness to Care measure. The measure contains seven open ended questions yielding qualitative data. Based on the caregiver’s responses, the researcher is then required to rate on a 7 point likert scale how willing they perceive the caregiver to be. This is a complex and time consuming measure and may not produce reliable data as it is the researcher’s perception of how willing the caregiver is and not the caregiver’s perception.

An alternative measure of willingness to care has also been developed by Abell (2001). The Willingness to Care Scale (WtCS) is a multi-factorial measure assessing the experience of informal caregivers of persons living with AIDS. The WtCS assesses the caregiver’s views on their own capacity to care for another across three domains: emotional, instrumental and nursing willingness to care. The scales have been found to demonstrate good internal reliability (Emotional scale $\alpha = 0.88$, Instrumental scale $\alpha = 0.84$ and Nursing scale $\alpha = 0.92$).

Reflection:

In the current study the WtCS was considered too complex and time consuming by the caregivers, which resulted in large amounts of missing data. The instrumental scale in particular appeared to be problematic for caregivers as many of the tasks listed in this scale were considered as “normal everyday tasks.” The caregivers in the current study were mainly providing care for a family member therefore having the care recipient live with them; cooking and cleaning were not considered care tasks. The willingness to care aspect was therefore dropped and the measure was used instead to identify the number of and types of tasks the caregiver performed in a week.

The scales were found to have good internal consistency at Time 1 and Time 3 (that is above 0.70) but during Time 2 demonstrated poor internal reliability (Emotional scale $\alpha = 0.37$, Instrumental scale $\alpha = 0.36$ and Nursing scale $\alpha = 0.70$). Translating the measure informally was also found to be problematic in particular the emotional subscale was found to be difficult as distinguishing between the 10 very similar items was complex. The measure has been validated into the Spanish language and also converted to assess the patient’s beliefs that they are able to provide care for themselves. The difficulties experienced with this measure suggests that perhaps willingness to care should be assessed through qualitative means in future research as the current measure appears to be too complex and time consuming for caregivers.

Coping

There are currently several measures available that explore either coping styles (personality traits) or coping processes. Lazarus (1991) suggests that there are three main factors when studying coping processes:

1. There is no universally effective or ineffective coping strategy.
2. When measuring coping responses, describe what the person in thinking and doing at each stage and the context which this occurs (a longitudinal design is recommended).
3. There are two major functions of coping: problem focused coping (coping actions are directed at the stressor) and emotional focused coping (regulation of emotions caused by the stressful environment).

Lazarus (1991) proposes that research should focus on coping as a process as opposed to a trait for several reasons mainly that coping processes are more amenable to change through interventions.

Folkman & Lazarus (1985) devised a coping checklist based on measuring coping processes. The Ways of Coping Checklist (WCC) contains a broad range of coping and behavioural strategies that people use to manage internal and external demands in a stressful encounter. The WCC consists of 8 scales (confrontive coping, distancing, self control, seeking social support, accepting responsibility, escape/avoidance, planful problem solving and positive reappraisal) and a total of 66 items.

Another coping measure that has proved popular in caregiver studies is the Coping Responses Inventory (CRI) developed by Moos (1988). This measure also assesses eight domains of coping: logical analysis, positive reappraisal, seek guidance and support, take problem solving action, cognitive avoidance, acceptance/resignation, seek alternative rewards and emotional discharge. The eight domains of coping are measured by six items per domain with a total of 48 items. Although both the WCC and the CRI have been found to be reliable and valid measures of coping, they are lengthy. Also the items within the measures have been derived through empirical means as opposed to theoretically. That is items were chosen initially as being representative of potential coping responses not because they represent theoretically interesting categories of coping (Carver, Scheier & Weintraub, (1989).

The COPE inventory developed by Carver et al (1989) is based on the Transactional Model of Stress and Coping (Lazarus, 1984; discussed in Chapter 1 and the main theoretical framework for this research). The COPE consists of 15 subscales with 4 items per subscale measured on a likert scale (total of 60 items). Although this measure was developed through theoretical means and includes a diverse range of coping strategies, it is inappropriate for the sample in the current study due to its length. A briefer version of the COPE has been developed by Carver (1997) which contains two items per subscale, with a total of 28 items. As well as the reduction in the number of items, a number of scales were renamed, the scale restraint coping was removed and the self blame scale was added. This is a widely used measure in Health Psychology and has been found to be psychometrically sound and would be the most suitable measure for the current sample.

Reflection:

The measure appeared to perform well in the current study with no reported problems from the caregivers. As each scale only contains two items, inter item correlations were calculated to test internal consistency. Briggs and Cheek (1986; as cited in Pallant, 2003) recommend an optimal range of 0.20 to 0.40 for inter item correlations. In this study the inter-item correlations ranged from 0.28 (self blame) to 0.90 (religious coping).

Many studies (Pakenham, 2001; Goode, Haley, Roth & Ford, 1998 and Haley, Levine, Brown & Bartolucci, 1987) have been found to focus on emotion and problem focused coping as opposed to the full range of coping strategies (perhaps to reduce the number of variables). In the current study the sample size (n = 123) was found to be too small for factor analysis. Tabachnick & Fidell (2007) recommend a minimum of 10 participants for each IV suggesting that a minimum sample of 140 caregivers would be required to conduct factor analysis on the brief COPE. Furthermore the strength of the inter item correlations (i.e. self distraction, behaviour disengagement, denial) was below the recommended 0.30. Although reducing the number of variables in the brief COPE would be useful for hierarchical multiple regression, in the current study we were able to study the diversity of coping responses and their association with caregiver outcomes.

Social Support

During the systematic review (see Chapter 2) it emerged that although a number of studies included a measure of social support, it was difficult to compare results as many did not make use of a validated measure. A number of studies devised their own social support measure by including an item asking how much support the caregiver received. Two basic elements were found to be measured in these studies including total number of support and satisfaction with support. The Social Support Questionnaire (SSQ) developed by Sarason, Levine, Basham & Sarason (1983) assesses both total support and satisfaction with support. The SSQ has been validated and found to be a reliable measure and has been used with caregiver populations (Goode et al, 1998). The SSQ requires the caregiver to list the number of people that they receive support from and then rate on a likert scale how satisfied they are with the support received from each person. This results in the formation of two subscales: total social support (SSN) and mean satisfaction with the social support (SSS). The measure is fairly simple to complete and thus suitable for the current sample.

Reflection:

The SSQ was found to be a reliable measure in the current study and no problems were reported by the caregivers. For the total support subscale, Cronbach alphas were found to be 0.72 at Time 1, 0.45 at Time 2 and 0.72 at Time 3. The satisfaction with support subscale was also found to be reliable over time with Cronbach alphas of 0.85 at Time 1, 0.81 at Time 2 and 0.84 at Time 3. The measure was simple to translate and caregivers found it undemanding to complete.

Anxiety and Depression

Many cross-cultural caregiver research studies focus on burden as the main outcome using the Zarit Burden Interview (1980). The Zarit Burden Interview is a 22 item scale which taps into three main factors including embarrassment/anger, reaction to patient dependency, and self criticism. During the focus group study (see Chapter 4) it emerged that caregivers were opposed to the use of the word burden within the care context and did not want to discuss burdens associated with the care role. It was therefore decided that a general clinical outcome measure (such as anxiety or depression) that was not specific to caregiving would be more appropriate for the current sample.

The majority of the studies included in the systematic review (Chapter 2) were found to assess caregiver anxiety and depression using separate measures. The State Anxiety Scale by Spielberger (1985) was found to be a popular measure of anxiety whereas the Centre for Epidemiologic Studies Depression Scale by Radloff (1977) was mainly used to assess depression. Both measures contain 20 items each and would be considered burdensome by the caregivers in the current study. An alternative measure is the Hospital Anxiety and Depression Scale (HADS) developed by Zigmond and Snaith (1983). This measure assesses both anxiety and depression using 14 items on a likert scale. It has successfully been used with caregiver samples and has been consistently found to be a reliable measure with a Cronbach's alpha of 0.88 for the depression scale and 0.90 for the anxiety scale (Iconomou, Viha, Kalofonos et al, 2001).

Reflection:

Although the measure is relatively short (14 items), it was found to be a challenge to translate informally. The two main items that caused problems during translation included "I get a sort of frightened feeling as if something awful is about to happen" and "I get a sort of frightened feeling like butterflies in the stomach". The two items are quite abstract and were difficult to explain. Interestingly the White-British caregivers also experienced problems, particularly with the item "I feel as if I am slowed down". As the White British caregivers were much older than the South-Asian caregivers, they perhaps considered "slowing down" as a normal part of the aging process. The difficulties with translating this measure highlight the need for further research in validating measures with different cultural populations. Despite the translation problems the HADS was found to have good internal reliability across the three time points. The anxiety subscale achieved a Cronbach's alpha of 0.81 at Time 1, 0.85 at Time 2 and 0.87 at Time 3. The depression subscale also performed well with a Cronbach's alpha of 0.80 at Time 1, 0.82 at Time 2 and 0.83 at Time 3.

Caregiver Gains:

During the focus group study (Chapter 4), it was found that many caregivers were keen to discuss the positive aspects of the care role that is, what they had gained from the role. This suggested that the questionnaire study should also contain a gains measure as opposed to only focusing on the negative outcomes of caregiving. There has been some debate concerning the nature of caregiver gains with some studies focusing on caregiver gains as a coping process (Pakenham, 2005) or as an outcome (Kramer, 1997 and Kim, Schulz & Carver, 1997). In the case of caregiving (which is considered as an ongoing stressor), caregiver perceived gains can be considered as a coping process or as an outcome (Pakenham, 2005). In the current study, caregiver gains will be assessed as an outcome.

The Benefit Finding Scale (BFS) developed by Mohr, Dick, Russo et al (1999) has been found to be commonly used with caregivers and patients. The scale was originally developed from interview data with 50 patients with a multiple sclerosis diagnosis. The BFS contains 19 items which are scored on a 5 point likert scale. The scale assesses two main domains of benefit finding: personal growth and family relations growth. The items of the scale are specific to the MS population and would require modifications prior to being implemented in the current multiple diagnoses sample.

An alternative scale which would not require modifications is the caregiver GAINS scale developed by Pearlin (1988). This is a 10 item measure developed on a sample of caregivers of an individual with Alzheimer's disease. The items are measured on a 4 point likert scale and the items are summed for a total score (possible score 0-30). The scale has been reported to be psychometrically sound with Chen and Greenberg (2004) reporting a Cronbach's alpha of 0.91. As the caregiver GAINS is the shorter of the two measures and would not require any modifications to be made, the GAINS will be used in the questionnaire study.

Reflection:

This GAINS scale was found to be a reliable measure with Cronbach's alphas of 0.87 at Time 1, 0.89 at Time 2 and 0.86 at Time 3. Caregivers did not report any problems with completing this measure and there was very little missing data. The measure was only available in the English language but was found to be simple to translate. Interestingly only 112 (out of 123) caregivers completed the GAINS. This may be caused by "questionnaire fatigue" that is although the scale was short and easy to complete, the questionnaire was long and time consuming, and the GAINS measure was located near the end of the questionnaire.

Quality of Life (QoL):

Quality of life has been defined as an individual's perception of their position based on their culture. Quality of life is not simply a health (physical or mental) status but is based on a subjective evaluation of the environmental and social context (World Health Organisation, 1996). Although the literature on caregiver burden and distress is growing, research on caregiver quality of life remain somewhat limited. The systematic review (Chapter 2) found no studies that included a measure of quality of life, suggesting that further research should also assess quality of life.

Studies that have assessed quality of life in caregivers (Jonsson, Lindgren, Hallstrom et al, 2005; Ekwall, Sivberg & Hallberg, 2004 and Markowitz, Gutterman, Sadik & Papadopoulos, 2003) have used the Short Form Health Survey (SF-36) developed by Wares, Snow & Kosinsky (1992) or the brief version SF12. The measure assesses general health related quality of life and the SF-36 assesses eight domains: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health. Although the measure has been reported to be reliable (with Cronbach's alphas reported to be between 0.63-0.94), it is limited in its ability to assess social and environmental quality of life.

An alternative assessment for quality of life is the WHOQOL instrument developed by the World Health Organisation (WHO). The WHOQOL instruments have been developed cross culturally and can assess quality of life in a variety of situations and populations. The original WHOQOL contains 100 items that assess six main domain of quality of life: physical health, psychological health, level of independence, social relationships, environment and spirituality/religion/personal beliefs. A briefer version is also available known as the WHOQOL brief which contains 26 items. The WHOQOL brief assesses four domains of quality of life: physical, psychological, social and environmental. The WHOQOL brief combines the physical health domain with level of independence and the psychological health domain is combined with the spirituality/religion/personal beliefs domain. The WHOQOL instruments have been found to be psychometrically sound with good discriminant validity, content validity and test retest reliability. The WHOQOL brief scores have been found to correlate at approximately 0.90 with the WHOQOL-100 scores. The current study will make use of the WHOQOL brief to assess quality of life in caregivers over four domains.

Reflection:

Although caregivers did not report any problems with completing the measure, the internal reliability was found to be low, particularly for the physical and environmental quality of life domains. The physical quality of life scale contained 7 items and at Time 1 Cronbach's alpha of 0.27 was achieved, however the reliability did improve over time with a Cronbach's alpha of 0.80 at Time 2 and 0.70 at Time 3. The main item to cause problems at Time 1 was "How much do you need any medical treatment to function in your daily life?" Removing this item would have increased the Cronbach's alpha to 0.50, however it was decided no items would be removed to enable comparison with other studies. The psychological quality of life scale contains 6 items and was found to have moderate reliability with Cronbach's alpha of 0.56 at Time 1, 0.64 at Time 2 and 0.60 at Time 3.

The social quality of life (3 items) performed well and inter item correlations were calculated to asses the reliability and were found to range from 0.30 to 0.68. The environmental quality of life scale (8 items) demonstrated poor reliability with a Cronbach's alpha of 0.39 at Time 1, but this improved to 0.81 at Time 2 and 0.77 at Time 3. It was found that if the item "How healthy is your physical environment?" was to be deleted the Cronbach's alpha would increase to 0.47. It is surprising that the reliability of the scales was only moderate as the measure has been so widely used and reported to be a valid and reliable instrument. As this was the last measure the caregivers completed, perhaps they did not read the items carefully due to fatigue. When the questionnaire was piloted, it was found to take on average 50 minutes to complete. Of the final sample of 123 caregivers, 118 caregivers completed the WHOQOL brief.

In summary the measures used in the questionnaire were found to be suitable for the sample and performed well, demonstrated by the lack of missing data. The only exception was the Willingness to Care Scale which was later modified to assess the number of and types of tasks performed by caregivers as opposed to willingness to perform care tasks.

The measures used had to be informally translated as they were not available in the required languages. Direct translation was found to be easier for scales that contained short concise items using a clear active voice such as the brief COPE. For other measures such as the HADS, a translation process of “de centering” was employed whereby direct translations were not used but the items were translated to retain the content and meaning of the original item. This method is commonly used within cross-cultural research (Cha, Kim & Erlen, 2007) and is recommended by Brislin (1976) when using well validated measures. However the question of whether the equivalence of meaning is retained emerges when using this method. Janevic & Connell (2001) note in their systematic review of studies examining ethnic differences in the dementia caregiving experience that the majority of researchers do not examine the extent to which the measures used are conceptually equivalent across cultures.

The loss of equivalence of meaning is an important concern in cross-cultural research and Brislin (1976) recommends four techniques that can be used to solve this problem; the first of which is commonly used and is known as back translation. This process involves a bilingual translator translating the original measure into the target language and a second independent translator blindly translating the target language version of the measure back to the original language. The two versions are then compared for conceptual equivalence. A problem with this method is that it requires resources that may not be available to a researcher as ideally the researcher requires two qualified bilingual translators who have knowledge of both cultures and the research area.

A second method is known as the bilingual technique which involves the researcher asking the question in both the original and target language to bilingual participants. The responses to the two versions are then compared. Although this method would be relatively simple to implement it was not possible in the current research. Although there may have been some caregivers who were bilingual, due to time constraints it was not possible to validate the measures using this method and bilingual caregivers completed the measures in the English language. The third method is known as the committee approach and as with the back translation approach requires considerable resources. The process involves more than three bilingual researchers (as opposed to qualified translators) translating the measure as a group. This was not possible to conduct with the current study as there was only one bilingual researcher involved with the research. The fourth recommended approach is the pre test procedure whereby a pilot study is conducted to enable the identification of potential problems regarding the equivalence of measures.

Janevic & Connell (2001) state that translation of measures and back translation does not ensure equivalence of meaning, other researchers also note problems with Brislin's (1976) back translation model (Cha et al, 2007). One cross-cultural study that overcomes this problem is that by Shaw et al (1997, discussed in Chapter 2) which makes use of a combination of the back translation and committee approach to ensure equivalence of meaning. Furthermore factor analysis is conducted on their scales separately for ethnic groups to ensure cross-cultural measurement equivalence. Although this is an interesting and useful method in comparison to the perhaps more demanding (with regards to time and resources) methods discussed earlier, it was not possible to implement due to sample size limitations in the current study.

The current study is limited as all measures were informally translated using the de centering approach which does not ensure equivalence of meaning. Whilst the ideal would be to use a combination of translation methods (back translation, use of bilingual participants in a pilot study and conducting factor analysis on scales) to ensure equivalence of meaning, this was not feasible due to the caregivers speaking a number of languages (Urdu, Hindi, Gujarati and Bengali) as well as the time and resource constraints associated with a PhD study. The lack of validated psychological measures in languages spoken by the British South-Asian population suggests that further research should focus on this issue. The next section of the chapter will discuss the data analysis strategies implemented and the statistical limitations that emerged.

Data Analysis

Missing Data Analysis:

123 caregivers completed a questionnaire at all three time points. As discussed earlier the majority of measures were completed well and as a result there was very little missing data. Whereby missing data did occur, an average score was computed for that item based on the scores from the remainder of the scale. This method of missing data analysis was only feasible for scales that contained more than 3 items. Average scores for items were not computed for scales that had more than 60% missing data. The Willingness to Care Scale was found to perform poorly with large amounts of missing data and was therefore removed from subsequent data analyses.

Group Comparisons:

Independent samples T tests were used to compare ethnic and gender groups on outcome scores of anxiety, depression, gains and quality of life. The main two assumptions of a T test are the scores must be normally distributed and there is homogeneity of variance (i.e. variability of scores is equal for both groups). One way ANOVAs were conducted to compare diagnosis groups using Tukey’s HSD as a post hoc test for multiple comparisons. The Tukeys HSD (honestly significant difference test) is the most widely used and offers adequate protection against Type 1 error without being excessively conservative as are the Bonferroni t test and the Scheffe test. As discussed in Chapter 6 and 8 due to multiple comparisons, a more stringent alpha level of $p < .01$ was applied (as recommended by Tabachnick & Fidell, 2007).

Group comparison tests were conducted to explore if demographic differences existed in outcomes, however the results should be interpreted with caution as the group sizes were small and thus the tests were underpowered. Nevertheless the group comparison analysis enabled the selection of demographic variables for later multiple regression analysis. Whereby demographic variables were continuous, such as age, hours caregiving per week and years in care role, correlation analysis was conducted, and only significant relationships entered into the regression. Repeated measures ANOVA were also conducted to examine if the change in scores for each scale, over the three time points was significant (results are presented in chapter 6). Multivariate statistics were used as the assumption of sphericity (the variance of the population difference scores for any two conditions are the same as the population difference scores for any two other conditions) did not have to be met. A paired sample t test was conducted for the EMECS and IMECS as these two scales were only administered at Time 2 and Time 3.

Longitudinal Data Analysis:

The Transactional Model of Stress and Coping (Lazarus, 1984) which is the main theoretical framework for this research, is dynamic in nature suggesting that research should focus on processes of change. A common method of analysis that has been used by past longitudinal caregiver research (Molloy, Johnston, Johnston et al, 2005, Pakenham, 2001 and Goode et al, 1998) is to compute residual change scores. Residual change scores are calculated by subtracting predicted scores from observed scores, where the predictive score is computed by regressing baseline scores on post test scores. Thus the residualised score is the post test score with the pre test score partialled out. In summary it is a measure of the degree to which an individual increased more than would be expected given their initial scores. A residual score above 0 reflects a higher IV score than would be expected given previous levels; a negative residual score reflects IV scores that are lower than would be predicted. Residual change scores are preferable to simple change score because they eliminate auto correlated error and regression to mean effects.

In the current study, data was collected at three time points which enabled the calculations for residual change scores for period 1 (early change) and period 2 (late change). Period 1 residual change scores were calculated by regressing Time 1 on Time 2 and period 2 by regressing Time 2 on Time 3. Previous longitudinal studies (Molloy et al, 2005, Pakenham, 2001 and Goode et al, 1998) have had only two time points and therefore only focused on change between Time 1-Time 2 IVs and the influence on change in the DV between T1-T2. Therefore although the design employed is longitudinal, the data analysis becomes cross-sectional as the processes of change are occurring during the same time frame. It was therefore decided that the DV to be used in the regression would be the final Time 3 score (not a residual change score). This would enable longitudinal analysis and furthermore the method is in accordance with statisticians who recommend against using residual change scores for DVs (Cronbach & Furby, 1970).

Prior to hierarchical multiple regression analysis, a number of assumptions had to be tested for this method. Based on the suggestions of Tabachnick & Fidell (2007), it was decided that a sample of 10 caregivers would be required per IV to be entered into the regression. As a sample of only 123 caregivers was available, we were only able to select 12 IVs from the 28 for the regression analysis. Selection of variables was therefore based on the results of the bivariate correlation analysis, whereby the relationship between an IV and the final outcome had to reach a significance level of $p < .05$ to be selected. This was thought to be the best method to overcome sample size limitations and it is a method that has been used in past research (Pakenham, 2001 and Goode et al, 1998).

Various other assumption of regression analysis also had to be met including checking the data for multicollinearity (this occurs when the IVs are highly correlated with one another). This assumption was not violated as all correlations were found to be below 0.40. The assumption of singularity was met by ensuring no IVs were a combination of other IVs (that is only single scales were used). The data was screened for outliers, and any found were adjusted so that they were not too different from the remaining cluster (an alternative method would be to delete outliers). Residual scatter plots confirmed that the assumptions of normality, linearity and homoscedasticity (variance of the residuals of predicted DV scores should be the same for all predicted scores) were also adequately met.

Selection and entry of variables was based on a combination of statistical and theoretical means. As described earlier, only those IVs that were significantly associated with the DV during bivariate correlation analysis were selected for hierarchical multiple regressions (due to sample size limitations). The selected IVs were then entered into the regression based on theoretical reasoning. In the first step, demographic factors were entered, with dummy variables created for categorical variables (such as ethnicity, gender and diagnosis). The creation of dummy variables when using categorical variables in regression analyses is a common and simple method. In the second step of the regression, the residual change score for period 1 of the DV was entered. The baseline scores for Time 1 and Time 2 had to be controlled when using the final Time 3 score as a DV. By using a residual change score for Time 1-Time 2 we were able to control for both Time 1 and 2 DVs whilst only entering one variable (as opposed to entering Time 1 and 2 separately). Also as the other predictors to be entered into the regression were residual change scores, it was appropriate to use a residual change score as a baseline control for the DV. The remaining predictor variables were entered based on the theoretical model. Familism and motivational factors were entered in the next step (if they were found to be significantly related to the DV in the correlation analysis), followed by illness perceptions, coping and social support. Each group of variables were entered into separate steps (for example, illness perceptions in one step followed by coping strategies in the next step) to examine the unique contribution each set of variables made to the final model.

It was originally planned that two hierarchical regression analyses would take place for each DV. That is in one model the predictors entered would be early regression residual scores for period 1, and a separate model for period 2 (late change). However it was found that this was not statistically possible for the outcomes of anxiety, depression and quality of life. The sample size was found to be adequate for the period 1 models but a much larger sample size was required for the period 2 models as the correlation analysis found a larger number of IVs had a significant relationship with the DVs. Although the regressions were conducted for the late change models (and presented in Appendix 5h), it was not appropriate to present them in the main chapters as they were statistically weak. When using caregiver gains as an IV it was found that the sample size was adequate for both early and late change models as only 11 IVs were entered in the early change model and 7 IVs for the late change model.

An alternative method to conducting bivariate correlation analysis for the selection of variables for the regression analyses would be to reduce the number of IVs through factor analysis. Research has often reduced the 14 subscales of the brief COPE to two main subscales: problem and emotion focused coping. However this was not possible in the current study as the sample size was not sufficient for factor analysis and the inter item correlations were below the recommended 0.30 (Tabachnick & Fidell, 2007). Another possible method would be to conduct stepwise regressions which select variables to be entered and which order they are entered into the equation based on statistical criteria. This method of analysis was thought to be inappropriate for the current sample as statisticians recommend 40 participants for each IV entered (Tabachnick & Fidell, 2007 and Pallant, 2001) and thus the current sample size would be inadequate. Furthermore the entry of IVs is based entirely on statistical criteria and would thus not be appropriate for testing a theoretical model.

Whilst the examination of early and late processes of change is of interest and has implications for the development of caregiver interventions (to reduce distress and improve quality of life) a major limitation needs to be noted. The caregivers in the current sample had been providing care for an average of nine years and therefore the “early changes” alluded to within this study do not represent early changes in real time. To overcome this limitation, caregivers would need to be recruited early in the role and a strict baseline for time in care role would have to be established. Although this would overcome the limitation cased by an artificial baseline, it would further reduce the sample size.

Chapter 10

Discussion

Discussion

The examination of the familial or informal caregiver experience is an important one in current society for a number of reasons. The ageing population is growing thus the prevalence of chronic disease and disability is increasing and as a result it is estimated that three in five people in the UK will be required to adopt the role of caregiver at some point in their life. Caregivers are reported to be of huge socio-economic benefit to the country, saving the National Health Service approximately £87 billion per year. Caregiving is also reported to vary by ethnic group with White-British and British South-Asian caregivers (Bangladeshi, Indian and Pakistani) spending the highest rate of providing care that is over 50 hours of caregiving per week (Carers UK, 2009).

The aim of the series of studies presented in this PhD thesis was primarily to examine the influence of ethnicity on the various aspects of the caregiving experience and its outcomes. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), dominant within the discipline of health psychology, was used as a theoretical framework to guide the selection of factors that may influence the relationship between ethnicity and caregiver outcomes. However it was also necessary to consider an extended model (the Socio-cultural model of stress and coping) proposed by Aranda & Knight (1997) which mainly focuses on "ethnicity as culture" and contains the additional factor of familism, defined throughout as "strong identification and attachment of individuals with their families including nuclear and extended, and strong feelings of loyalty, reciprocity and solidarity among members of the same family;" Sabogal et al, 1987, 397-398).

A systematic review of the literature was conducted (Chapter 2) to identify gaps in the evidence base and the empirical studies that followed were designed with the intention of addressing these gaps where possible. The main aims of the empirical studies were to examine ethnic differences in cultural values (familism), appraisals, coping and use of social support (Chapter 3, 4 and 5); examine the influence of the aforementioned variables on caregiver outcomes cross-sectionally (Chapter 5) and longitudinally (Chapter 6, 7 and 8). At the time of submission, two of the empirical studies have been published (Chapter 3 and 4) and the remaining are currently under review. As all the studies have been presented for publication, they have been presented in this thesis as a series of articles. The aim of this final chapter is to provide a summary of the main findings from the empirical studies and discuss the theoretical and practical implications of these findings. The chapter will also discuss the limitations encountered in conducting this research before presenting a number of directions for future research.

General Discussion

The systematic review pointed to several factors which supported the need for further empirical study. For example, of the 17 studies included in the systematic review, only three included South-Asian caregiver samples of which one was based in the U.K. All 17 of the studies were cross-sectional and the majority focused on ethnic differences in familism and the influence of social support on caregiver outcomes. The studies mainly examined anxiety, depression and burden as outcomes and no study addressed caregiver quality of life.

The first aim of the research was to identify if ethnic variation existed in the key variables identified using the Transactional Model of Stress (Lazarus & Folkman, 1984) and an extension of this, the Socio-cultural Model of Stress (Aranda & Knight, 1997). It was found that young British South-Asian caregivers consistently had significantly higher levels of familism than White-British Caregivers (Chapters 3-8) and this difference remained significant when the factor of age was controlled. Various studies have previously found differences in familism between different ethnic groups (discussed in chapter 2), but there has been very little research examining familism values in the South-Asian population. One exception is a qualitative study by Katbamna et al (1998) which found that obligations to provide care were common among South-Asian caregivers. There has also been little research on the influence of familism on caregiver factors such as coping, as past research (discussed in chapter 2) has focused on exploring the direct relationship of familism on caregiver outcomes rather than potential mediating processes.

Although there is little empirical research to compare the current findings with, perhaps it is not surprising that South-Asian caregivers had higher levels of familism. Henry & Schott (1999) propose that groups that have been uprooted from their “homeland” often become more conservative in their cultural values due to fear of loosing their identity; that is the South-Asian population may follow the family rules more strictly in the UK as they want to maintain their cultural identity. The age of caregivers was also found to be consistently related to familism (and South-Asian caregivers were significantly younger than White-British caregivers); with young caregivers endorsing higher levels of familism. This is consistent with the relational theory of familism (Gans & Silverstein, 2006) which suggests that younger individuals will have higher levels of familism as they have had fewer opportunities to “repay” their parents. Although significant differences in familism were found, perhaps surprisingly, caregivers did not significantly differ in their willingness to provide care (Chapter 5). We had assumed that familism would be related to willingness to care because values such as familism may be reflected in subsequent actions/behaviours by means of influencing motivational processes. However behavioural intention does not always lead to actual behaviour due to circumstantial limitations. Although the caregivers portrayed strong family values it was perhaps not always possible for them to transfer these attitudes into actual behaviour due to their circumstances, e.g. the disintegration of the family network (Mann, 2009) and having other pressures such as employment and young dependents.

Although the two ethnic groups were found to differ in their demographic profile (age, diagnosis group, relationship with care recipient), they did not significantly differ in caregiver demands (measured as the self reported number and type of care tasks per week, hours per week caregiving and years spent in care role). The main ethnic variations established were in regards to coping and social support (Chapter 3, 4 and 5). South-Asian caregivers were more likely to use behavioural disengagement and religious coping than White-British caregivers, who were more likely to use substances and humour. There has been little if any research on caregiver coping using the South-Asian population, therefore it is difficult to contextualise these findings, however we suggest from the current findings, that the differences in coping may be due to the influence of familism (Chapter 3).Familism was found to be related to increased religious coping in South-Asian caregivers and negatively related to substance use, and also the more religious the South-Asian caregivers the less likely they were to use substances as a form of coping (Chapter 4). Also due to the high levels of familism (which was found consistently across all studies), a value which dictates respect for your elders, perhaps it is not surprising the South-Asian caregivers did not use humour as a form of coping as it may be conceived as disrespectful.

The two ethnic groups significantly differed in their use of support with low perceived availability of support also reported by South-Asian caregivers. However whilst the two groups did not significantly differ in use of family support, South-

Asian caregivers had significantly lower support from friends and formal services than White-British caregivers. This may be due to cultural and socio economic factors, for example the South-Asian caregivers stated that they had attempted to access formal services but perceived many barriers and social inequalities. Furthermore many of them did not consider friends as a potential source of support and preferred family support perhaps due to privacy issues (Chapter 4). It has previously been believed that South-Asian caregivers have large extended family networks and thus access to support (Atkin, & Rollings, 1992) but this was not supported by the current findings. This may be due to the current socio economic situation in the UK, whereby more and more adult children have to move away from extended family networks for employment, causing a breakdown in the family network (Mann, 2009). A number of qualitative studies (discussed in Chapter 1) have focused on perceived and actual social support in the South-Asian communities and have suggested that South-Asian caregivers often lack support from within their families and also lack awareness of formal services. The current findings (Chapter 5) extended on this evidence base by quantifying the findings and also by using a comparison group of non Asian caregivers (Chapter 4 and 5).

Although ethnic differences in various outcomes such as anxiety, depression, gains and quality of life (Chapter 5, 6, 7 and 8) were found they were often confounded by age. However this is representative of the South Asian population which according to national statistics has a mean age of approximately ten years less than the White-British population. South-Asian caregivers were still found to have significantly higher levels of depression than White-British once age was controlled (Chapter 5), but were also found to experience more gains (Chapter 7) suggesting interesting differences in appraisals of their role. No significant ethnic differences in psychological and social quality of life were found but South-Asian caregivers had significantly lower levels of physical and environmental quality of life.

The differences in physical and environmental quality of life may also be due to socio economic status. Individuals from a lower socio economic group are more likely to be exposed to harmful and dangerous environments due to their employment and lower quality living conditions. Although, the UK has a national health service, differences in use of health services have been found by socio economic status and ethnicity. For example, Dixon, Le Grant, Henderson, Murray & Poteliakhoff (2007) report that although use of general practioners is equal among the socio economic groups, specialist treatment such as cardiac surgery, elective surgery, cancer care, preventive care and chronic care is higher (relative to need) amongst individuals in high socio economic groups. Furthermore, Sadler, Jothimani, Zanetto & Anderson (2009) have found that ethnicity is associated with health seeking behaviour. In their study White-British individuals were found to be more likely to present earlier for medical attention whereas those of an Asian background were found to be less likely to be referred for urgent endoscopy. Perhaps these differences may be due to education differences and perceived language barriers by the Asian group as indeed in the current research, South-Asian caregivers perceived cultural and language barriers in accessing health care services.

It is interesting that although South-Asian caregivers reported more gains, they also had higher levels of self reported depression. This suggests that the two outcomes being conceptually distinct and independent from one another (Rapp & Chao, 2000) and current findings support that the positive effects of caregiving should not simply be measured as an absence of depressive symptoms. Whilst the two concepts maybe distinct the balance between gains and losses needs to be considered, for example

South-Asian caregivers may report gains but may have also experienced more loss which would explain the high level of self reported depression. Also use of denial was found to be related to more perceived gains which suggests that perhaps the South-Asian caregivers were experiencing some burden associated with the role but were either in denial or attempting to focus on the positive aspects of the role. Indeed in chapter 5 it was found that South Asian caregivers were significantly more likely to make use of denial and behavioural disengagement coping strategies. In chapter 4, British Bangladeshi caregivers were reluctant to acknowledge the negative aspects of the care role and stated that they preferred to focus on the positives they were gaining from the role. It is also important to note that denial has been consistently been shown to be related to depression in the current research, for example in chapter 5, use of denial was associated with anxiety and depression for both ethnic groups and in chapter 6 increased use of denial was positive predictor of depression. Although in chapter 7, early increase in denial was a positive predictor of caregiver gains, late change analysis found that denial was negatively associated with gains (although the relationship did not reach statistical significance).

In line with the second aim of the research, the influence of familism, willingness to provide care, coping and social support on caregiver anxiety and depression was examined in Chapter 5. Interestingly familism was not significantly related to distress, and willingness to care appeared to be only related to South-Asian anxiety. This may be due to a global measure of familism being used as opposed to a specific cultural value such as felt responsibility (Stein, Wemmerus, Ward, Gaines, Freeberg & Thomas, 1998) which may be related to distress. Previous research (discussed in Chapter 2) has found conflicting results when exploring the relationship between familism and distress. Coping and use of social support were more significantly associated with caregiver distress in both groups, which confirms the associations proposed by the Transactional Model of Stress.

The above findings were further investigated in a longitudinal study examining changes in key variables and their association with distress (Chapter 6), gains (Chapter 7) and quality of life (Chapter 8). The studies focus on *change* as opposed to absolute scores for a number of reasons. The Transactional model of stress and coping is dynamic in nature and thus exploring change in variables is more appropriate. Also a focus on change in predictor variables forms the basis for intervention development. As expected changes in caregiver coping remained a significant predictor of changes in caregiver distress levels and quality of life longitudinally. Early illness perceptions were also significant predictors of changes in caregiver distress and quality of life. Previous findings suggest that social support acts as a buffer against stress/distress, perhaps surprisingly, in our data social support was not found to be a particularly strong predictor of outcomes although mean satisfaction with support did account for some variance in quality of life. These findings (Chapter 6 and 8) are consistent with the Transactional Model of Stress in that coping and illness perceptions are important mediators of stress. The current research adds to the evidence base by examining change in key independent variables which will have implications for phased interventions (as discussed later). The study described in Chapter 8 also extends on previous quality of life research by examining all four domains (physical, psychological, social and environmental quality of life). The study also goes beyond the examination of caregiver situation factors (number of hours caregiving, diagnosis and social support) in relation to quality of life which appears to be the norm in the field.

The influence of changes in caregiver variables on gains was also examined in a longitudinal study (Chapter 7). Although change in familism was not significantly associated with negative outcomes such as caregiver distress or with aspects of quality of life either in the current research or previous research, it was found to be associated with more gains prospectively. This is an interesting finding as past research examining the influence on familism on outcomes has focused on negative outcomes such as burden and depression and produced mixed results (perhaps due to the variety of measures used to assess outcomes). In addition to familism early increase in illness coherence and use of self distraction and denial were predictive of caregiver gains at time 3. Later change in use of emotional support became a stronger predictor of caregiver gains.

Theoretical Implications

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) was used as the underpinning health psychology theoretical model in the research. The model is a generic stress model that has often been applied to caregiver research. The model has been fully described in Chapter 1, but in general it describes the transaction between the individual’s appraisal of the situation and the resulting behaviours and emotions. Stress is experienced when there is a perceived mismatch between the demands of the situation and the coping resources available to deal with the problem. The model has received a great deal of support from past caregiver research (described in Chapter 1) and findings reported in chapter 5, 6, and 8 are generally supportive of the model.

Changes in illness perceptions i.e. threat appraisals (perceptions of personal control and emotional representations) were found to be predictive of distress longitudinally; changes in perceptions of consequences and emotional representations were associated with longitudinal changes in quality of life and increased illness coherence was associated with increased caregiver gains. Coping (religious coping and self blame) was consistently associated with distress and quality of life, concurrently and longitudinally in both ethnic groups. Social support however, commonly reported as a stress 'buffer' or a moderator (Thoits, 1995; Goode at al, 1998 & Ergh et al, 2002) was not a significant predictor of outcomes and only accounted for small amount of variance. This finding is surprising considering that past research using Caucasian and Asian caregivers has found social support to be a consistent significant moderator between caregiver factors and outcomes (chapter 2). Perhaps the amount of support received by South-Asian caregivers was too low to have an impact on outcomes, whereas White-British caregivers reported higher levels of social support. Findings from chapter 5 suggest that social support, satisfaction with support in particular, had a stronger negative effect on distress.

Whilst the current findings have provided a great deal of support for the Transactional Model, the findings also suggest that the model needs to be extended to include other relevant factors. For example, Chapter 5 reported that high willingness to care was associated with increased anxiety in South-Asian caregivers. The model also does not address cultural values such as familism which has been found to be associated with caregiver gains (Chapter 7). The Socio-cultural Model of Stress and Coping (Aranda & Knight, 1997) is an extension of the Transactional Model of Stress and includes additional factors such as familism as factors that precede appraisal processes. The model is often applied in caregiver studies examining ethnic differences and posits that the varying cultural differences between ethnic groups will directly affect caregiver appraisal and indirectly via appraisals, influence coping and social support (The model is fully described in Chapter 1).

The model predicts that ethnic groups will differ in regards to variables such as age and relationship status, and the findings here are supportive of this in that South-Asian caregivers were found to be significantly younger than White-British caregivers, were more likely to be female and were more often non spousal caregivers. The current findings are not supportive of the second component of the model which suggests that ethnic groups will differ in caregiver demands. The caregivers in the studies presented in this thesis did not significantly differ in the number of hours caregiving per week, number of tasks or years in care role. The third component was also not supported as familism was not significantly related to how the caregiver perceived the illness of the person they were providing care for. However the fourth component was supported as familism was found to be related to different coping methods in different ethnic groups (Chapter 3) but not significantly related to social support. The fifth component suggests that resource variables (coping and social support) will mediate the effect of familism on caregiver distress. In the current research, familism was not directly related to caregiver distress and quality of life nor did it have indirect effect on outcomes through social support for either ethnic group, however change in familism was found to have a relationship with caregiver gains.

The Socio-cultural Model of Stress has not previously been applied to White-British or South-Asian caregivers and certainly our findings suggest that the model is worth greater consideration. The findings of past research suggest that model shows promise in accounting for stress and coping in Eastern Asian (particularly Korean) caregivers). It is worth noting that Asian American and British-Asian caregivers may differ in their socio-economic status. It has been reported that Asian American caregivers have a similar socioeconomic background (similar level of education and income) with their White American counterparts (Pinquart & Sorensen, 2005); however British-Asian caregivers have a lower socio-economic status compared to White-British caregivers. According to government statistics individuals in an ethnic minority group had higher unemployment rates that White-British people and 60% of the Pakistani and Bangladeshi people were living in low income households. Individuals from the Pakistani and Bangladeshi groups were the most likely to have no qualifications and 3 to 4 times more likely than White-British to describe their health as bad or very bad.

Markides, Liang & Jackson (1990) propose that ethnicity is confounded by socio-economic status thus ethnic minority caregivers should experience double the stressors of being from a minority ethnic group as well as being a caregiver. Indeed South-Asian caregivers in the current research were found to have higher levels of anxiety and depression (Chapter 5 and 6) and a lower physical and environmental (which is related to socio-economic status) quality of life (Chapter 8). However the “disadvantaged minority group model” overlooks the potentially positive effects of cultural values on the stress process (which the socio-cultural model of stress considers), certainly familism was found to be related to more perceived gains and South-Asian caregivers (who had high levels of familism) reported more perceived gains than White-British caregivers (Chapter 7). Also use of religious coping was associated with low depression and increased gains and physical quality of life.

Perhaps the socio-cultural model can be adapted to the British South-Asian caregiver population by using more specific cultural values such as filial responsibility (considered as a societal attitude toward adult children’s duty to meet the needs of aging parents) as opposed to the global value of familism. The South-Asian caregivers (Chapter 4) discussed the issue of responsibility within families and who upon culture (and religion) dictates the care duties should fall upon. The common themes of religious obligations and religious coping throughout the studies suggest that religiosity should also be incorporated into the model as an independent factor. Religion is an integral part of cultural values and religious beliefs underlie family values. Religion may also be used as a resource by caregivers (Miltiades & Pruchno, 2002), perhaps ethnic minority caregivers rely on religious coping and use it as a resource as they lack access to health care services and other resources.

Limitations

Whilst considering the implications of these findings, a number of limitations need to be noted that necessitate some caution being taken with regards to specific findings. A general point however is that the majority of caregivers employed in the studies reported here were recruited from caregiver support groups as the intended use of other recruitment methods, such as posters, adverts in newsletters and word of mouth/snowballing resulted in a minimal response. The recruitment from support groups may have influenced the findings as caregivers already in contact with services may be more distressed (or less distressed as they are receiving support) than caregivers not involved in support groups. However the recruitment of caregivers from support groups appears to be the norm in recent caregiver research (Knight & Sayegh, 2010) and thus we are comparing our sample with findings drawn, in the main, from samples with similar bias.

Secondly, despite best recruitment efforts, the South-Asian caregiver sample was smaller than the White-British sample, which led to a situation whereby ethnic differences and processes could not be fully examined longitudinally due to only 27 South-Asian caregivers compared to 96 White-British caregivers. This also limits that data available to develop culturally specific caregiver interventions. The smaller

South-Asian sample may be due to the caregiver’s limited English language ability and the length of the questionnaire may have been off putting for some. It is worth noting however that in comparison to previous South-Asian caregiver studies e.g. (Perry et al, 1999; Bowes & Wilkinson, 2003 & Lawrence et al, 2008), the sample is adequate, however as a result of the smaller size of the South-Asian sample, sub ethnic group differences i.e. between British Bangladeshi, Indian and Pakistani caregivers could only be examined in a small qualitative study (Chapter 4).

Also despite using well validated measures in the questionnaires studies, the Hospital Anxiety and Depression Scale (HADS) and the WHO-QOL brief achieved poor reliability in the studies reported in Chapter 5 and 8. This may be due to the measures being informally translated for the South-Asian caregivers which highlights the need for the full and proper translation, back translation and validation of measures in common South-Asian languages (Urdu, Gujarati, and Hindi). Further problems were encountered with the willingness to care measure originally developed by Abell (2001) whereby the caregiver had to indicate which tasks they performed, how often it was performed in a week, how able they were to complete the task and how willing they were to perform the task. Caregivers in the current study found it to be a lengthy and complicated measure resulting in high levels of missing data. The measure was therefore not used to measure willingness to care during the longitudinal studies but was retained as a list of tasks that caregivers ticked to say how many tasks they performed during a week. This provided a measure of the number of caregiver demands and type: emotional, instrumental and nursing. Perhaps the Willingness to Care measure could be improved by reducing the number of items in each scale and removing the question pertaining to how often the task was performed by the caregiver. Also many of the caregivers felt that the instrumental items were not related to specific care tasks but were considered general household chores such as cooking and cleaning.

The different demographic profiles of the two ethnic groups are another possible influence on current findings. South-Asian caregivers were significantly younger and more likely to be female adult children whereas White-British caregivers were largely spousal caregivers. Attempts during data analysis were made to control for the possible confounding effect of these variables (particularly age) through the use of partial correlations, ANCOVAs and hierarchical multiple regressions. The younger age of the South-Asian population is inline with general demographic differences in the wider population.

Finally, a fairly small response rate of 30.8% was achieved for the longitudinal study; however 79.87% of the sample who were recruited at baseline remained in the study nine months later which is comparable to Pakenham et al (2001) and Goode et al (1998). The low response rate may be due to a number of reasons, often cited in other research as ell as our own such as caregivers stating they were busy with their care responsibilities and found it difficult to complete a lengthy questionnaire. Another potential reason maybe that the support groups who were involved in the recruitment also regularly made use of questionnaires to collect information from caregivers regarding their services. Caregivers may therefore be experiencing “questionnaire fatigue” (caregivers commented on the number of questionnaires they had completed recently for their support groups and thus felt unable to complete another questionnaire); however those caregivers who did participate in the study often discussed that they enjoyed the experience and found completing a questionnaire therapeutic.

The longitudinal study also made use of an artificial baseline that is caregivers were not individuals who had recently adopted the role. Whilst the research we are comparing with occasionally has ‘new’ carers (Molloy et al, 2005) it is not always the case (e.g. Goode et al, 1998 & Pakenham, 2001) and wherever possible we have compared our findings with those recruited similarly (i.e. not ‘new’ carers). However the timing of recruitment within the carer ‘career’ as such may have influenced the results in a number of ways. Firstly if the caregivers had been providing care for a number of years, they may have established more effective coping strategies and developed a network of support contacts. This would influence their levels of distress and quality of life. Caregivers who were relatively new in the role may experience more distress as they will be attempting to understand the care recipient’s condition and may not have the resources or lack awareness as how to access the support they require.

The current findings attempted to control for this possible confounding factor through hierarchical regression analysis (entering length of caring provision in the first step) and no effect was found in relation to outcomes that is length of caregiving was not consistently associated with outcomes. Although it would be of interest to follow up the experience of new caregivers, this would have further reduced the sample size available to the author in the geographical area in which the research was conducted. Recruitment of “new caregivers” would be reliant on newly diagnosed patients identifying an individual who would be providing care. Recruitment through support services may not be appropriate as the majority of new caregivers may not have yet accessed such groups.

Furthermore the results of the longitudinal studies require replication in a larger sample. As a sample of only 123 caregivers participated in the longitudinal study, this limited the statistical analysis. To reduce the number of variables for regression analysis, statistical methods were used to select variables as opposed to theoretical reasons. For example only relationships reaching statistical significance during bivariate correlation analysis were selected for regression analysis. Due to the small sample size, only early processes of change in caregiver factors could be examined as the late processes of change analyses were statistically underpowered (and therefore only included in the appendix). A larger sample would allow the analysis of both early and late changes and would form the basis of the development of time specific interventions. Although the sample size in the current longitudinal study is small it is comparable to other longitudinal caregiver outcome related studies (Goode et al 1998; Pakenham, 2001 & Molloy et al, 2005) and therefore add to the limited body of research focusing on change processes in caregiver factors.

Implications for health and social care services

Despite the limitations discussed above, the research presented in this thesis has a number of practical implications. Primarily the research has addressed an important gap in the evidence base by examining ethnic differences (White-British and South-Asian) in the caregiver role and the influence on outcomes. The studies presented in Chapter 3-8 extend on previous research by examining the above in a systematic manner using qualitative, cross-sectional and a longitudinal design. The inclusion of South-Asian caregivers is particularly important for a number of reasons. The South-Asian population is the largest minority group in the UK and alongside the White-British group are most likely to be providing care. The South-Asian population is younger than the White-British; however demographic trends suggest that the population is steadily aging. The recent changes in family structure, low socio-economic status and language barriers faced by the South-Asian population indicate that South-Asian caregivers will be vulnerable to the negative effects of providing care.

The findings of the research presented in this thesis have implications for the development of health services and interventions aiming to reduce distress and improving quality of life. Previously it was assumed that South-Asian caregivers were not presented to services because they did not want the aid of formal services as they had family support (Atkin & Rollings, 1992). The caregivers in the current research in fact reported very little family support and had attempted to make use of formal support but had experienced problems with access. This suggests that access to formal services needs to be improved for ethnic minority caregivers by removing language and cultural barriers and focusing on culturally competent health care (Sue, Zane, Hall & Berger, 2009).

Culturally competency adaptations include removal of language barriers (this could be achieved in a number of ways such as training more translators) and use of culturally adapted therapy (such as incorporating family therapy formats as family is important to South-Asian caregivers and familism was found to be associated with gains in the current study). A number of caregiver support groups currently meet in public bars and cafes which may be inappropriate for South-Asian caregivers (i.e. religious issues); perhaps using premises at local community centres would remove cultural barriers. During the recruitment phase of the research it also became more apparent that South-Asian caregivers were more likely to become involved with research and liaison with health professionals if they perceived a friendship bond with the service provider. This importance in the concept of friendship between the caregiver and the support service has also been highlighted by Mir & Tovey (2003). The development of family based support groups and the active involvement of health services on liaising with the family (as opposed to the primary caregiver) has the potential to increase family support for caregivers. The effects of such culturally competent interventions have been examined in a meta-analysis of 76 studies and found to have a positive effect (Griner & Smith, 2006).

In Chapter 5 it was found that high willingness to care was related to increased anxiety in South-Asian caregivers. As South-Asian caregivers were found to be significantly younger than White-British caregivers, they perhaps have unrealistic expectations of what they are able to achieve in the care role leading to role engulfment and thus anxiety. Skaff & Pearlin (1992) suggest that caregiver role engulfment will occur when the caregiver has a limited social network (as is the case with South-Asian caregivers) and will lead to a loss of self. Loss of self is reported to be common amongst young female caregivers, which was also found in the current research (Chapter 4) whereby the South-Asian caregivers discuss a loss of self and self sacrifice as care recipients became more dependent. This suggests that interventions specifically focused on South-Asian caregivers should attempt to increase the social network of the caregivers (perhaps by support services organising family events for caregivers).

Whilst encouraging willing caregivers through emotional support, support services should also promote instrumental support in terms of aid with general practical tasks (such as grocery shopping for the caregiver or attending a hospital appointment with the caregiver) available to caregivers so that caregivers do not develop unrealistic fears and expectations. It is important to note that although current provision of services for caregivers may be adequate, many caregivers will lack awareness of services or face barriers in accessing support. The main point of action for many support services should be to promote their services (promotion material should be available in a number of languages) as widely as possible and remove barriers by employing more translators. Services should try and integrate with the community and attempt to form more personal bonds with the individuals they serve. Also as for many caregivers the first point of access to health services is their G.P., the family doctor should be more involved in helping the caregiver access support services.

The longitudinal research also has implications for the development of interventions suitable for both ethnic groups. Sorensen, Pinquart, Habil & Duberstein (2002) in their review of 78 caregiver interventions studies highlight two main types of caregiver interventions. The first includes respite interventions which aim to reduce the amount of care provided by the caregiver and the second group are the psycho-educational interventions/support groups which aim to improve well being through teaching effective coping strategies and providing support. The review found that interventions generally had a small to moderate effect size (0.14 to 0.41), but the psycho-educational interventions, focussing for example on coping skills training and provision of support (either setting up support groups or individually tailored counselling) had the most consistent effects on all outcome variables. The current findings support that idea that a psycho-educational intervention would be appropriate as coping was consistently associated with outcomes cross-sectionally and longitudinally.

The findings from chapter 6 suggest that early illness perceptions are important in predicting longitudinal distress. By reducing threat appraisals (high perceptions of consequences and emotional representations), there is potential to reduce caregiver distress thus improving psychological health. Coping appears to be important in predicting distress and quality of life. The findings suggest that by reducing self blame and venting in caregivers, this will result in reduced distress and improved quality of life. Caregivers who were found to use more religious coping were found to experience more gains (specifically South-Asian caregivers), lower depression and improved quality of life. Perhaps by increasing religious support in health services, there is potential to improve caregiver quality of life (which has been found in cancer patient populations by Balboni et al, 2007). Also by providing religious support in health care services, potentially more South-Asian caregivers will be willing to access support services. For example male caregivers within the South-Asian population are somewhat rare (caregiving is usually considered a role for an adult daughter/daughter in law) and may require further support and may deem support from health care services appropriate if it is made more culturally/religiously suitable (e.g. more Asian males running support groups).

Furthermore the data from chapter 7 additionally supports the notion that the caregiver role is a dynamic process and different intervention should be implemented at different times in the role. The findings from chapter 7 suggest that early educational interventions focusing on increasing caregiver understanding of the care recipient’s diagnosis would be beneficial but later in the care role individually tailored emotional support through counselling would be appropriate. The current findings support the development of a multi component intervention that is time phased; that is targeting illness perceptions through education earlier in the role, followed by effective coping strategies training and provision of social support. Also including an appreciation of cultural diversity in interventions may further improve caregiver outcomes. It should be noted that due to the vastly different needs of caregivers, interventions and support provision should be tailor based to individuals needs, that is a one size fits all approach will not be useful.

Future Directions

Further research is required regarding the influence of cultural values on caregiver outcomes. Previous research has produced mixed results when examining the influence of familism on caregiver distress and although the current research found that familism was not significantly associated with caregiver distress or quality of life, it had a relationship with the experience of positive outcomes that is caregiver gains. Although the Socio-cultural Model of Stress has been successfully applied to research with Eastern Asian caregivers, the current research provided limited support for this model. Perhaps future research needs to focus on a specific cultural value and on different coping responses/illness perceptions held by the South-Asian caregiver population (possibly identified through further qualitative research) and their effect on caregiver outcomes. Although it is not possible to change cultural values, the focus and acknowledgment of cultural values in caregiver research is important. An understanding of cultural values will enable a greater understanding of the motivations for caregiving and a better rapport could be built with the community, enabling health services to become better matched to their needs.

The role of gender in the South-Asian caregiver population also warrants further exploration. Within the South-Asian culture, it appears to be the norm for daughters or daughter in laws to adopt the care role. However with the aging population and the extended family being diminished, more South-Asian males will have to adopt the role (as found in Chapter 4). Their experience warrants further research as they may be more vulnerable to distress due to the care role being socially perceived as more appropriate for females. The ethnic differences in illness perceptions and the influence of outcomes also require further exploration for example illness perceptions are a main target in many health psychology interventions, however there is a lack of research examining illness perceptions amongst minority ethnic groups particularly within the caregiver population.

It is also necessary to include non caregiver comparison groups in future caregiver research examining ethnic differences. The inclusion of an equivalent non caregiver group would help establish if the current findings are exclusive to the caregiver population or whether they are due to national ethnic differences. Finally the current measures used in caregiver research to address distress and quality of life require translation and validation for the use in South-Asian populations. This is a major challenge for health and social research in an increasingly diverse country. Although no caregiver was excluded in the current research on the basis of language, the measures were only informally translated by the researcher.

In conclusion, the research presented in this thesis has succeeded in examining ethnic differences in the caregiver role and the influence on caregiver outcomes using core health psychology models. The research made use of mixed methodologies (qualitative and quantitative) as well as a longitudinal design to address the research questions using the two main caregiver ethnic groups in the UK: White-British and British South-Asian. The findings have theoretical implications but more importantly practical implications for the development of culturally sensitive services and interventions to reduce caregiver distress and improve quality of life.

References

Abell, N (2001). Assessing willingness to care for persons with AIDS: Validation of a new measure. *Research on Social work practice. 11(1),* 118-130.

Adams, K. B (2008). Specific effects of caring for a spouse with dementia: differences in depressive symptoms between caregiver and non caregiver spouses. *International Psychogeriatrics, 20 (3),* 508-520.

Adams, B., Aranda, M. P., Kemp, B., & Takagi, K. (2002). Ethnic and gender differences in distress among Anglo American, African American, Japanese American, and Mexican American spousal caregivers of persons with dementia. *Journal of Clinical Geropsychology, 8*(4), 279-301.

Ahmad, W.I.U. (2000). *Ethnicity, disability and chronic Illness.* Buckingham, Policy Press.

Ahmad, W.I.U & Atkin, K. (1996). *"Race" and Community Care.* Buckingham, Policy Press.

Aranda, M. P & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A socio-cultural review and analysis. *The Gerontologist, 37 (3),* 342-354.

Atkin, K & Rollingns, J (1992). Informal care in Asian and Afro-Caribbean communities: A literature review. *British Journal of Social Work, 22,* 405-418.

Bacon, E., Milne, D. L., Sheikh, A. I & Freeston, M . H (2009). Positive experiences in caregivers: An exploratory case series. *Behavioural and Cognitive Psychotherapy, 37,* 95-114.

Bakas, T & Burgener, S.C (2002). Predictors of emotional distress, general health and caregiving outcomes in family caregivers of stroke survivors. *Topics in Stroke and Rehabilitation, 9 (1),* 34-45.

Balboni, T. A., Vanderweker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S. Peteet, J. R & Prigerson, H. G (2007). Religiousness and spiritual support among advanced cancer patients and associations with end of life treatment preferences and quality of life. *Journal of Clinical Oncology, 25 (5),* 555-560.

Baron, R.M & Kenny, D.A (1986). The moderator-mediator variable distinction in Social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social psychology, 51 (6),* 1173-1182.

Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F & Lance, C. E (2005). Risk factors for potentially harmful informal caregiver behaviour. *Journal of American Geriatrics Society, 53,* 255-261.

Beach, S. R., Schulz, R., Yee, J. L & Jackson, S (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15 (2),* 259-271.

Bhopal, R (2004). Glossary of terms relating to ethnicity and race: for reflection and debate. *Journal of Epidemiol Community Health, 58,* 441-445.
Braun. V & Clarke, V (2006). Using Thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77-101.

Breakwell, G.M., Hammond, S., & Fife-Schaw, C. (2000). *Research methods in Psychology (2nd Ed).* SAGE Publications.

Brereton, L. (1997). Preparation for a family care-giving: stroke as a paradigm case. *Journal of Clinical Nursing. 6,* 425-434.

Brereton, L. & Nolan, M. (2002). Seeking: a key activity for new family carers of stroke survivors. *Journal of Clinical Nursing, 11,* 22-31.

Brien, M .T (1993). Multiple Sclerosis: Stressors and coping strategies in spousal caregivers. *Journal of Community Health Nursing, 10 (3),* 123-135.

Brislin, R. W. (1976). Back-translation for cross-cultural research. *Journal of Cross-cultural Psychology, 1,* 185-216.

Broadbent, E., Kaptein, A. A & Petrie, K. J (2011). Double Dutch: The “think aloud” brief IPQ study uses a Dutch translation with confusing wording and the wrong instructions. *British Journal of Health Psychology, 16,* 246-249.

Broadbent, E., Petrie, K.J., Main, J & Weinman, J (2006). The Brief Illness Perception questionnaire. *Journal of Psychosomatic Research, 60,* 631-637.

Bowes, A & Wilkinson, H. (2003). “We didn’t know it would get that bad.” South Asian experiences of dementia and the service response. *Health and Social Care in the Community, 11(5),* 387-396.

Bridges, B.J. (1995). *Therapeutic caregiving: A practical guide for caregivers of person’s with Alzheimer’s disease and other dementia causing diseases.* Washington, DC: BJB.

Campbell, L.D & Matthews, A.M. (2003). The gendered nature of men’s filial care. *Journal of Gerontology: Social Sciences, 58B(6),* 350-358.

Carers UK (2009). Facts about carers. [Brochure]. London: Carers UK.

Carers UK (2007). [Brochure]. London: Carers UK.

Carers UK (2003). [Brochure]. London: Carers UK.

Carers UK (2001). [Brochure]. London: Carers UK.

Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56,* 267-283.

Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioural Medicine, 4,* 92-100.

Census, (2001). Office for National statistics; General register office for Scotland. www.statistics.gov.uk

Cha, E. S., Kim, K. H & Erlen, J. A. (2007). Translation of scales in cross-cultural research: issues and techniques. *Journal of Advanced Nursing, 58 (4),* 386-395.

Chada, R. K., Singh, T. B & Ganguly, K. K (2007). Caregiver burden and coping. *Social Psychiatry, 42,* 923-930.

Chalmers, B (1996). Western and African conceptualisations of health. *Psychology and Health, 12 (1),* 1-10.

Charlton, G.S & Barrow, C.J. (2002). Coping and self-help group membership in Parkinson's disease: An exploratory qualitative study. *Health and social care in the community, 10 (6),* 472-478.

Chun, M., Knight, B. G., & Youn, G. (2007). Differences in stress and coping models of emotional distress among Korean, Korean American and White-American caregivers. *Aging & Mental Health., 11*(1), 20-29.

Cohen, C. A., Colantonio, A & Vernich, L (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17,* 184-188.

Cornwell, E. Y & Waite, L. J (2009). Social disconnectedness, perceived isolation and health among older adults. *Journal of Health and Social Behaviour. 50 (1),* 31-48.

Covic, A., Seica, A., Gusbeth-Tatomir, P., Gavrilovic, O & Goldsmith, D. J. A (2004). Illness representations and quality of life scores in haemodialysis patients. *Nephrology Dialysis Transplantation, 19,* 2078-2083.

Cox, C, & Monk, A. (1993). Hispanic culture and family care of Alzheimer's patients. *Health and Social Work, 18(2),* 92-100

Cronbach, L. J & Furby, L (1970). How we should measure "change"-Or should we? *Psychological Bulletin, 74 (1),* 68-80.

Croog, S. H., Burleson, J. A., Sudilovsky, A & Baume, R. M (2006). Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging and Mental Health, 10 (2),* 87-100.

Davis, J.G, Hermanson, K, Koopman, C.L, Weibel, D, & Spiegel, D. (2000). Quality of couples' relationship and adjustment to Metastatic Breast cancer. *Journal of Family Psychology, 14(2),* 251-266.

Dellmann-Jenkins, M & Brittain, L. (2003). Young adult's attitudes towards filial responsibility and actual assistance to elderly family members. *The Journal of Applied Gerontology, 23 (2),* 214-239.

Dilworth-Anderson, P, Williams, I.C & Gibson, B. E (2000). Issues of race, ethnicity and culture in caregiving research: A 20 year review 1980-2000. *The Gerontologist, 42 (2),* 237-272.

Dixon, A., Le Grant, J., Henderson, J., Murray, R & Poteliakhoff, E (2007). Is the British National Health Service equitable? The evidence on socio economic differences in utilisation. *Journal of Health Service Research Policy, 12*, 104-109.

Dobson, K. S. (1985). The relationship between anxiety and depression. *Clinical Psychology Review,* 5, 307-324.

Ekwall, A., Sivberg, B & Hallberg, I. R (2004). Dimensions of informal care and quality of life among elderly family caregivers. *Scandinavian Journal of Caring Sciences, 18,* 239-248.

Ergh, T. C., Rapport, L., Coleman, R. D & Hank, R. A (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation, 17 (2),* 155-174.

Fiore, J, Becker, J & Coppel, D.B. (1983). Social network interactions: a buffer or a stress. *American Journal of Community Psychology, 11(4),* 423-439.

Fischer, M., Scharloo, M., Abbink, J., van't Hul, A., van Ranst, D., Rudolphus, A., Weinman, J., Rabe, K & Kaptein, A. A. (2010). The dynamics of illness perceptions: Testing assumptions of Leventhal's common-sense model in a pulmonary rehabilitation setting. *British Journal of Health Psychology, 15,* 887-903.

Flynn, N & James, J. E (2009). Relative effects of demand and control on task related cardio vascular reactivity, task perceptions, performance accuracy and mood. *International Journal of Psychophysiology, 72,* 217-227.

Fredriksen-Goldsen, K. I., & Farwell, N. (2004). Dual responsibilities among black, Hispanic, Asian, and white employed caregivers. *Journal of Gerontological Social Work, 43*(4), 25-44.

Friedmann, E., Thomas, S. A., Liu, F., Morton, P. G., Chapa, D & Gottlieb, S. S (2006). Relationship of depression, anxiety and social isolation to chronic heart failure outpatient mortality. *American Heart Journal, 152 (5),* 140-148.

Fuligni, A.J., Tseng, V & Lam, M. (1999). Attitudes towards family obligations among American adolescents with Asian, Latin American, and European backgrounds. *Child Development, 70 (4),* 1030-1044.

Furnham, A., Akande, D & Baguma, A (1996). Beliefs about health and illness in three countries: Britain, South Africa and Uganda. *Psychology, Health and Medicine, 4 (2),* 189-201.

Gaines, S.O., Marelich, W.D., Bledsoe, K.L., Steers,W.N., Henderson, M.C., Granrose, C.S., Barajas, L., Hicks, D., Lyde, M., Takahashi, Y., Yum, N., Rios, D., Garcia, B.F., Farris, K.R., & Page, M.S. (1997). Links between race/ethnicity and cultural values as mediated by racial/ethnic identity and moderated by gender. *Journal of Personality and Social Psychology, 72 (6),* 1460-1476.

Gallant, M.P & Connell, C.M. (2003). Neuroticism and depressive symptoms among spouse caregivers: Do health behaviours mediate this relationship? *Psychology and Aging, 18(3),* 587-592.

Gans, D & Silverstein, M. (2006). Norms of filial responsibility for aging parents across time and generations. *Journal of Marriage and Family, 68,* 961-976.

Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T & Newcomer, R.C. (2005). The effects of duration of caregiving on institutionalisation. The Gerontologist, 45 (1), 78-89.

Gerrish, K. (2000). The nature and effect of communication difficulties arising from interaction between district nurses and South Asian patients and their carers. *Journal of Advanced Nursing, 33(5),* 566-574.

Giunta, N., Chow, J., Scharlach, A. E., & Dal Santo, T. S. (2004). Racial and ethnic differences in family caregiving in California. *Journal of Human Behaviour in the Social Environment, 9*(4), 85-109.

Goode, K.T., Hayley, W.E., Roth, D.L & Ford, G.R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17(2),* 190-198.

Greenberg, J. S., Seltzer, M. M., Orsmond, G .I & Krauss, M. W (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 50 (9),* 1214-1219.

Griner, D & Smith, T. B (2006). Culturally adapted mental health interventions: A meta-analytic review. *Psychotherapy Theory, Research, Practitioner, Training, 43 (4),* 531-548.

Groger, L & Mayberry. (2001). Caring too much? Cultural lag in African American perceptions of filial responsibilities. *Journal of Cross-Cultural Gerontology, 16,* 21-39.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., Willan, A., Viola, R., Coristine, M., Janz, T & Glossop, R (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principle caregivers. *Cancer Medical Association Journal, 170 (12),* 1795-1801.

Gupta, R., Rowe, N., & Pillai, V. K. (2009). Perceived caregiver burden in India: Implications for social services. *Affilia: Journal of Women & Social Work, 24*(1), 69-79.

Gupta, R. (2002). Impact of mental health on perceived caregiver burden in South Asian families. *Journal of Mental Health and Aging, 8*(1), 45-57.

Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T & Sanderman, R (2000) Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho Oncology, 9,* 232-242.

Hagger, M. S & Orbell, S (2003). A meta-analytic review of the common sense model of illness representations. *Psychology and Health, 18 (2),* 141-184.

Haley, W.E., Levine, E.G., Brown, S.L & Bartolucci, A. A (1987). Stress, appraisal, coping and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2 (4),* 323-330.

Hatfield, A. B & Lefley, H. P (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal, 41 (3),* 327-338.

Hanks, A. R., Rapport, L.J & Vangel, S (2007). Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support & family functioning. NeuroRehabilitation, 22, 43-52.

Hawthorne, G (2008). Perceived social isolation in a community sample: Its prevalence and correlates with aspects of people's lives. *Social Psychiatry and Psychiatric Epidemiology, 43 (2),* 140-150.

Heller, P. L (1976). Familism Scale: Revalidation and revision. *Journal of Marriage and the Family, 38 (3),* 423-429.

Hennessy, C.H & John, A. (1996). American Indian family caregiver's perceptions of burden and needed support services. *Journal of Applied Gerontology, 15,* 275-293.

Henry, A & Schott, J. (1999). *Culture, Religion and Patient Care in a Multi-Ethnic Society. A Handbook for Professionals.* Age Concern: England.

Hepworth, D (2005). Asian carer's perceptions of care assessment and support in the community. *British Journal of Social Work, 35,* 337-353.

Hooker, K., Monahan, D. J., Bowman, S. R., Frazier, L. D & Shifren, K (1998). Personality counts for a lot! Predictors of mental and physical health of spouse caregivers in two disease groups. *Journal of Gerontology, Psychological Sciences, 53B (2),* 73-85.

Hung, S., Loong, C.S.F., Liu, J. H & Weatherall, A. (2000). Will the young support the old? An individual and family level study of filial obligations in two New Zealand cultures. *Asian Journal of Social Psychology, 3,* 163-182.

Hussain, A.F & Cochrane, R. (2003). Living with depression: Coping strategies used by South Asian women living in the U.K, suffering from depression. *Mental Health, Religion and Culture, 6(1),* 21-44.

Hutchinson, J & Smith, A.D (1996). *Ethnicity.* Oxford University Press: New York.

Janevic, M.R & Connell, C.M. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist, 41(3),* 334-347.

Jones, P. S., Jaceldo, K. B., Lee, J. R., Zhang, X. E., & Meleis, A. I. (2001). Role integration and perceived health in Asian American women caregivers. *Research in Nursing & Health, 24*(2), 133-144.

Jonsson, A.C., Lindgren, I., Hallstrom, B., Norrving, B & Lindgren, A (2005). Determinants of quality of life in stroke survivors and their informal caregivers. *Stroke, 36,* 803-808.

Karasek, R. A. (1979). Job demands, job decision latitude and mental strain: Implications for job redesign. *Administrative Science Quarterly, 24,* 285-308.

Karasek, R. A & Theorell, T. (1990). *Healthy Work: Stress, productivity and the reconstruction of working life.* New York: Basic Books.

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R & Parker, G. (2004). Do they look after their own? Informal support for South Asian carer. *Health and Social Care in the Community. 12(5),* 398-406.

Katbamna, S & Bhakta, P (1998). *Experiences and needs of carers from the South-Asian communities.* Working paper no 62, Nuffield Community Care Studies (NCCSU), University of Leicester, Leicester.

Kelleher, D & Hillier, S. (1996). *Researching cultural differences in health.* Routledge: London.

Kessler, R.C, Price, R.H & Wortman, C.B. (1985). Social factors in psychopathology: Stress, social support and coping processes. *Annual Review, 36,* 531-572.

Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, O.J & Glase, R (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. *Psychosomatic medicine, 53 (4), 345*-362.

Kiecolt-Glaser, J.K., Marucha, P.T., Mercado, A.M., Malarkey, W.B & Glaser, R (1995). Slowing of wound healing by psychological stress. *The Lancet, 346 (8984),* 1194-1196.

Killian, T & Ganong, L. H (2002). Ideology, context, and obligations to assist older persons. *Journal of Marriage and Family, 64,* 1080-1088.

Kim, Y., Schulz, R & Carver, C. S (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69,* 283, 291.

Kim, Y & Schulz, R (2008). Family caregiver's strain: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health, 20(5),* 483-503.

Knight, B.G & Sayegh, P (2010). Cultural values and caregiving: The updated Socio-cultural stress and coping model. *Journal of Gerontology: Psychological Sciences, 65B (1),* 5-13.

Knight, B.G., Silverstein, M., McCallum, T.J & Fox, L.S (2000). A Socio-cultural stress and coping model for mental health outcomes among African American caregivers in southern California. *Journal of Gerontology: Psychological Sciences,55B (3),* 142-150

Kolb, J.P (2000). Continuing to care: Black and Latina daughter's assistance to their mother's in nursing homes. *Affilia, 15 (4),* 502-525.

Kramer, B. J (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist, 37 (2),* 239-249.

Lai, D. W. L. (2007). Cultural predictors of caregiving burden of Chinese Canadian family caregivers. *Canadian Journal on Aging-Revue Canadienne Du Vieillissement, 26,* 133-147.

Lawrence, V., Murray, J., Samsi, K & Banarjee, S. (2008). Attitudes and support needs of Black Caribbean, Asian, and White British carers of people with dementia in the UK. *The British Journal of Psychiatry, 193,* 240-246.

Lazarus, R.S. (2000). Towards better research on stress and coping. *American Psychologist. 55(6),* 665-673.

Lazarus, R.S. (1999). *Stress and Emotions: A new synthesis*. Free Association books: London.

Lazarus, R.S & Folkman, S (1984). *Stress, Appraisal, and Coping.* New York: Springer.

Lee, S., Colditz, G.A., Berkman, L.F & Kawachi, I (2003). Caregiving and risk of coronary heart disease in US women: A prospective study. *American Journal of Preventative Medicine, 24(2),* 113-119.

Lee, E. E., & Farran, C. J. (2004). Depression among Korean, Korean American, and Caucasian American family caregivers. *Journal of Transcultural Nursing, 15*(1), 18-25.

Lee, M. (2007). Correlates of consequences of intergenerational caregiving in Taiwan. *Journal of Advanced Nursing, 59*(1), 47-56.

Leventhal, H., Nerenz, D. & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor & J. E. Singer (Eds.), *Handbook of psychology and health: Social psychological aspects of health* (Vol. 4, pp. 219-252). Hillsdale, NJ: Erlbaum.

Levy, B., Hillygus, J., Lui, B., & Levkoff, S. (2000). The relationship between illness attributions and caregiver burden: A cross-cultural analysis. *Journal of Mental Health and Aging, 6*(3), 213-225.

Lindeberg, S. I., Rosvall, M., Choi, B., Canivet, C., Isacsson, S. O., Karasek, R & Ostergren, P. O (2010). Psychosocial working conditions and exhaustion in working population sample of Swedish middle aged men and women. *European Journal of Public Health*, 1-7.

Losada, A, Robinson, G.S, Knight, B.G, Marquez, M, Montorio, I, Izal, M & Ruiz, M.A. (2006). Cross-cultural study comparing the association of familism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. *Aging & Mental Health. 10(1),* 69-76.

Lyonette, C & Yardley, L (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing & Society, 23,* 487-506.

Iconomou, G., Viha, A., Kalofonos, H. P & Kardamakis, D (2001). Impact of cancer on primary caregivers of patients receiving radiation therapy. *Acta Oncologica, 40 (6),* 766-771.

Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G., & Mann, H. (2007). Family carers of stroke survivors: Needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation, 29*(2), 111-121.

Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia, 5(2),* 233-247.

MacLachlan, M. (2006). *Culture and Health (2nd ed).* John Wiley and sons Ltd.

Mann, R (2009). Evolving family structures, roles and relationships in light of ethnic and social change. http:// www.beyondcurrenthorizons.org.uk

Markides, K., Liang, J & Jackson, J (1990). Race, ethnicity and aging: Conceptual and methodological issues. In R. H. Binstock & L. K. George (Eds), *Handbook of aging and the social sciences* (p112-129). San Diego, CA: Academy Press.

Markowitz, J. S., Guttermna, E. M., Sadik, K & Papadopoulos, G (2003). Health related quality of life for caregivers of patients with Alzheimer's Disease. *Alzheimer's Disease Association Discord, 17 (4),* 209-214.

Martinez-Martin, P., Benito-Leon, J., Alonso, F., Catalan, M. J., Pondal, M., Zamarbide, I., Tobias, A & dePedro, J (2005). Quality of life of caregivers in Parkinson's disease. *Quality of Life Research, 14,* 463-472.

McCabe, K. M., Yeh, M., Lau, A., Garland, A., & Hough, R. (2003). Racial/Ethnic differences in caregiver strain and perceived social support among parents of youth with emotional and behavioral problems. *Mental Health Services Research, 5*(3), 137-147.

McCullagh, E., Brigstocke, G., Donaldson, N & Ka;ra, L (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke,* 36, 2181-2186.

McKee, K. J., Whittick, J. E., Gilhooly, M. M. L., Ballinger, B. R., Gordon, D. S., Mutch, W. J & Philp, I. (1999). The willingness to continue caring in family supporters of older people. *Health and Social Care in the Community, 7 (2),* 100-108.

McMillan, S.C., Small, B. J., Schonwetter, R., Tittle, M., Moody, L & Haley, W. E (2005). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106 (1),* 214-222.

Mercier, C., Peladeau, N & Tempier, R (1998). Age, gender and quality of life. *Community Mental Health Journal, 34 (5),* 487-500.

Merrell, J., Kinsella, F., Murphy, F., Philpin, S & Ali, A (2005). Support needs of carers of dependent adults from a Bangladeshi community. *Journal of Advanced Nursing, 51(6),* 549-557.

Miller, B & Guo, S. (2000). Social support for spouse caregivers of persons with dementia. *Journal of Gerontology: Social Sciences, 55B(3),* 163-172.

Miller, B, Townsend, Carpenter, E, Montgomey, R.V.J, Stull, D & Young, R.F. (2001). Social support and caregiver distress: a replication analysis. *Journal of Gerontology, 56B(4),* 249-256.

Milne, A & Chryssanthopoulou, C. (2005). Dementia and care-giving in Black and Asian populations: Reviewing and refining the research agenda. *Journal of Community and Applied Social Psychology, 15,* 319-337. #

Miltiades, H. B & Puchno, R (2002). The effect of religious coping on caregiving appraisals of mothers of adults with developmental disabilities. *The Gerontologist, 42 (1),* 82-91.

Mir. G & Tovey, P (2003). Asian carers' experiences of medical and social care: The case of Cerebral palsy. *British Journal of Social work, 33*, 465-479.

Molloy, G. J., Johnston, D. W., Johnston, M., Gao, C., Witham, M. D., Struthers, A. D & McMurdo, M. E. T (2008). Using the demand-control model of job strain to predict caregiver burden and caregiver satisfaction in the informal caregivers of heart failure patients. *British Journal of Health Psychology, 13,* 401-417.

Molloy, G. J., Johnston, D. W., Johnston, M., Morrison, V., Pollard, B., Bonetti, D., Joice, S & MacWalter, R (2005). Extending the demand control model to informal caregiving. *Journal of Psychosomatic Research, 58,* 243-251.

Morano, C. L & King, D (2010). Religiosity as a mediator of caregiver wellbeing. *Journal of Gerontological Social Work, 45 (1),* 69-84.

Morrison, V & Bennet, P. (2006). *An introduction to health psychology.* Pearson Prentice Hall.

Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D & Buick, D (2002). The Revised Illness Perception Questionnaire. *Psychology and Health, 17 (1),* 1-16.

Murdock, G. P (1980). *Theories of illness: A world survey.* Pittsburgh: University of Pittsburgh Press.

Nazroo, J. (1997). *Genetic, cultural, or socioeconomic vulnerability? Explaining ethnic inequalities in health.* Oxford: Blackwell.

Neugarten, B. L (1969). Continuities and discontinuities of psychological issues into adult life. *Human Development, 12,* 121-130.

Newton, C. J & Jimmieson, N. L (2008). Role stressors, participative control, and subjective fit with organisational values: Main and moderating effects on employee outcomes. *Journal of Management and Organisation, 14 (1),* 20-39.

NFER-Nelson (1995). *Measures in Health Psychology: A User's Portfolio*. Windsor: NFER-Nelson.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R & van den Bos, G. A. M (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer, 86 (4),* 577-588.

Noblett, A., Rodwell, J & McWilliams, J (2006). Organisational change in the public sector: Augmenting the demand control model to predict employee outcomes under new public management. *Work and Stress, 20 (4),* 335-352.

Nolan, M., Keady, J & Grant, G (1995). Developing a typology of family care: Implications for nurses and other service providers. *Journal of Advanced Nursing, 21 (2),* 256-265.

O'Brien, M. T (1993). Multiple Sclerosis: Stressors and coping strategies in spousal caregivers. *Journal of Community Health Nursing, 10 (3),* 123-135.

Ofstedal, M.B., Knodel, J & Chayovan, N. (1999). Intergenerational support and gender: A comparison of four Asian countries. *Asian Journal of Social Science, 27 (2),* 21-41.

Orbell, S & Gillies, B (1993). Whats stressful about caring? *Journal of Applied Social Psychology, 23 (4),* 272-290.

Pakenham, K. I (2005). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology, 24 (2),* 123-132.

Pakenham, K. I (2001). Application of a stress and coping model to caregiving in Multiple Sclerosis. *Psychology, Health & Medicine, 6 (1*), 13-27.

Pallant, J. (2003). SPSS Survival manual. Open University Press.

Pariante, C. M., Carpiniello, B., Orru, G., Sitzia, R., Piras, A., Farci, G., Giacco, S. D., Piludu, G & Miller, A. H (1997). Chronic caregiving stress alters peripheral blood immune parameter: The role of age and severity of stress. *Psychotherapy and Psychosomatics, 66 (4),* 199-207.

Parveen, S., Morrison, V & Robinson, C. A (2011). Ethnic variations in the caregiver role: A qualitative study. *Journal of Health Psychology, 16 (6),* 862-872.

Parveen, S & Morrison, V. (2009). Predictors of Familism: A Pilot Study. *Journal of Health Psychology, 14 (8),* 1135-11-43.

Patton, M.Q (2002). *Qualitative research and evaluation methods (3rd ed)* Sage.

Payne, S (2004). Carers *and caregivers in Death, dying and social differences*. Edited by Oliviere, D & Monroe, B. Oxford University Press.

Pearlin, L. I (1988). *Caregiver's stress and coping study*. (NIMH ROI MH42122). San Francisco, CA: University of California, Human Development and Aging Programs.

Perry, S.I., Hsu, R.T., Brooks, W & Cherry, D (1999). Perceptions of community services among Asian and White stroke survivors and their carers: An Exploratory Study. *Ethnicity and health, 4 (1/2*), 101-105.

Pinquart, M & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45(1),* 90-106.

Pinquart, M & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta analysis. *Journal of Gerontology: Psychological Sciences, 61B(1),* 33-45.

Phinney, J.S (1996). When we talk about American ethnic groups, what do we mean? *American Psychologist, 51(9),* 918-927

Quinn, C., Clare, L & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics, 22 (1),* 43-55.

Ramos, B.M. (2004). Culture, Ethnicity and caregiver stress among Puerto Ricans. *Journal of Applied Gerontology, 23 (4),* 469-486.

Rapp, S. R & Chao, D (2000). Appraisals of strain and gain: effects on psychological well-being of caregivers of dementia patients. *Aging and Mental Health, 4 (2),* 142-147.

Rowe, J. W. Kahn, R. L (1998). *Successful Aging.* New York: Pantheon Books.

Sabogal, F., Marin, G., & Otero-Sabogal, R., Marin, B.V & Perez-Stable, E.J. (1987). Hispanic familism and acculturation: What changes and what doesn’t? *Hispanic Journal of Behavioural Sciences, 9 (4),* 397-412.

Sadler, G. J., Jothimani, D., Zanetto, U & Anderson, M. R. (2009). The effect of ethnicity on the presentation and management of oesophageal and gastric cancers: A UK perspective. *European Journal of Gastroenterology and Hepatology, 21 (9),* 996-1000.

Saranson, I.G., Levine, H.M., Basham, R.B & Saranson, B.R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44(1),* 127-139.

Sayegh, P & Knight, B. (2010). The effects of familism and cultural justification in the mental and physical health of family caregivers. *Journal of Gerontology: Psychological Sciences, 66B (1),* 3-14.

Schulz, R & Beach, S. R (1999). Caregiving as a risk factor for mortality. The caregiver health effects study. *Journal of American Medical Association, 282 (23),* 2215-2219.

Shurgot, G.R & Knight, B.G. (2005). Influence of neuroticism, ethnicity, familism, and social support on perceived burden in dementia caregivers: pilot test of the transactional stress and social support model. *Journal of Gerontology: Psychological Sciences, 60B(6),* 331-334.

Sisk, R.J (2000). Caregiver burden and health promotion. *International Journal of Nursing Studies, 37(1),* 37-43.

Skaff, M. M & Pearlin, L. I (1992). Caregiving: Role engulfment and the loss of self. *The Gerontologist, 32 (5),* 656-664.

Sorensen, S., Pinquart, M., Habil, D & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 43 (3),* 356-372.

Stein, C., Wemmerus, V., Ward, M., Gaines, M., Freeberg, A & Thomas, J. (1998) Because they're my parents: An intergenerational study of felt obligation and parental caregiving. *Journal of Marriage and the Family, 60*, 611-622.

Stephens, M. A. P., Norris, V. K., Kinney, J. M., Ritchie, S. W & Grotz, R. C (1988). Stressful situations in caregiving: Relations between caregiver coping and wellbeing, *Psychology and Aging, 3 (2*), 208-209.

Strawbridge, W. J., Wallhagen, M. I., Schema, S. J & Kaplan, G. A (1997). New burdens or more of the same? Comparing grandparent spouse, and adult child caregivers. *The Gerontologist, 37 (4),* 505-510.

Sue, S., Zane, N., Hall, G. C. N., Berger, L. K (2009). The case for cultural competency in psychotherapeutic interventions. *Annual Review Psychology, 60,* 525-548.

Tabachnick, B. G & Fidell, L. S (2007). *Using Multivariate Statistics.* Pearson Education.

Takahashi, M, Tanaka, K & Miyaoka, H. (2005). Depression and associated factors of informal caregivers versus professional caregivers of demented patients. *Psychiatry and Clinical Neuroscience, 59,* 473-480.

Tangney, J. P., Stuewig, J & Mashek, D. J (2007). Moral emotions and moral behaviours. *Annual Review Psychology*, 58, 345-372.

Taris, T.W., Kompier, M. A. J., Geurts, S. A. E., Houtman, I. L. D & Floor, F. M (2010). Professional efficacy, exhaustion and work characteristics among police officers: A longitudinal test of the learning related to predictions of the demand-control model. *Journal of Occupational and Organisational Psychology, 83,* 455-474.

The WHOQOL Group (1998). Development of the World Health Organisation WHOQOL-Bref QOL assessment. *Psychological Medicine, 28,* 551-559.

Thoits, P.A . (1995). Stress, coping and social support processes: Where are we? What next? *Journal of Health and Social Behavior, 35,* 53-79.

Tsai, S., & Wang, H. (2009). The relationship between caregiver's strain and social support among mothers with intellectually disabled children. *Journal of Clinical Nursing, 18*(4), 539-548.

Utsey, S. O., Chae, M. H., Brown C. F & Kelly, F (2002). Effect of ethnic group membership on ethnic identity, race related stress, and quality of life. *Cultural Diversity and Ethnic Minority Psychology, 8 (4),* 366-377.

van Oort, L., Schroder, C & French, D. P (2011). What do people think about when they anser the brief Illness Perceptions Questionnaire? A "think aloud" study. *British Journal of Health Psychology, 16,* 231-245.

Weinman, J., Petrie, K.J., Moss-Morris, R & Horne, R (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health,* 11, 431-445.

Wells, Y. (1999). Intentions to care for a spouse: Gender differences in anticipated willingness to care and expected burden. *Journal of family studies, 5 (2),* 220-234.

Williamson, G. M & Schulz, R (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging, 5 (4),* 502-509.

Willis, R. (2008). Ethnicity and family support. *Working with older people, 12 (3),* 27-30.

Vitaliano, P. P., Zhang, J., Young, H. M., Caswell, L. W., Scanlan, J. M & Echeverria, D (2009). Depressed mood mediates decline in cognitive processing speed in caregivers. *The Gerontologist, 10,* 1-10.

Vitaliano, P.P, Zhang, J & Scanlan, J.M. (2003). Is care giving hazardous to one's physical health? A meta analysis. *Psychological Bulletin, 129(6),* 946-972.

Yeung, S., Lui, M. H., Ross, F., & Murrells, T. (2007). Family carers in stroke care: Examining the relationship between problem-solving, depression and general health. *Journal of Clinical Nursing, 16*(2), 344-352.

Youn, G., Knight, B. G., Jeong, H., & Benton, D. (1999). Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology and Aging, 14*(3), 355-364.

Zigmond, A. S & Snaith, R. P (1983). The Hospital Anxiety and Depression Scale. *Acca Psychiatrica Scandinavica, 63,* 361-370.

Zhan, H. J. (2006). Joy and sorrow: Explaining Chinese caregivers' reward and stress. *Journal of Aging Studies, 20*(1), 27-38.

Appendices

The importance of ethnicity on caregiver outcomes: A systematic review.

Review Protocol

Introduction:

The aim of this study is to conduct a systematic review of the current literature concerning the influence of ethnicity and culture on the caregiver experience. The systematic review will be conducted to assess the breadth, depth and quality of research findings to date based on guidance bodies such as the Cochrane group. The systematic review will inform the hypotheses developed and measures used in a later longitudinal questionnaire based study. Whilst the thesis study will specifically focus on British South Asian and White-British caregivers, the current review will take into account all Asian groups in order to gain an in depth understanding of the literature.

Background (adapted from PhD proposal):

Eighty percent of the care required to manage those suffering from chronic illness in the home environment is now provided by family members and close friends (Brereton, 2002). It is estimated that every year a further 301, 000 individuals adopt the role of caregiver, with many not recognising themselves as such due to considering their care as part of their relationship with the ill family member. Despite the difficulty of placing a value on the contribution of carers to society, Carers UK (2007) suggests that informal caregivers providing support in the community save the NHS approximately £87 billion per year. The majority of the caregiver literature in the U.K has focused on Caucasian caregivers with ethnic minority caregivers being neglected due to the common inclusion criteria of caregiver research being spoken English. Government statistics (Census, 2001) show that 10% of the caregiver population consists of South Asians (Indian, Pakistani and Bangladeshi). It was also observed that South Asian carers had the highest rate of spending 50 or more hours per week caring. 1.5% of the Asian carers were below the age of 16 years compared to 0.9% of White-British carers.

A common cultural value held by British Asians is the role of the family in providing care for the ill or disabled family member. This cultural value has been termed as familism (Merrell et al, 2005) and filial obligation (Janevic, 2001). Filial obligation has been defined as “strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity and solidarity among members of the same family” (Brody, 1985; as cited in Losada et al, 2006). Familism is defined as the individual’s reliance upon the family for emotional and practical support (Losada, 2006). Both terms therefore concern attachment and feelings of reciprocity and are likely correlates of actions towards other family members.

Cox and Monk (1993) examined the ways filial obligation influenced the care giving experience of 86 American Hispanic caregivers of those with Alzheimer’s disease. High endorsements of filial obligation were strongly related to perceived burden and stress and those with strong feelings of familism made less use of social support which they suggested may have contributed toward higher stress levels. Whilst research has explored the effect of familism/ filial obligation upon caregiver outcomes in ethnic minority groups, research has not yet attempted to investigate the *processes* by which familism/filial obligation affect outcomes.

Objectives

A systematic review will be conducted to find as many primary studies related to the research question as possible using an unbiased search strategy. The premise behind a systematic review is that all evidence is included in review but weighted differently according to study hierarchy (with RCTs being the best design) and study methodological and statistical quality and appropriateness (Lewis et al, 1997; Slavin, 1995). Only good quality studies that are similar in methodology and outcome measurement can be entered into a meta-analysis, and at this stage it is unclear whether sufficient studies of satisfactory homogeneity in measurement/quality in design shall be identified as suitable for meta-analysis. The systematic review will enable the formulation of general conclusions regarding existing research in the area and act as a prelude to further research activities. The aim of this study is to conduct a systematic review of literature investigating the role of ethnicity and familism in influencing coping (including use of social support) and the effect on caregiver outcomes of burden, anxiety and depression. The review will endeavour to answer the following questions whilst assessing the methodological and statistical quality of the literature and summarising the findings to inform future studies.

1. Is ethnicity associated with caregiver outcomes?
2. What is the process by which ethnicity influences caregiver outcomes?

A separate search will be conducted for each question and findings will be discussed separately.

Method

The methodology will follow the recommendations of Altman (2001) and Egger, Smith & Altman (2001).

Resources:

- Electronic databases
- Journals
- Grey literature and conference proceedings
- The Internet
- Ref works will be used to eliminate duplication

Selection of studies

Relevancy

Abstracts will be screened for relevancy for all identified studies. Relevant studies will also be assessed on inclusion criteria.

Inclusion criteria

All English language experimental studies investigating ethnicity and caregiver outcomes. Studies must have used individuals who have adopted the informal (family) caregiver role. Qualitative studies and commentary articles will not be included. Other systematic reviews may be used as reference points for articles that don't appear in the electronic databases search.

Sample

The samples used in the studies must consist of actual informal (that is non professional) caregivers (as opposed to those anticipating the role). The sample will be of adult caregivers (those above the age of 18 years) but there will be no restrictions on age and gender.

Measures

Table 1. *Variables examined in research questions.*

Question	Predictor Variable	Outcome Variable
1	Ethnicity	Burden Strain Stress
2	Ethnicity	Anxiety Depression
3	Ethnicity	Quality of life

Data extraction

A preliminary search will be conducted to identify existing systematic reviews and to assess the volume of potentially relevant studies. Data will be extracted from studies using a form documenting the following details: author and date, sample, design, measures, statistics, evaluation and reviewers own comments on the study. The data extraction form will initially be piloted on a small number of studies and any required changes will be made before major data collection.

Quality assessment

See checklist.

Table 2. *CRD hierarchy of evidence.* (Kitchenham, 2004)

Level	Description
1	Experimental studies (i.e. RCT with concealed allocation)
2	**Quasi-experimental studies (i.e. studies without randomisation)**
3	**Controlled observational studies**
3a	**Cohort studies**
3b	**Case control studies**
4	**Observational studies without control groups**
5	Expert opinion based on theory, laboratory research or consensus

Methods of analysis

Data synthesis will involve collating and summarising the results of the included primary studies in accordance to each research question. The data may be synthesised quantitatively (meta-analysis) or qualitatively. However it is difficult to predict at this stage whether sufficient number of studies of satisfactory homogeneity will be obtained for a meta-analysis. Extracted data will be tabulated in a manner consistent with the review questions. The tables will be structured in order to highlight the similarities and differences between study outcomes.

Advice and expert review

Dr Val Morrison and Dr Catherine Robinson will provide guidance.

Dissemination

The systematic review will form a chapter in the reviewers PhD thesis and may also be written as a journal article and presented at conferences.

Search strategy

1. Care*
2. Ethnic*
3. Race*
4. Asian
5. Burden
6. Strain
7. Stress
8. Distress
9. Anxiety
10. Depression
11. Quality of life

Search log

Database	Date	Dates covered	Research focus	Hits	Saved as	Notes

Data Extraction Form

Study Title: ____

____

Date: _______________

Authors: ____

Author Location: ____

Hypotheses: ____

____

____

Sample Description

Ethnicity: ____

Gender: ____

Age: ____

Illness group: ____

Relationship with recipient: ____

Time caring: ____

Other care experience: ____

Employment status: ____

Recruitment

Method: ____

Inclusion/Exclusion Criteria: ____

____

____

Final sample size: __________________________

Response/drop out rate: ______________________

Study design: ____

Time points: ____

Outcomes used	Yes	No
Burden		
Strain		
Stress		
Anxiety		
Depression		
Quality of life		

Other Variables used	Yes	No
Familism		
Coping		
Social support		
Illness perceptions		

Statistics

Controlled Variables: ____

____

Main findings: ____

____

____

____

____

Limitations of study: ____

____

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Implications: ____

____

____

____

____

Comments: ____

____

____

____

____

Name of scale	Author	Date	Subscales	Rel/Val

Information Sheet

Research Study Title:

Factors that can affect you as a caregiver.

Invitation:

We are conducting a research study to investigate coping and stress among informal caregivers. We will examine the roles of:

- social support,
- mood,
- demands,
- control and
- types of care-giving tasks.

We would appreciate if you would read the remaining information sheet as it aims to provide you with information about what the study is and why it is being conducted, so you can make an informed decision about whether to participate or not.

If you would like to take part in the study, please complete the attached 1) consent form and 2) questionnaire, then return these in the pre-paid envelope.

What is the purpose of the study?

The aim of the study is to find out both:

- Whether the amount of social support a caregiver receives and the satisfaction with that support, influences how caregivers cope and their levels of stress.

- How tasks, demands and control interact with mood.

The researchers are also interested in whether:

- Family obligation to provide care influences how much social support you use, and whether this differs between different ethnic groups.

- The information from this study will be used to improve support services for carers.

- Also, please indicate on the consent form if you would mind being approached later to be part of a small random group of carers asked to complete a short daily measure of coping.

Results:

If you wish to know the results of the study please tick the box in the consent form and a summary will be sent to you in September.

Risks and benefits of participating:

There are no known risks associated with this study. However, there are potential long-term benefits as your contribution may help improve carer services.

Do you have to participate?

Your participation in this study is voluntary and you do not have to complete the questionnaire. Also if you do not wish to answer any of the questions, you may skip them. You may withdraw from the study at any point without providing a reason.

Confidentiality:

Your participation in the study will remain completely confidential. Your questionnaire will be coded to ensure you are completely unidentifiable to others including the researchers. If you would like to participate in this study please sign and return the attached consent form with a completed questionnaire.

Who is organising this study?

This study is being carried out by Ieuan Hopper and Sahdia Parveen as part of their Masters Research thesis. It is supervised by Dr Val Morrison who is a chartered Health Psychologist.

Who has reviewed the ethics of this study?

This study has been reviewed by the University of Wales, School of Psychology Research Ethics and Governance Committee.

Contacts:

If you would like any further information about the study, please feel free to contact the researcher or supervisor:

Sahdia Parveen:	psp419@bangor.ac.uk	07949 385 482
Ieuan Hopper:	psp45f@bangor.ac.uk	07926 164 136
Dr Val Morrison:	v.morrison@bangor.ac.uk	

Complaints:

If you have any complaints about the study, please contact:

Professor Richard Hastings, Acting Head of School, School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG.

Consent form

Title of Project: Factors that can affect you as a caregiver.

Name of Researchers: Dr Val Morrison, Miss Sahdia Parveen & Mr Ieuan Hopper

	Please Tick
I confirm that I have read and fully understood the information sheet provided for this study and have had the opportunity to ask any questions.	☐
I understand that my participation in this study is completely voluntary and that that I have the right to withdraw at any time without having to provide a reason.	☐
I agree to take part in this study.	☐
I would like to receive a summary of the results:	☐

Name ____________ Date ____________ Signature ____________

Please sign and return with your completed questionnaire in the pre paid envelope or at a location specified by the researcher.

If at any time you have any complaints about the way the research has conducted, contact:

Professor Richard Hastings, Acting Head of School, School of Psychology, University of Wales, Bangor, Gwynedd, LL57 2DG.

Debrief Sheet

Factors that can affect you as a caregiver.

Thank you very much for participating in this study. The questionnaire you have completed explored a range of factors including:

- Social support
- Coping
- Stress
- Willingness to care, and
- Family obligations.

The first part of the study is concerned with how social and family support affects coping and stress. It is possible that social support will influence coping that in turn affects the caregiver's experience of stress and how this is different between ethnic groups. Studies have rarely examined the role of social support and coping within the same study.

The study is also concerned with family relationships and how this affects the support used by caregivers. High levels of family obligations may cause higher levels of stress, as people feel they should not ask for help. This study aimed to compare British Asian and Caucasian caregivers to identify support barriers faced by each group and to improve access to services.

A small selection of caregivers were also asked to rate daily levels of:

- Tasks,
- Demands,
- Control and
- Mood.

This was to investigate how they change and affect both peoples' mood and their ability to cope. This may be used to improve the assessment of support needed by carers and design programs to tackle the specific needs of caregivers.

The results of this study should be available in September 2007. If you have not already indicated that you wish to receive a summary of the results, please contact the researchers using the details provided below. We hope that participating in this study has been an enjoyable experience. The researchers would like to apologise if any undue distress has been caused during the study. If any of the issues highlighted in this study have caused discomfort, you can receive support from the following services (please see attached sheet).

Information Sheet

Research Study Title:

Cultural variations in the experience of providing care

Invitation:

We are conducting a research study to investigate various issues caregivers may face in their role which includes what motivates the caregiver to provide support and care, how they cope with the role and their use of social support.

We would appreciate if you would read the remaining information sheet as it aims to provide you with information about what the study is and why it is being conducted, so you can make an informed decision about whether to participate or not.

If you would like to take part in the study, please complete the attached 1) consent form and 2) questionnaire, and then return these to the researcher when you attend the focus group session.

What is the purpose of the study?

There has been very little research focusing on the influence of ethnicity and cultural values in the individual's experience of the caregiver role. The current study aims to bridge this gap by examining the emerging themes in the caregiver role using caregivers from a variety of ethnic and cultural backgrounds. This study will not only aid future research into the caregiver role but may also help inform further development of culturally sensitive services.

Invitation

We would like to invite you to take part in a discussion group regarding your experience as someone who provides care and support for a family member or friend with the following diagnoses

- Cancer
- Stroke
- Alzheimer's disease
- Parkinson's disease
- Multiple Sclerosis
- Or a combination of the above.

The discussion group will involve 5-10 people and be taped but please remain reassured that all data (paper and tapes) will remain confidential.

Payment:

Expense forms will be provided at the session if you require reimbursement for travel and respite costs.

Findings of the study:

If you wish to know the findings of the study please tick the box in the consent form and a summary will be sent to you once the study is completed.

Risks and benefits of participating:

There are no known risks associated with this study. However, there are potential long-term benefits as your contribution may help improve carer services.

Do you have to participate?

Your participation in this study is voluntary and you may withdraw from the study at any point without providing a reason.

Confidentiality:

Your participation in the study will remain completely confidential. Each participant's data will be coded to ensure they are completely unidentifiable to others including the researchers. If you would like to participate in this study please sign and return the attached consent form with a completed questionnaire.

Who is organising this study?

This study is being carried out by Sahdia Parveen as part of her PhD research. It is supervised by Dr Val Morrison (chartered Health Psychologist) and Dr Catherine Robinson (senior researcher for health and social care).

Future Research

We will also be running a questionnaire-based study from September 2008. The questionnaire will consist of a range of questions including carer coping, use of support services and their quality of life. If you would be interested in receiving further information about this study please indicate on the consent form.

Who has reviewed the ethics of this study?

This study has been reviewed by the Bangor University, School of Psychology Research Ethics and Governance Committee.

Contacts:

If you would like any further information about the study, please feel free to contact the researcher or supervisor:

Sahdia Parveen:	psp419@bangor.ac.uk	01248 388723
Dr Val Morrison (supervisor):	v.morrison@bangor.ac.uk	
Dr Catherine Robinson (supervisor):	catherine.robinson@awardresearch.org.uk	

Complaints:

If you have any complaints about the study, please contact:

Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University,
Bangor, Gwynedd, LL57 2DG

Consent form (Support group manager)

Title of Project: Cultural variations in the experience of providing care.

Name of Researchers: Dr Val Morrison, Dr Catherine Robinson and Miss Sahdia Parveen

Please Tick

I confirm that I have read and fully understood the information sheet provided for this study and have had the opportunity to ask any questions. ☐

I authorize the researcher to discuss the project with the caregivers in the group . ☐

I permit to the focus group session taking place in the usual support group venue. ☐

I would like to receive a summary of the findings: ☐

____
Name

____
____
____
Address

Phone _________________ ____________ Date __________________ Signature

____
Email

If you have any further questions and comments about the study please contact the researcher or supervisor:

Sahdia Parveen: psp419@bangor.ac.uk 01248 388723

Dr Val Morrison (supervisor): v.morrison@bangor.ac.uk

Dr Catherine Robinson (supervisor): catherine.robinson@awardresearch.org.uk

c/o School of Psychology, Brigantia Building, Penrallt Road, Bangor, Gwynedd, LL57 2AS.

If you have any complaints about the way this research has been conducted, please contact:

Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG

Consent form

Title of Project: Cultural variations in the experience of providing care.

Name of Researchers: Dr Val Morrison, Dr Catherine Robinson and Miss Sahdia Parveen

	Please Tick
I confirm that I have read and fully understood the information sheet provided for this study and have had the opportunity to ask any questions.	☐
I understand that my participation in this study is completely voluntary and that that I have the right to withdraw at any time without having to provide a reason.	☐
I agree to take part in this discussion group and be taped.	☐
I would be happy to hear about being part of a questionnaire study to take place next year.	☐
I would like to receive a summary of the findings:	☐

____
Name

____

____

____
Address

Phone _________________ ____________ Date __________________ Signature

____
Email

Please sign and return with the completed questionnaire in the pre-paid envelope provided. You will then receive a postcard confirming the venue, date and time of the session.

If at any time you have any complaints about the way the research has conducted, contact:
Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG.

Focus Group Questionnaire

Thank you for taking the time to participate in this study. Please ensure you have read and fully understood the information sheet and signed the consent form. Please try to answer all the questions honestly and according to your present situation. The information that you provide will be kept completely confidential and the data will be coded so that you are unidentifiable.

Demographic questions.

Please tick the appropriate box.

Gender:

Male [ ]

Female [ ]

Age

____

Ethnic Group:

White British [ ]
Other White [ ]
European [ ]
Black or Black British [ ]
African [ ]
Caribbean [ ]
Pakistani or British Pakistani [ ]
Bengali or British Bengali [ ]
Indian Or British Indian [ ]
Asian Other [ ]
Mixed White and Black [ ]
Mixed White and Asian [ ]
Mixed White and other [ ]
Other ethnicity [ ]

Main diagnosis of the person you care for:

Stroke [ ]

Cancer [ ]

Alzheimer’s disease [ ]

Parkinson’s disease [ ]

Multiple Sclerosis [ ]

Multiple diagnoses [ ]

Other please specify ______________________

Relationship to the person you care for _____________________

Number of hours per week of caring_____________

How long have you been caring for this person: _______________

Have you provided unpaid care for any other person?

Yes [ ]

No [ ]

How long have you been attending this support group: ____________

How regularly do you attend these sessions: _______________________

Focus group format

Introduction

- Welcome and introduce myself. Describe my role as asking questions and "listening to all the different things you have to say and helping to make sure that we hear from each of you." Introduce second researcher as note taker and observer of the session.
- Goals of the research: the project is about cultural variations in the carer role. We will be discussing why you became a carer, how you cope with your role and how your experience as a carer changed over time.
- Talk about the session being taped, but no names will be used in final report and only I will listen to the tapes.
- Guidelines: Before we begin I just need to discuss some guidelines with you:
    1. First of all the session is being taped so could you all please talk clearly and only one at a time.
    2. Please refer to each other on a first name basis
    3. Even if you don't agree with someone please listen respectfully
    4. I am interested in everyone's point of view so please can I hear from everyone today.

- Ask everyone to introduce themselves for the tape (first name only!)

Topics to be discussed

I. Why did you become a carer?
II. How do you feel about your role?
III. How willing are you to provide care?
IV. Do you feel you're expected to provide care?
V. How long have you been caring for?
VI. How has your experience changed over time?
VII. How do you cope with your role?
VIII. How long do you think you can continue with your role?
IX. Do you receive help from others?
X. What kind of help do you get?
XI. What is your experience in accessing formal help?

The session will be kept unstructured and above questions are guidelines.

Probe questions:

- Would you explain further?
- Can you give me an example?
- Is there anything else…
- Please describe what you mean…

Debrief

We have come to the end of the session, are there any other questions or comments anyone would like to raise?

Thank the carers, hand out debrief sheets and pay them. Some people may speak to us as they are leaving be ready to take notes!!!

Debriefing Sheet

Cultural variations in the experience of providing care

Thank you very much for taking part in this study. The purpose of this discussion group was to explore the various issues affecting the experience of the caregiver in their role and how this was influenced by caregiver ethnicity.

The findings of this study will help us develop a more detailed understanding of the caregiver role. The topics discussed today will be used to develop a questionnaire, which will be used later this year in a longitudinal study of caregivers. The discussion today may also be useful in informing the development of more culturally sensitive services.

The findings of this study should be available by July 2008. If you have not already indicated that you wish to receive a summary of the results, please contact the researchers using the details provided below. We hope that participating in this study has been an enjoyable experience, however if any undue distress has been caused during the study please contact:

Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG

If you have any further questions and comments about the study or would like a summary of the results please contact the researcher or supervisor:

Sahdia Parveen: psp419@bangor.ac.uk 01248 388723

Dr Val Morrison (supervisor): v.morrison@bangor.ac.uk

Dr Catherine Robinson (supervisor): catherine.robinson@awardresearch.org.uk

c/o School of Psychology, Brigantia Building, Penrallt Road, Bangor, Gwynedd, LL57 2AS.

Cultural variation in the experience of caregiving
Focus group 1: Preston 27/4/2008
(Mixed Pakistani and Indian)

Sahdia: Welcome
Farzana: Translates above
Farida: I care for my aunty and for my husband
Nazma: I care for my husband
Hazra: I care for my daughter
Mohammed: I care for my wife
Naseem: I care for my mother

Rukeya: I'm a carer for both people, er my mum who is 74 years of age and also my son who suffers from serious depression and also has *** I'm also working with people with complex needs and er learning difficulties. I'm also a youth worker as well, that means I'm working 44 hours a week, I'm a single parent, er and I have to do everything for my mum and my son, my mum lives separate independently but I also have to look after her as well, my son lives with so I also have to look after him, so I don't have time for myself.

Farzana: Aww my heart goes out to you! Introduces herself as ethnic minority carers support officer.

Sahdia: first of all I want to know why you all became a carer in the first place.
Farzana: translates

Farida: I also work in the hospital with women's health. When I was working there I found out how difficult it was for some of the women and then it came onto my door step with my aunty who is 75 years of age, I mean she's not dependent but most of the things I do for her and she won't let anybody else do it for her.

Sahdia: erm did you become a carer because there was no one else?
Farida: Yeah there was no one else and she doesn't like to get any help from the social services at this very moment

Sahdia: Ok

Zohra: I'm a carer for my father who's got physical disabilities, he's had an operation and now he's disabled from the leg downwards. So basically I've become because it's fallen on me, its not that I've chosen to be.

Sahdia: Yes that's what I mean when I say why did you become a carer, did you choose to become a carer or was there no one else …

Zohra: There was no one else to do it

Nazma: My husband is not well; he's had a mental illness problem that's why I'm a carer. I'm a carer because its fallen on me an I also have children, young children, and basically there has been no other support for me, I took it on as my role to do the next best thing really and to care for my husband.

Sahdia: Does anyone else want to add to why they became a carer?

Hazra: I've been caring for my daughter, me and my husband have been caring for her because she needs more than well more than 2 people so yeah we care for her, she's epileptic and has suffered from brain damage. So yeah that's why I became a carer.

Mohammed: My wife is seriously sick, cancer. Yeah and it's been 8 weeks, I've been crying, I don't know what's happened, how to do care things.

Sahdia: Is there nobody else to help you?

Mohammed: Nobody else, my son is in London, one is here but he's afar, my daughter lives in Bolton she gives some food, she send for me.

Sahdia: Is it just you and your wife?

Mohammed: yes.

Naseem: Er I actually became a carer by choice as well as it fell upon me, because even after getting married, I'm the youngest in the family, we are a family of 6 brothers and sisters, unfortunately, coz I'm living with my mum, who I care for, even after getting married, I still live with my mum, erm when she became ill it was considered as my role to look after her because all the other sons and daughter live in separate houses, further away from my mother because I was nearest to her, it fell upon me to look after her. Fortunately I didn't think of it as a burden or anything, I considered it as a role for me to do, to look after my mum.

Rukeya: 10 years ago, my youngest son was suffering from severe depression because my other son died, and the mental health service did not provide any service for 7 years, I went round in circles asking them to help me and they said unfortunately we have no services to provide to children under 17 so my son was without education without financial support without a social worker and without any medication as well because the doctors were not very helpful either. So I waited for 7 years to get help, for 7 years he was completely isolated, completely excluded from education and erm only 3 years ago a law has passed that they can provide service for children under 17 but its too late for my son and its very difficult because I'm a single parent and I care for my son. The most important thing I want to say is lots of agency and professional people don't understand our culture, don't understand our faith, and the most important thing is our voice not being heard, so I'm speaking on behalf of all the Muslim community, especially when my son ended up in a mental hospital, they did not understand our culture, they did not want me to stay with my son, they did not provide any halal food, er and the needs were not met for my son. So after 5 weeks I said I had a meeting and I said I'm not bringing my son here because it was hell for him and I returned my son from the hospital because everyday he was crying because he was put with the adults and he was the youngest child, he wasn't suffering from mental illness before, he was suffering bereavement because he lost his brother who was only 19 years of age but the professional people did not give us a choice, they put him into a mental institution with adults with serious mental health problems and er that's why I became a carer.

Sahdia: You said you care for you mother as well…

Rukeya: Yeah after 3 years my mum had a stroke so I looked after her until she go better and then 4 years ago she fell down the stairs so she can’t walk, she’s not mobile, so I do everything for my mother, I make sure she has medication, I make sure she’s got food, I do all her laundry, I do her cleaning. When I went to the social worker, the social worker said to me we haven’t got anybody, we can’t provide any home help because we can’t find anyone who can speak Gujarati language, my mum stayed in hospital for 2 months, and I said I’m going into work and I need desperately someone to come in for home help and they couldn’t find any home help so I’m a carer for my mum as well.

Farida: That’s ridiculous what they said, they can’t find anybody who speaks Gujarati, there are social workers who speak it, I know there are for some of them speak Gujarati, Urdu…

Rukeya: Well for home help, they can’t find anyone after 3 o clock because most home help who speak Gujarati only work part time and object to after 3 and that’s what I was told so its all waiting and she needed help straight away because she can’t walk, I’ve become a carer and she’s 74 years of age.

Farida: So how long have you been caring?

Rukeya: For the past 8 years.

Farida: So have the social services not got anybody with …

Rukeya starts talking over Farida

Farzana: You’ve just lost a lot of faith haven’t you (to Rukeya)?

Rukeya: Yes, I might as well do it myself.

Farida: But I can understand your frustration but you have to fight for her, you have to keep asking them again for it I mean the law changes, I mean now the social services and authorities get more of our Asian people with the language. They can’t say, I mean as far as I know, I work in hospital, most of the department can not turn around and say we can't speak or we haven't got an interpreter, by law they have to or the doctor and the nurses or the hospital workers they speak the languages as well.

Naseem: Have you heard of the direct payment system? (To Rukeya) That's what my mum is on, we've just joined that scheme and it's very beneficial because you can, your mum can employ people who speak her language.

Rukeya: Well now she doesn't want anybody she wants me to look after her so I don't mind looking after her, because she is my mum and it's our responsibility.

Farida: Yes it is our responsibility

Rukeya: We need the time to have debates when you have lots of emotional problems you can't speak out, because you haven't got the time, its exhausting. When second time its happened to me I can't be bothered to ask for help, I'm happy to do it myself because through my own experience, I've had a lot of bad experiences with social workers, because when my son was not going to school I told the social worker, I used to be a supervisor, I was running my own mother/toddler group in the community centre, one of the mums got fined because she had not sent her daughter to school so that made me so angry, I came home and I phone the social worker, I said to the social worker, by the way one of the mums from my mother/toddler group got fined because she had not sent her daughter to school, I really want my son to go to school, why are you not telling? Why are you not coming to me? The social worker came banging on the door and it was so impolite, he said I want to see your son and I said my son is suffering from severe depression and doesn't want to see anyone. He just came barging in and he was so impolite and he made my son upset…

Farida: That's a case of…

Rukeya: I've had so many bad experiences…

Farida: if that's the case I think you should put in a complaint to it, they shouldn't be I mean if the social workers has come to you, that's very unfair and it's not right. If they have treated you like that if I'm in your shoes I would definitely complain about them.

Rukeya: Sometimes it's too late to complain

Farida: No it's never too late to complain; it's the not complaining is the worst bit. Because then it doesn't get heard.

Naseem: You still have to go through each avenue to get there.

Farida: But at least you've done it then.

Naseem: In my experience I've had good liaison with the social workers although I've done everything myself, any avenue that was open I took that, but eventually we got there I know some people say we had difficulties in the beginning because it's the same as Rukeya, all my time is taken looking after my mum, she can't rely on anybody else its got to be me, even now I was going away for about 2 hours and she was oh where are you going away from me and when will you be back. She becomes anxious erm (to Rukeya) I think you should speak to social services, speak to someone again.

Sahdia: I would like to open this question to everyone…You have discussed who you care for and why you care for them, whether it was willingly or whether you had no choice but now that you are a carer, how do you feel about the role?

Mohammed: Says something (in English) I can't hear properly from the tape
Farzana: Uncle (referring to Mohammed) was totally looking after his wife without any provisions any social services help what or ever; I came along and told him about..
Mohammed: (to Farzana) I complained to you and you've done a very good job for me. Everything she did for me, I pray to God to keep her healthy.

(It is frowned upon young people to refer to older Asian adults by their name therefore it will be heard on tape from myself and Farzana referring to the participants as uncle or aunty.)

Sahdia: I just wondered how you feel about you having to provide care and you son and daughter not helping?

Mohammed: My own son cannot do. God has given me other angels (looking at Farzana)

Farzana: What uncle is trying to say is that his son basically hasn't helped in the caring role that he has sort of basically fallen upon him. Let me just explain, before aunty (Mohammed's wife) was diagnosed with terminal cancer uncle had Parkinson's disease himself so the roles have reversed if you will up until now, aunty was caring for uncle because he was ill and she was ok but the roles have reversed now in that uncle has become more of the strong one if you will in health and he has become a carer for aunty who has terminal cancer, so basically he's trying to do the best he can with help from outside agencies and myself of course.
Mohammed: In 2 weeks she maybe die. I cry…(cries)

I say to her I hope you stay in this world….words become indistinguishable because Mohammed is distressed.

Farzana: Basically uncle is saying he wasn't getting any help before I sort of went in and provided some social services provisions, I got into touch with social services, and told them about aunties and uncles situation and got help straight away and other agencies

Farida: Being a carer for the time being is alright but as it gets longer you do need a bit of time for yourself, and the person you are caring for they depend on you and they rely on you and they trust you. As Naseem was saying if somebody else come to look after them or care about them, they don't want to discuss with them, its just sort of that relation thing and bond you get between them like my aunty, I mean she tells me to do everything, if her brother comes or anything she don't want to talk about her financial or anything else in front of him, even though he is her brother but then she relies on me and says ok you do this, you do that, what ever financially, whatever medically what ever reason. You get satisfaction, you are helping somebody to a certain extent then it does catch you then at a time, it sometimes depends on how long I've been doing it and if you are working as well…

Sahdia: Do you mean it gets more burdensome?

Farida: Of course it does, I mean don't use the word burden but it does cover that term, I mean sometimes if I wanted to go like today, I know I can't come out of that house all day and from here when I finish I got to go to my aunty but yeah if I want to spend 3 hours extra in the town but because I've told her I'll be there after 3 today I know she will be waiting for me, so its sort of burden, there are times you do get satisfaction as well but then you need that break, then with the services and authorities, you have to fight with your arms and legs with them.

Naseem: Yes you do. I find that sometimes it can be a strain, with wanting to get out of the house its like with what Farida said about it being about relationships, it's the same with my mother as well even when her daughter in laws or my sister or somebody else will come, she won't ask them to do that job, although I do get help from my other sister and my bahbi (sister in law) but not anyone outside of the 2 people in immediate family, they do come and help but even then she will never ask them to that chore and my sister is always saying why is that, she knows that you need time to , she says you need that time for yourself, I'll come and sit with mum for a couple of hours and she does that like for instance today I've asked her to come down and sit with her but I still gave my mum her dinner before I came and I know she won't ask my sister because the minute I walk into the house she will say I'm feeling a bit peckish, she's diabetic as well amongst other illnesses. My sister will quickly get up and say I've been sitting here and asking mum for the last 2 hours does she need anything but she won't have said. Sometimes I think I feel guilty, the other family think she's taken over that role like with the financial, I'm in control, of my mum's financial, well I wouldn't say control of everything but 90% of what goes on with her, through her allowance and how she lives I mean I do her grocery shopping, everything, bill wise, she doesn't know, for the last 20 years she doesn't know where

her money is going, she knows that I tell her every month, this is where your money is but sometimes I feel that I sometimes get the feeling from my family especially from my brothers that our sister is taking over this role and that they say that I will probably benefit in her will but I think…
Everyone talks at once in shock “all they’re after in her money”

Naseem: its not about inheritance, everyone else says you are getting your mums blessing, what ever little thing you do for your mother you are taking time out of your life, and to be honest with you I have sacrificed a lot of my life, I’ve given up a lot of things to look after my mum. I am pleased and proud to be, because I wouldn’t like it any other way. We recently just took her to hajj as well (religious pilgrimage) and now she’s suffering from dementia from the last 18 months, it is very very difficult, we had a really difficult time in Mecca (Hajj), but with Gods help we did our best. I know there’s always a niggling in my mind that do I do everything for my mum, when I go to bed every night I think did I do enough for my mum, did I raise my voice at my mum for anything coz she’s asking me so many times because of her dementia she forgets what she’s eaten what she’s had, her medication, so its like she’s like a little child now.

Sahdia: Do you think it’s become more of a role reversal now?

Naseem: Well yes it has sort of reversed, its like we’re in charge although my mum still likes to be independent and she’s always lived an independent life, shes had a very good life, she’s worked herself, shes run the family business, shes worked very hard but I know its very difficult for her, when I see her in her bed with the tears rolling down I know she feels like shes got nothing left, she feels shes got nothing to give, it’s a shame really but that’s how things are and that’s the way God’s will is.

Shianta: I am caring for my daughter who has mental health problems; I don’t get any help from outside agencies, to get help a referral has to be made from the G.P when it concerns mental health issues. I’ve been passed from pillar to post and I’m fed up, I had a meeting with a support officer and got fobbed off.

Rukeya: We find that the mental health service has not been properly funded at all and another thing is if you have a good doctor you will be ok but if you have a doctor who doesn’t listen to you, then you’ve had it, then you don’t get any help at all. I’ve dealt with mental health problems with my son, it’s been nearly 10 years, in mental health service, the service is very very bad. It needs to be improved, because we go round in circles we have a lot of different agencies but no body seems to understand and no body seems to help us at the moment my son only gets 2 and half hours only which is not very good and he’s only young.

Sahdia: You’ve said mental health services aren’t very good but how does this make you feel?

Farzana: As a carers support officer it frustrates me I can’t access a simple service that should be accessible to anybody. If I’m struggling as a carer support officer I don’t how the service users will feel! I talked to the mental health service manager the other day which he didn’t seem to be able to have an answer for, but basically I feel you’re pushed from pillar to post, it’s as if they don’t seem to understand the needs of certainly the minority ethnic communities.

Sahdia: Can I hear what the carers want to say about this?

Farida: Frustrated, if you go to a meeting or service, something like that the service provider just fob you off and they say I haven’t got anything or phone this number and that number, if they haven’t got any details, they don’t sign post you directly, it does make you feel frustrated. If you are a carer if you are caring for mental people you know more than the service provider what you are going through, its not just within our community, within all cultures all races, mental health problem is not just within the Asian community.

Rukeya: I get so emotionally upset, it’s a good job I can speak English if I had not spoken English I’m sure they would have taken my son away at a very young age, what I did I wrote a letter to house of commons and she really helped me, she wrote a letter to all the different agencies, and she was the one that helped me in the end, and I had to change the doctors because my own doctor did not understand depression illness, he said to me your eldest son died because I did not know how to treat him well and now with this other son I'm not going to treat him.

Farida: A doctor can say that?
Rukeya: Yes he said that to me
Farida: I don't understand, what did you do?
Rukeya: I changed my doctor
Farida: But that doesn't matter, the doctor is still practising, someone else will go with a problem and if the doctor says he doesn't understand what mental health or what depression is, he can't treat the patient.

Rukeya: What he does is refer you to the psychologist or psychiatrist, that's what he does because he said he doesn't know how to deal with depression, well he's very good in other fields, just mental he's not very good

Farida: I mean doctors g.ps can refer you but they do know the illness

Rukeya: Not most doctors, not the doctor which I had.

Farida: Some of the consultants I mean say the consultant is a heart consultant he know more about the heart than say something else but if you go to the G.P, what ever your problem is, you tell them, fair enough he will refer you but he should know where he is going to send you.

Farzana: Not all doctors are that clued up when it comes to mental health. I can really back that up because when I had to make a referral to the doctor about a mental health patient and I said what's your knowledge of this patient and how would you describe them. He said basically I think they are making it up I think they are having a laugh, and that is a doctor saying that to a carer support officer and I was just so taken aback. I was shocked.

Sahdia: And how do the carers feel about this?
All: disgusting all talk over one another

Rukeya: I just want to say after my son died, my other 2 children are suffering from severe depression and even then I didn’t get any help, so most of the time some professional people don’t seem to understand depression illness. Not all of them, some of them.
Sahdia: Do you think there’s a cultural element involved in this, with the lack of understanding in mental illness, with services and at home?

Farida: The culture I mean as a parent of a family I know I do know they try to put a blanket on it, its not a nice thing to say oh he’s mental health but that’s what I would say a couple of years ago but now its widely known and its not a culture thing only.

Naseem: No barriers

Farida: No barriers involved

Sahdia: So there’s no stigma within the community?

Farida and Naseem: No I don’t think so

Nazma: I have language barriers and therefore find it a struggle to access mental health services, the social workers take advantage of that, they think well they don’t know what’s out there so I’ll leave them to it. When I told the consultant that I wasn’t getting any service support he wasn’t much help either.

Farzana: Before I came along aunty did not get any help from services

Sahdia: What has you experience been (to Hazra)

Hazra: at the moment its alright, everything is fine, my daughter is 29 and we’ve been looking after her all the family members so I didn’t need a social worker, they said call me if you need me and I said I will tell you when I need you but then Farzana came along and then yeah she told me someone can come help you but I don’t need help at the moment and everything fine.

Farzana: to add to that Hazra has got a very good core family support and that’s important as well as getting some services

Sahdia: How do you cope with the role? (to everyone)

Farida: well with me I was working full time before and now I have to cut down my hours and now working part time. Sometimes it does get to you, I’ve had to sacrifice so many things

Sahdia: So does your job provide you with an outlet…?

Farida: Yes an outlet, it’s a part time job, it’s the only time I can get out and away from it

Nazma: I’m coping the best I can but sometimes I feel like I’m not getting anywhere

Farida: Sometimes I mean like myself you just have to cry

Zohra: I have readjusted my lifestyle to fit around my caring role, as in getting up early in the morning, bathing, cooking and cleaning basically I’ve changed my whole lifestyle to fit around the care.

Rukeya: In my situation I was completely isolated, nobody helped me not even my own relations, the only thing that kept me going is prayers. I pray every day to God, God has really helped me a lot, I wake up really early in the morning, I don’t have any social life at all, because I can’t leave my mum alone so I don’t have any holidays either but I thank God for giving me the strength and at the workplace the managers don’t understand especially when I have to take my mum for an appointment sometimes I had to tell them, but when I tell them the truth they don’t believe me so its one of those things, but it has been very difficult for me because my suffers from dementia and sometimes she looses her temper so much, one minute she’s ok the next minute she’s shouting at me so sometimes I get emotionally upset but I can’t share it with my son either so I just keep quite. I’ve got no one to share my emotional problems, so I just keep it to myself but today I've really opened up and spoke out a lot. Thank you very much for listening to me.

Naseem: She feels better about it now

Farida: Yeah you have to take it out from your chest; you can't just bottle it up

Hazra: I think I've had a normal life with my daughter because I have all my family that help me with my daughter. Whenever I want to go out everywhere you know there's always someone to look after her. So at the moment I'm so lucky.

Farida: Your parents live next door isn't it?

Hazra: My sisters, my parents, my brothers are all very good

All: You're very lucky

Hazra: I've got a very good life thank God

Sahdia: What way does the family help?

Hazra: With everything, you know like bathing, everything, she's epileptic, she has fits everyday

Sahdia: What has your experience been with your families whilst in the care role? (to everyone)

Mr Mistry: Other carers come in daily for my wife who has dementia an mental health problems and she has physical disabilities as well, they do what they have to as in bathing and do what they have to in an hour or two, they come to do domestic duties, hovering, cleaning, polishing but basically other than that I do everything myself.
Sahdia: Do you get any help from family members?

Mr Mistry: My daughter comes in and cooks for me and my wife so I do rely on her. About twice a week she comes in and does cooking.

Rukeya: None of my family, none of my relations want to know us so I’m completely isolated.

Sahdia: How does that make you feel?

Rukeya: It’s a big worry for me because I think what going to happen when I die, what’s going to happen to my children when I die, that’s the main worry.

Sahdia: Why do they not want to know you?

Rukeya: It’s a big type of thing because I got divorced 12 years ago they did not agree with my divorce and that’s why all this has happened. So I’ve got nobody, no support from no one.

Farida: So do you think your family blame you for your children not being well with depression, it’s everything to do with your divorce?

Rukeya: That’s all linked together; the family don’t seem to understand because they haven’t gone through that experience.

Farida: Is it both sides of the family?

Rukeya: Both because I was marrying a relation, so his relations and my relations all got together and they don’t want to know me and they don’t understand so my son hasn’t got a dad because you know we got divorced and all that so he feels really isolated. So my main worry is what’s going to happen when I die because I really want him to be in the faith, Islam religion, I really want my children to be with me at the moment but what going to happen when I die? That’s my biggest worry and fear.

Naseem: I just want to say I do get some support especially from my sister, I won’t vouch for the rest of the family but my sister does especially when I need to go out as

I said for example today I've come out. She seems to realise that I have sacrificed a lot of my time and most of life for my mum and she thinks I deserve to have a bit of time to myself and I won't hesitate to tell my sister to come and sit with mum and I appreciate her very much for that although it is very difficult for her as well because she needs to get a lift to get to my mum because she can't drive herself, even so I know my sister will give up everything to come around so I'm very appreciative for what she does for us.

Farida: If the family are living near that's fine, if they are not living nearer, yeah my son are working away from home but when ever they are here that's fine, but if I need him anytime of the day or night, they are not here because they are working away from home. Its not that they don't want to help but they are not here.

Sahdia: Those who have an extended family helping out are you satisfied with the help or do you think they could do more?

Nazma: If I ask for help from the in-laws, yes they will help me but if there are times when I need to go shopping I need to make a point of asking on of the in-laws to go out and do the shopping for me. On occasions when I become ill and I am unable to carry out the care duties and the daily household chores, I ask the children, yes they are willing to help but only when I ask do I receive the help, nobody comes around and says can I do something for you, to relieve some of your stresses.

Sahdia: How do you feel about having to ask family members for help rather than them offering?
Zohra: Because my daughter is a trained nurse she is able to change dressings for me, she offers as much help as she can when she is available other than that, I only get help if I ask for it. They live nearby but they don't make it on a daily basis to ask if I want to help.

Farida: Its very rare in any extended family to knock on the door, they know that you are still up at midnight or 4 o clock you are still in hospital with the aunty or whoever you are caring for but still you don't expect them to come knocking on the door in the morning saying oh you were in hospital till 3am, so I will make food for you or I'll come and do the ironing for you.

Hazra: But my parents are like that

Farida: But yours, its your parents, we are talking about the relatives in the extended family. With you it's your parents and that's different.

Hara: Our parents, that is the girls side of the family are more helpful

Naseem: I find it quite difficult myself, I would never ask one of my brothers or sister in laws to come and help because I know they wouldn't and they should be doing this themselves, it's really their duty not my duty. You see I have 2 strains; I have my mother and the added strain of my husband breathing down my neck. I'm looking after mum and recently an incident happened, she was taken into hospital in the middle of the night with a heart problem, she has a problem with her heart, and she was taken in the middle of the night and this time I rang my youngest brother and the rest of them, I never told them, I thought its for them to find out, they should know, they should come and see mum on a regular basis, we didn't get a complaint, I said if anyone has a complaint come to me but nobody dared because they know I am doing a superb job 24 hours 24/7 job and nobody can take that place.

Sahdia: You mentioned that you felt it was your brother's obligation to provide care, Do you feel you were expected to provide care because they weren't?
Rukeya: I feel that the brothers should take responsibility and sister in laws, especially in my situation, sister in laws are not working at all but they do not want to take any responsibility to do anything and I think its not right, they should understand that I'm a carer for 2 persons, I go to work but they don't want to take any role at all, even when I take my mum to hospital, my sister in law doesn't want to do anything at all. She doesn't even want to take my mum to hospital so I have to take a day off from my other job to take my mum to hospital. My brother is excellent; he will take a day off from his job to take my mum to the hospital but not my sister in law. So I feel the sister in law should take some responsibility.

Naseem: Yes I agree, if the sister in laws expect you to do all the work, then why is it we can not think they have an obligation, that it's their obligation first to come and look after their mother in law.

Farzana: I just want to back up what Naseem means is that especially in the Muslim culture it is culturally appropriate also religiously, it does fall on the daughter in law, for my mother in law, it would be more expected for me to be able to look after my mother in law than it would be for my sister in law that is my husbands sister. It is almost a religious obligation that the daughter in laws are expected to look after their in laws. That is swaying a little bit with time though.

Naseem: I don't about the times, but it's always been like that in our family, I don't really want to say too much on that but that how my experience has been. It has always fallen on us daughters of the house to help out.

Sahdia: To the carers who are daughter in laws, do you think you provide care because you are obligated to?

Farida: I did care for my father in law who was terminally ill 29 years ago who had a cancer, and I didn't know anything about this caring social services thing, So I did care for my father in law, and it was my duty, it was my obligation, or whatever you call it, he lived with us, and he passed away at home, he was never taken to any centres or anywhere. He used to sleep downstairs, we brought his bed downstairs into the dining room and at that time my husband was working full time and I had small children, but between me and my husband, we did a shift, night shift as well. I'm glad I did it and I'm proud of, it was my duty and it was my obligation and I'm very proud, if I had my mother in law I would have done the same thing for her as well. At one time I remember he was so ill they said they were going to take him to the hospice but me and my husband said oh no, nobody can take him from here, my Dr G.P is very good and he would bring in the mobile x ray thing to do his x rays and I'm talking about this 29 years back, not now.

Zohra: Because in the Muslim religion you are obligated as a daughter in law to look after your in laws, and who ever becomes ill I would say, it is in the understanding that if you become ill, every bodies time comes and basically I will get the same sort of help and reward from my own daughters and sons and the extended family.

Rukeya: In our religion we have to look after our mother in law and father in law the same as our mother and father. I do the same, I look after my mother in law, even when I got divorced, I still went and looked after my father in law, I stayed with him for a week, I stayed with my mother in law last week when she became very ill, I do everything for my mother in law and my father in law, in our religion we have to look after our mother in law and our father in law and both parents.

Farida: It's the word mother in law and father in law, in our culture and in our religion, its mother and father, we have been taught from a very young age, from the beginning, you get 2 sets of parents. You are to take his parents as your parents, not mother in law, father in law.

Shianta: In the past it was like you did it on a routinely basis to care for your in laws, your parents. It's not like a chore, something you are obligated to do; you just do it, its second nature, Part of you daily life.

Naseem: You don't have to think about it, you just do it.

Mohammed: I have a daughter who lives quite local but she's got her own problems because she's got children with disabilities and I have a son who lives in London. Because of the way the world, people have to go where the jobs are, I have a daughter in law and a son but they don't live with me. They do input into the care role but I am very grateful for the provisions that social services have provided meaning that I don't have to rely on the help of family members. My family are committed to their own work and I do appreciate they have their own life.

Sahdia: Now that you all have been caring for a while would you be willing to continue your role as you are now?

Naseem & Farida: mumble yes

Zohra: As long as God gives us strength and enough help to carry out the duties for as long as they live.
All agree

Mohammed: Up until 1993 I was wheelchair bound because of my Parkinson's and my wife took care of me and now my wife has cancer and the roles have reversed. Its Gods test to see if he is able to do it for her. Thank God I have been able to do that and I intend to do it for the rest of my life.

Sahdia: End of questions, any comments?

Appendix 3h

Theme 1: Motivations to care

Key:

British-Bangladeshi British-Indian British-Pakistani White-British

Similarities	Differences
"Yeah there was no one else and she doesn't like to get any help from the social services at this very moment" "There was no one else to do it." "I'm a carer because its fallen on me" "Well now she doesn't want anybody she wants me to look after her so I don't mind looking after her, because she is my mum and it's our responsibility." "In the past it was like you did it on a routinely basis to care for your in laws, your parents. It's not like a chore, something you are obligated to do; you just do it, its second nature. Part of you daily life." "Didn't have any option, my husband suddenly became ill." "We are expected because it is our duty towards our family" "We chose because they (care recipient) would like it to be a family carer."	"He's my husband and I love him, He's good to me." "And it's your husband, you've been married to him a long time, it's in your marriage vows, its something you want to do for him." "I think it's the emotional attachment that makes you want to care." "It feels nice, if someone else is ill and requires care, it feels good to help." "Its part of your nature, it is part of our nature."

"There's nobody else in the house so I'm the carer" "If sometimes the daughter in law doesn't want to do the caring, sometimes by force she has to do it, not choice, because she is a daughter in law, its her duty." "I'm caring for my husband and he can't care for himself, so I have to take care of him, he's unable to do things on his own."	
"It's my son so sometimes I do it as a loving thing, and sometimes I have to do it because there's no choice."	

Notes:

BB, BI and BP motivations are mainly extrinsic: duty/obligation/no choice/care recipient's choice
WB are mainly intrinsically motivated: caring nature and emotional attachments

Theme 2: Willingness to care

Similarities	Differences
Unwilling (Issue over whose responsibility care role should be):	Willing (related to fulfilling cultural obligations and feeling an emotional attachment)
"Yes I agree, if the sister in law expects you to do all the work, then why is it we can not think they have an obligation, that it's their obligation first to come and look after their mother in law."	"We are happy to be taking care of our kids, we find it rewarding, culturally we have to care for our own, it's rewarding."
"I would never ask one of my brothers or sister in laws to come and help because I know they wouldn't and they should be doing this themselves, its really their duty not my duty."	"We are willing to give as much as we can, do our best."
"I feel that the brothers should take responsibility and sister in laws, especially in my situation, sister in laws are not working at all but they do not want to take any responsibility to do anything and I think its not right, they should understand that I'm a carer for 2 persons, I go to work but they don't want to take any role at all, even when I take my mum to hospital, my sister in law doesn't want to do anything at all. She doesn't even want to take my mum to hospital so I have to take a day off from my other job to take my mum to hospital. My brother is excellent; he will take a day off from his job to take my mum to the hospital but not my sister in law. So I feel the sister in law should take some responsibility."	"We won't hand our family over to anyone else, it's our blood. We'll do it ourselves. We will try as long as we are here. We don't want anybody else to look after our family."
"I'm beginning to find as I get older I'm not really willing, because I've got to be there and because I don't really feel willing I feel awfully guilty feeling like that."	"I am willing to do it. However long we can do it for, we will do."

"I feel absolutely obliged because you're brought up like that to look after people." "I agree with jenny, I don't think willing is a bit…. i don't feel willing, I feel I've got to. If I had a choice…" "If sometimes the daughter in law doesn't want to do the caring, sometimes by force she has to do it, not choice, because she is a daughter in law, it's her duty."	"I'll do it as long as I'm able to, I'll ask for help if I struggle." "However long we are here for, we will give help, we won't give our family away." "That's true we need to do our duty." "As long as God gives us strength and enough help to carry out the duties for as long as they live." "I think it just comes into your life and you you're more than willing and you want to do it." "I would never put my husband into a home" "I vowed that I will never ever put Trevor, and I've had dealings with nursing homes and I don't want to go in one I'd rather be given a tablet!"

Notes:

All caregivers are willing to continue providing care. With Asian caregivers this is related to cultural/religious obligations. With White-British this is related to avoiding nursing homes. BI & BP have issues over whose responsibility it should be to provide care.

Theme 3: Experience of role

Similarities	Differences
Positives:	Positives:
“You get satisfaction, you are helping somebody to a certain extent then it does catch you then at a time”	“Well you find out who your friends are”
“everyone else says you are getting your mums blessing, what ever little thing you do for your mother you are taking time out of your life”	“I’ve learned how to use a computer and I love that, I mean I didn’t know what it was like to pay bills or anything like that, my husband did that.”
“I’m glad I did it and I’m proud of, it was my duty and it was my obligation and I’m very proud, if I had my mother in law I would have done the same thing for her as well.”	“I never touched the garden whilst he was all right, never did anything like that, cleaning the windows.”
“We are happy to be taking care of our kids, we find it rewarding, culturally we have to care for our own, it’s rewarding.”	“It’s made me a stronger person; it’s made me more independent.”
“Yeah we’re fine, everything’s fine.” “I like it any way I enjoy myself.”	
“Yes we would because you learn a lot and gain more life experience.”	
Negatives:	Negatives:
“I’m a single parent, er and I have to do everything for my mum and my son, my mum lives separate independently but I also have to look after her as well, my son lives with so I also have to look after him, so I don’t have time for myself.”	“Unless you’re actually in the role you don’t actually understand how isolating it is. I think that is the hardest thing.”
“All my time is taken looking after my mum, she can’t rely on anybody else its got to be me, even now I was	“I do feel very resentful and to be perfectly honest I find it an awful burden.”

going away for about 2 hours and she was oh where are you going away from me and when will you be back. She becomes anxious erm..” “I find that sometimes it can be a strain, with wanting to get out of the house” “to be honest with you I have sacrificed a lot of my life, I’ve given up a lot of things to look after my mum” “Well with me I was working full time before and now I have to cut down my hours and now working part time. Sometimes it does get to you, I’ve had to sacrifice so many things” “No, the work, when I feel tired, I feel burdened. Sometimes I like the care role.”	“It is tiring, its exhausting, its gruelling, your life goes on hold, and the friends that you have, they can carry on with their lives and you miss all that” “Bloody awful! Erm lonely, frustrated, angry, lots and lots of things, completely changes your life, can’t do what you want to do, and erm it spoils your retirement.”

Notes:

All caregivers discussed positive and negative aspects of the role.
Asian positives related to religious blessings and White-British related to skill learning.
BB caregivers were very reluctant to discuss negative aspects.

Theme 4: Adaptation to care role

Similarities	Differences
Role becomes more difficult over time “its something you take on and it gradually increases the workload, increases till you realise that you are doing so much, its something that’s just how it happens. You find you are doing more and more before you realise it.” “I would have done some but I would not have thought it would be so hard by now it been going on so long, as time has gone, I’m worn out and I have become depressed my self.” “It becomes very demanding.” “he’s not the man you married is he? That’s how I feel about mine….I do begrudge that” “I have been doing caring for my husband for a long time but for the last 2 years my husbands condition is getting worse, so I’m coping badly now, sometimes he is irritated, he shouts for no reason, sometimes argues, so I’m coping very badly.” “I get tired and it becomes very hard.” “Yes it’s become harder, since I started the pressure has gone up and up.” “Being a carer for the time being is alright but as it gets	Role becomes easier over time “It becomes like a habit.” “It was harder from the start to the middle and then we got used to it.” “6 or 7 months ago it was hard, I’m used to it now”

longer you do need a bit of time for yourself, and the person you are caring for they depend on you and they rely on you and they trust you."	

Theme 5: Coping

Similarities	Differences
Behavioural disengagement “Yes an outlet, it’s a part time job, it’s the only time I can get out and away from it” “I’ve got my outlets, otherwise I would go crazy” “There’s not a lot you can do except try meditation, deep breathing.” “I ride a bike and I go down on the prom” “I started doing family history because it gets my mind off my own life and I spend time on my computer, and that’s my way, I worked as long as I could because that was getting my mind off my problems” “When my husband is irritated with me, then I keep away from him and try to do some other work, read a religious book, go into the kitchen, go out.”	Religious coping “that’s how things are and that’s the way God’s will is.” “I pray every day to God, God has really helped me a lot, I wake up really early in the morning, I don’t have any social life at all, because I can’t leave my mum alone so I don’t have any holidays either but I thank God for giving me the strength”
Venting “Sometimes I mean like myself you just have to cry” “Yeah you have to take it out from your chest; you can’t just bottle it up”	Fighting spirit/Acceptance/Use of substances “It gradually creeps on you how much care is needed so you’re not offered help so you have to fight to get it, that is you get any.” “We just accept it because there isn’t any other alternative you just have to get on with life and look after him the best you can.”

"NEWCIS is a real blessing because you meet up with people and have a good moan, and there's nothing like a good moan." "Used more four letter words than I've ever known and er sometimes I could smack someone" "But I just don't like it when I get frustrated and angry and shout at him, I don't think that's right I shouldn't be doing that but its difficult not to." "If I have a moan to somebody, then I feel really guilty about it."	"I take st johns wort."

Theme 6: Use of and satisfaction with support

Similarities	Differences
Family support: All caregivers lack family support "Nobody else, My son is in London, one is here but he's afar, my daughter lives in Bolton she gives some food, she send for me" "In my situation I was completely isolated, nobody helped me not even my own relations, the only thing that kept me going is prayers." "My daughter comes in and cooks for me and my wife so I do rely on her. About twice a week she comes in and does cooking." "None of my family, none of my relations want to know us so I'm completely isolated" "I just want to say I do get some support especially from my sister, I won't vouch for the rest of the family but my sister does especially when I need to go out as I said for example today I've come out….. so I'm very appreciative for what she does for us" "If the family are living near that's fine, if they are not living nearer, yeah my son are working away from home but when ever they are here that's fine, but if I need him anytime of the day or night, they are not here because they are working away from home. Its not that they don't want to help but they are not here." "I ask the children, yes they are willing to help but only	Family support:

when I ask do I receive the help, nobody comes around and says can I do something for you, to relieve some of your stresses."

"Its very rare in any extended family to knock on the door, they know that you are still up at midnight or 4 o clock you are still in hospital with the aunty or whoever you are caring for but still you don't expect them to come knocking on the door in the morning saying oh you were in hospital till 3am, so I will make food for you or I'll come and do the ironing for you."

"I find it quite difficult myself, I would never ask one of my brothers or sister in laws to come and help because I know they wouldn't and they should be doing this themselves, it's really their duty not my duty."

"I have a daughter who lives quite local but she's got her own problems because she's got children with disabilities and I have a son who lives in London. Because of the way the world, people have to go where the jobs are, I have a daughter in law and a son but they don't live with me. They do input into the care role but I am very grateful for the provisions that social services have provided meaning that I don't have to rely on the help of family members."

"Nothing, nobody lives near here."

"If you don't have any help, it's very upsetting, but I have plenty of family, I have a sister in law and she does stuff, if I'm ill, she'll do it, it would be very upsetting if she didn't."

"When I can't do something, other people in my family help me for example they will give me a lift to the Drs."

“Maybe when they’re (family members) helping they might not be happy. What can I do if they’re not happy, but I can’t always look after them (care recipient) on my own? To me, I’m grateful when the boys and the girls are looking after them (care recipient).”
“Our nearest is Chester, that’s our daughter, 30 miles, and at Easter she said mum how about we come and take you in our car and take you back to Chester, have lunch with us, and then our grand daughter and her hubby will take us back. But we couldn’t do it; he couldn’t stand up that day.”

“No I don’t because all my family are in the midlands.”

“I’m happy in what they would want to do, but because they live away and quite pressurised with their careers, all of them have grand children, accept our son, he’s got children, so their lives are quite full.”

“I think the problem now is that’s years ago we came from large families who lived in the same area, but now we’ve all moved away and there’s not as much help, the daughters aren’t at home, because they used to be at home minding the children and they used to also look after the parents, and that’s what the problem in this country is, isolation, whereas if you go to Spain, if you go to India they still got the big families to look after, grandmother, when she’s fine she looks after the baby for the mum, when the grandmother is not well they look after her, that’s what’s wrong with us now.”

“Its because my daughter has her own problems and that’s the only family here and his family live in Scotland, and my other son in Germany and that’s all the family I’ve got.”	

Similarities	Differences
Friend support: All caregivers lack support from friends “Everybody is busy here, they go to work and come home and look after their children, and we are home so do it ourselves, a little at a time, slowly slowly.” “Not liking giving them trouble.” “its not needed to ask a friend, you just get a family member” “We prefer the families help. There’s the daughter in laws, boys, they’re here to help. If we can’t do it we’ll ask for help.” “There’s no way we’d agree to other people taking care of our family. There’s no word for it! We wouldn’t understand what care they could give which we couldn’t.” “We’ve lost friends since Barry has been in a wheel chair; I think people are frightened….in my husbands mind he can still do the things he used to be able to do” “There are some friends that I call true friends, that have been absolutely wonderful, but some friends because of Barry being in a wheel chair, don’t know how to deal with it. I think they consider it as a burden, it hurts, it hurts” “Even your neighbours, when we used to be in the garden, they used to stop and chat but once the neighbours knew that he had cancer, it was like an invisible wall around us, didn’t talk to us, and that’s when I needed the support. When you need the support,	Friend support: Asian caregivers don’t perceive friends as a potential source of friends. White-British caregivers are not as accepting of the lack of support from friends.

people back off. There should be a sign across the door saying there but for the grace of God, because nobody knows when it's going to happen." "Well you find out who your friends are"	

Similarities	Differences
Formal support: All caregivers lack support from services	Formal support: White British caregivers have a more positive view of formal services, but are aware of the limitations of formal services.
“The most important thing I want to say is lots of agency and professional people don’t understand our culture, don’t understand our faith, and the most important thing is our voice not being heard, so I’m speaking on behalf of all the Muslim community, especially when my son ended up in a mental hospital, they did not understand our culture, they did not want me to stay with my son, they did not provide any halal food, er and the needs were not met for my son.”	“I do feel there are a lot of good care teams around, EMI I have to say are absolutely excellent, I just don’t know what I would do without them, absolutely brilliant.”
“When I went to the social worker, the social worker said to me we haven’t got anybody, we can’t provide any home help because we can’t find anyone who can speak Gujarati language, my mum stayed in hospital for 2 months, and I said I’m going into work and I need desperately someone to come in for home help and they couldn’t find any home help”	“There are things for younger people, and there are things for elderly people but nothing for people in the middle.”
“then with the services and authorities, you have to fight with your arms and legs with them.” “I don’t get any help from outside agencies, to get help a referral has to be made from the G.P when it concerns mental health issues. I’ve been passed from pillar to post and I’m fed up, I had a meeting with a support officer and got fobbed off.”	“He doesn’t have anywhere to go, it would help to have a place where younger people could go.” “With doctors and things like that I don’t think we get the support that we need.”
“We find that the mental health service has not been properly funded at all and another thing is if you have a	“With the Care line thing I feel as though I can go to Sainsbury’s and I know if anything happens, if he falls

good doctor you will be ok but if you have a doctor who doesn’t listen to you, then you’ve had it, then you don’t get any help at all.”	out of the wheelchair or anything, hes just go to press that button, so it is a little bit easier for me.”
“Frustrated, if you go to a meeting or service, something like that the service provider just fob you off and they say I haven’t got anything or phone this number and that number, if they haven’t got any details, they don’t sign post you directly, it does make you feel frustrated. If you are a carer if you are caring for mental people you know more than the service provider what you are going through, its not just within our community, within all cultures all races, mental health problem is not just within the Asian community.”	“The support has to be ongoing, because the problem is not going to go away within 6 weeks, you need something fairly regular, The NEWCIS group is good, you can go and meet other people.”
“I have language barriers and therefore find it a struggle to access mental health services, the social workers take advantage of that, they think well they don’t know what’s out there so I’ll leave them to it. When I told the consultant that I wasn’t getting any service support he wasn’t much help either.”	“After hospitalisation its very good, we had 7 weeks free carer who came in and watched him but that’s 7 weeks and that is I think for everybody which is good.”
“Other carers come in daily for my wife who has dementia an mental health problems and she has physical disabilities as well, they do what they have to as in bathing and do what they have to in an hour or two, they come to do domestic duties, hovering, cleaning, polishing but basically other than that I do everything myself.”	“I’m not sure I was not too pleased about the social workers.”
“I did ask for my father, but they kept saying ring tomorrow, they’re so busy, they weren’t much help. I wanted help in the morning, not during the day, but they said mid day, but I need someone in the morning to bath him I can’t keep him waiting around, so that’s why my	“That maybe because they learn from a book, they think everybody is the same, but everybody’s got their own circumstances, they need to tie it to that person’s needs.”

son and my nephew do it now. I waited 6 months to be told they can't come in the mornings." "Ask social services? But why, what are they going to do? I have to do everything, cooing, cleaning, washing, they can't help with that." "These days Drs aren't even any help, at the moment, they never come to help, they've seen my father twice this year. We used to get nurses coming to do blood pressure etc, but now no one comes." "no one listens, I've told everyone my story, before the Dr used to come home and see me, but no one is coming"	"Social services allow me an hour and half to give me someone to come and do my floors for me, I did like that, that was great and financially its fine. I think its more moral support that we need. Social workers are always over stretched"

Table 1. Familism correlated with other IVs for ethnic groups

		Ethnicity	
		South Asian (*n* = 73)	White-British (*n* = 162)
brief COPE	Self distraction	0.17	-0.07
	Active coping	0.19	0.17
	Denial	-0.26*	0.13*
	Substance use	-0.27*	0.004
	Emotional support	0.12	0.08
	Instrumental support	0.02	0.24**
	Venting	-0.05	-0.04
	Positive reframing	0.08	0.14
	Self blame	-0.14	0.12
	Planning	-0.001	-0.01
	Behaviour disengagement	0.12	0.12
	Humour	-0.14	-0.19*
	Acceptance	0.03	0.03
	Religious coping	0.47***	0.23**
Social Support	Total support	0.10	0.03
	Mean satisfaction	0.18	0.44***
Willingness to care	Emotional	0.06	-0.10
	Instrumental	0.17	-0.07
	Nursing	-0.05	0.001

Note

* p < .05 ** p < .01 *** p < .001

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Dear

I am a PhD researcher at Bangor University undertaking a research study that examines cultural variations in the carer experience. The study will involve family carers who **currently** provide support for a family member or friend who has been diagnosed with either cancer, stroke, Parkinson's disease, multiple sclerosis or dementia. Carers will be asked to complete a questionnaire that aims to examine how carers cope with their experience, their use of social support, their perceptions of illness and their general quality of life.

I am writing to you to request assistance in identifying family carers that would be interested in taking part in the research. This can be done in a number of ways:

- By displaying a poster advertising the study
- Allowing me to attend support group meetings to discuss the study with the carers in more detail and hand out questionnaires personally
- Or you could post questionnaires directly to the carers on your mailing list on my behalf without revealing any confidential details. The questionnaire packs would be sent in prepaid blank envelopes and I would cover any related costs.

With this letter I have included a cover letter, an information sheet, a consent form and a debrief sheet that will be sent to interested carers. A copy of questionnaire can be made available upon request.

The research project (funded by a Welsh Office Research grant) addresses the targets of many UK and Wales relevant policy documents. It is intended that the research will make a real contribution to debate around carer assessment and the development of effective and ethnically aware services across the UK. The results will be disseminated beyond academia and findings will be discussed with stroke, cancer, dementia, MS and Parkinson's disease organisations, also including the National Black Carers and Carers workers Alliance. The research is in compliance with the British Psychological Society (BPS) ethical guidelines and has received full ethical approval from the School of Psychology ethics committee.

If you have any further questions please do not hesitate to contact me using the details provided above. Alternatively you can contact my supervisor Dr Val Morrison at v.morssion@bangor.ac.uk.

Your assistance would be greatly appreciated and I look forward to hearing from you.

Yours sincerely,

Sahdia Parveen.

Information Sheet

Research title: Culture and the family carer role

Invitation
We are inviting you to participate in a questionnaire based research study, which aims to examine the influence of ethnicity and culture on the family carer experience in relation to caring for someone with a chronic/physical illness (e.g. cancer, stroke, Parkinson's disease, multiple sclerosis and dementia)

We refer to individuals who carry out activities for a family member or friend who is experiencing problems as a carer and the family member or friend receiving help as the care recipient.

We would appreciate if you would read the remaining information sheet as it aims to provide you with information about what the study is and why it is being conducted, so you can make an informed decision about whether to participate or not.

Purpose of study
This study will explore the similarities and differences amongst various ethnic groups and cultures in the experience of the carer role. This will hopefully aid the development of more services, which are sensitive to your needs as a carer. The questionnaire will ask you questions related to your feelings, your use of support and how you cope with the role. By completing the same questionnaire over 3 points in time we also hope to explore the changes in the carer experience.

Do I have to take part?
Your participation in this study is voluntary and you do not have to complete the questionnaire. You may withdraw from the study at any point without providing a reason. Whether you participate or not will in no way affect the level of help you receive from services.

Can I Participate?
To be eligible to participate in the current study you must

- Be a family/friend carer (that is you are not hired in a professional capacity to provide care for that individual)
- Provide a minimum of 1 hour of care per day for a family member or friend who has been diagnosed with a chronic/physical illness/disease.
- Due to ethical reasons you must be 18 years or over of age.
- The care recipient must also be over the age of 18 years.

What do I have to do to participate?
If you would like to participate in the current study you must first sign the consent form once you have finished reading the information sheet. Next complete the attached questionnaire, which should take you approximately 50 minutes. After completing the questionnaire please return in the freepost pre-addressed envelope provided in the pack. 3 months after completion of the questionnaire you will receive a telephone call from Miss Parveen asking whether you

are willing to continue participating in the study. You will then be sent the second questionnaire and the above process will take place again. After 6 months of completing your second questionnaire you will be sent your final questionnaire.

Once you have completed all 3 questionnaires and signed the consent forms you will receive a thank you letter and a brief explanation of the study. You will be entered into a free prize draw and winners will be notified shortly afterwards. You will also receive a summary of the final results of the study if you have made a request on the consent forms.

What are the risks and benefits of taking part?

There are no known risks associated with this study. In fact, studies of this nature have found that many carers perceive a benefit in completing these types of questionnaires and sharing their experience. If you find certain questions distressing, you are under no obligation to answer them. It is hoped that by conducting this research study we may help carers and care recipients.

Confidentiality:

Your participation in the study will remain completely confidential. All data will be kept confidential in accordance to the Data Protection Act 1998. Your questionnaire will be coded to ensure you are completely unidentifiable to others including the researchers. All questionnaires will be kept in locked drawers in a secure office at Bangor University.

What will happen to the results of the study?

The results of the study will be used as part of a PhD thesis and may be published in academic journals and reports.

The research addresses the targets of many UK and Wales relevant policy documents. It is intended that the research will make a real contribution to debate around carer assessment and the development of effective and ethnically aware services across the UK.

The results will be disseminated beyond academia and will be discussed with stroke, cancer, dementia, MS and Parkinson’s disease organisations, also including the National Black Carers and Carers workers Alliance.

If you wish to know the results of the study please tick the box in the consent form and a summary will be sent to you on completion of the full study.

Who is organising the study?

This study is being carried Sahdia Parveen as part of a PhD research thesis and is funded by the Welsh Office of Research and Development (WORD) studentship award. It is supervised by Dr Val Morrison (chartered Health Psychologist) and Dr Catherine Robinson (Senior Researcher for health and social care).

Who has reviewed this research study?

This study has been reviewed by the Bangor University, School of Psychology Research Ethics and Governance Committee.

Contacts:

If you would like any further information about the study, please feel free to contact the researcher or supervisors:

Sahdia Parveen: psp419@bangor.ac.uk 01248 388723

Dr Val Morrison (supervisor): v.morrison@bangor.ac.uk

Dr Catherine Robinson (supervisor): catherine.robinson@awardresearch.org.uk

Complaints:
If you have any complaints about the study, please contact:

Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University,
Bangor, Gwynedd, LL57 2DG

Support Services.

Gwynedd:

Carers outreach service: 60 Dieniol Road, Bangor. Tel : 01248 370797

Bangor counselling and psychotherapy, 12 College Road, Craig Y Don, Upper Bangor. Tel: 01248 601951.

Disability welfare rights, Canolfan Lafan, 1-2 Glanrafon, Bangor. Tel: 01248 352227.

Arfon mental health resource centre, College road, Bangor. Tel: 01248 37017

The Stroke Assocition. Bodfan, The Park, Caernarfon, Gwynedd, LL55 2YF. Tel: 01286 669325

Alzheimer's Society: 6 Llys Onnen, Parc Menai, Bangor, LL57 4FG. Tel: 01248 672622

Caredig, Cyf, Unit F10, Intec, Parc Menai, Bangor, LL57 4FG. Tel: 01248 672622

Complete home care, Unit 12B, Gladmin business quarters, Llyss onnen, Parc Menai, Bangor, LL57 4DF. Tel: 01248 674925

Headway Gwynedd: 8 Rhyd y Groes, Pentir, Bangor, LL57 4YA. Tel: 01248 360303

National:

Carers website: www.carersuk.org/home

Mental Health foundation: www.mhilli.org.uk

Alzheimer's society: www.alzheimers.org.uk

Dementia advocacy and support international: www.dasni.org

The Stroke Association: www.stroke.org.uk
Helpline: 0845 3033100
Address: Stroke Information Service. The Stroke Association,
240 City Road, London, EC1V 2PR.

The MS Society: www.mssociety.org.uk
Helpline (for carers and patients): 0808 800 8000

The PD Society: www.parkinsons.org.uk
Helpline (for carers and patients): 0808 800 0303

Consent Form

Research study title: Culture and the carer role

Name of researcher: Miss Sahdia Parveen

Please Tick

I confirm that I have read and fully understood the information sheet provided for this study and have had the opportunity to ask any questions. ☐

I understand that my participation in this study is completely voluntary and that that I have the right to withdraw at any time without having to provide a reason. ☐

I agree to take part in this study. ☐

I would like to receive a summary of the results: ☐

____________________	__________	________________
Name	Date	Signature

Contacts:

If you would like any further information about the study, please feel free to contact the researcher or supervisor:

Sahdia Parveen:	psp419@bangor.ac.uk	01248 388723
Dr Val Morrison:	v.morrison@bangor.ac.uk	
Dr Catherine Robinson:	catherine.robinson@awardresearch.org.uk	

Please sign and return with your completed questionnaire in the pre paid envelope or at a location specified by the researcher.

Culture & Caregiving

Questionnaire 2

First Name: ___________________________

Surname: ___________________________

Date completed: ________________________

Personal code: _________________

This sheet will be removed from the questionnaire on receipt.

Dear Carer
Thank you for taking the time to participate in this study. Please ensure you have read and fully understood the information sheet and signed the consent form before completing this questionnaire. Throughout the questionnaire the person who carries out activities for an individual experiencing problem will be referred to as a carer/caregiver. The term used to describe the individual you carry out activities for will be care-recipient. The questionnaire should not take longer than 50 minutes to complete and please try to read all instructions and questions carefully. Also please answer all the questions honestly and according to your present situation and thoughts. The information that you provide will be kept completely confidential and the data will be coded so that you are unidentifiable.

Section One

Please tick the appropriate box

Your gender	**Care recipient's gender**
Male ☐	Male ☐
Female ☐	Female ☐
Your age ________	**Care recipient's age** ________

What **county** in the UK are you from __________________

Your Ethnic group:

White English	[ ]	Black Caribbean	[ ]	Asian Pakistani	[ ]
White Irish	[ ]	Black African	[ ]	Asian Indian	[ ]
White Scottish	[ ]	Black Other	[ ]	Asian Bengali	[ ]
White Welsh	[ ]			Asian Chinese	[ ]
White Other	[ ]			Asian Japanese	[ ]
				Asian Other	[ ]

The above list is not exhaustive, if you believe your ethnic group is not listed above please feel free to specify you ethnicity in the empty spaces.

Marital status: _____________________

Occupation: _______________________

Previous occupation: ______________________

Do you have any **previous** experience in providing care for a dependent?

Yes ☐ No ☐

If yes please provide further details (e.g. father aged 82, provided care for 6 years)

____

Relationship to care recipient (e.g. daughter) ______________________

On a scale of 1 to 5 (1 = Not at all good and 5 = Excellent) how would you rate your **quality of relationship** with care recipient? ________

Main diagnosis of care recipient ______________________________

How long have you provided care for this person ________________

Number of hours per week of providing care ______________

Do you have any children (under 18) or **dependents other than the above** care recipient that depend on your care?

Yes ☐ No ☐

If yes please provide further details (e.g. son aged 12)

____

How would you rate **your** current health?

Good ☐ Above Average ☐ Average ☐ Below Average ☐ Poor ☐

How would you rate the **care recipient's** current health status?

Good ☐ Above Average ☐ Average ☐ Below Average ☐ Poor ☐

Section two (Motivations in Elder Caregiving Scale)

The following statements describe some of the reasons why people begin caring for a relative or friend. Please answer each question by circling the number which best describes your own situation.

1 = Strongly disagree
2 = Disagree
3 = Neither agree or disagree
4 = Agree
5 = Strongly agree

1) **I felt that I had no choice but to care for the care recipient:**

SA SD

5 4 3 2 1

2) **I would feel guilty if I didn't care for the care recipient:**

SA SD

5 4 3 2 1

3) **The care recipient expected me to care for him/her:**

SA SD

5 4 3 2 1

4) **I felt that people would disapprove if I didn't care for the care recipient:**

SA SD

5 4 3 2 1

5) **It's part of my nature to care for others:**

SA SD

5 4 3 2 1

6) **I felt it was my duty to care for the care recipient:**

SA SD

5 4 3 2 1

7) **I wanted to make sure the care recipient was safe:**

SA SD

5 4 3 2 1

8) **Caring for the care recipient was an automatic decision:**

SA SD

5 4 3 2 1

9) **I do not/did not want the care recipient to go into a home:**

SA SD

5 4 3 2 1

10) **I wanted to provide care for the care recipient myself:**

SA SD

5 4 3 2 1

11) **Caring for the care recipient is a way of living up to my principles:**

SA SD

5 4 3 2 1

12) **The care recipient was gradually becoming more dependent on me:**

SA SD

5 4 3 2 1

13) **I felt that I had a responsibility towards the care recipient:**

SA SD

5 4 3 2 1

Please turn to section three

Section 3 Brief IPQ

The following questions are related to your perceptions of the care recipient's illness. Please circle the number that best corresponds to your **views regarding the care recipient.**

1) **How much does the care recipient's illness affect his/her life?**

0	1	2	3	4	5	6	7	8	9	10
No affect										Severely affects life

2) **How long do you think the care recipient's illness will continue?**

0	1	2	3	4	5	6	7	8	9	10
Very short Time										Forever

3) **How much control do you feel your care recipient has over their illness?**

0	1	2	3	4	5	6	7	8	9	10
No control										Extreme amount of control

4) **How much do you think the care recipient's treatment can help with their illness?**

0	1	2	3	4	5	6	7	8	9	10
Not at all										Extremely helpful

5) **How much do you think your care recipient's symptoms are attributed to his/her illness?**

0	1	2	3	4	5	6	7	8	9	10
No symptoms										Many severe symptoms

6) **How concerned are you about the care recipient's illness?**

0	1	2	3	4	5	6	7	8	9	10
No Concern										Extremely concerned

7) **How well do you feel you understand the care recipient's illness?**

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										Understand very clearly

8) **How much does the care recipient's illness affect him/her emotionally? (e.g. does it make them angry, depressed, scared or upset?**

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										Extremely affected emotionally

9) **Please list in rank order the three most important factors that you believe caused the care recipient's illness.**

The most important causes for me are:-

1)________________________________

2)________________________________

3)________________________________

Please turn to section four

Section four Heller Familism Scale

The following questions examine family relationships. Please rate on the scale how much you agree or disagree with each statement:

0 = Strongly disagree
1 = Disagree
2 = Neither agree or disagree
3 = Agree
4 = Strongly agree

1) **A married person should be willing to share his home with brothers and sisters of his husband or wife.**

SA SD

4 3 2 1 0

2) **Married children should live close to their parents so that they can help each other.**

SA SD

4 3 2 1 0

3) **If a member of the family is insulted or injured, you should feel more strongly about it than if the injured person is not a member of the family.**

SA SD

4 3 2 1 0

4) **It is the responsibility of married children to be with their parents in time of serious illness even if the children have moved some distance away from the parents.**

SA SD

4 3 2 1 0

5) **Children owe it to their parents to put family interests above their own personal interests.**

SA SD

4 3 2 1 0

6) **If a family group has strong views, a member should not let himself be influenced by outsiders to change these views.**

SA SD

4 3 2 1 0

7) **As many activities as possible should be shared by married children and their parents.**

SA SD

4 3 2 1 0

8) **If a person finds that his job runs so much against family values that severe conflict develops, he should find a new job.**

SA SD

4 3 2 1 0

9) **Whenever possible to do so, a person should talk over his important life decisions (such as marriage, employment, and residence) with family members before taking action.**

SA SD

4 3 2 1 0

10) **Marriage should be viewed as keeping families going rather than creating new families.**

SA SD

4 3 2 1 0

11) **It is important that the family name be carried on.**

SA SD

4 3 2 1 0

12) **Children of elderly parents have as much responsibility for the welfare of their parents as they have for the welfare of their own children.**

SA SD

4 3 2 1 0

13) **Keeping the family going is a very important reason why sons and daughters should expect to marry and have children.**

SA SD

4 3 2 1 0

14) **At a community or social affair, a family should participate pretty much as a group rather than allow members to go their own way with their personal friends.**

SA SD

4 3 2 1 0

15) **If a person's father has a medical bill of £750 that he cannot pay, the son is morally obligated to pay the debt.**

SA SD

4 3 2 1 0

Section five brief COPE

These questions are related to what you've been doing to cope with the carer role. 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. Make your answers as true FOR YOU as you can.

Use these response choices.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things. ___

2. I've been concentrating my efforts on doing something about the

situation I'm in ___

3. I've been saying to myself "this isn't real." ___

4. I've been using alcohol or other drugs to make myself feel better. ___

5. I've been getting emotional support from others. ___

6. I've been giving up trying to deal with it. ___

7. I've been taking action to try to make the situation better. ___

8. I've been refusing to believe that it has happened. ___

9. I've been saying things to let my unpleasant feelings escape. ___

10. I’ve been getting help and advice from other people. ___

11. I've been using alcohol or other drugs to help me get through it. ___

12. I've been trying to see it in a different light, to make it seem more positive. ___

13. I’ve been criticizing myself. ___

14. I've been trying to come up with a strategy about what to do. ___

15. I've been getting comfort and understanding from someone. ___

16. I've been giving up the attempt to cope. ___
17. I've been looking for something good in what is happening. ___
18. I've been making jokes about it. ___
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. ___
20. I've been accepting the reality of the fact that it has happened. ___
21. I've been expressing my negative feelings. ___
22. I've been trying to find comfort in my religion or spiritual beliefs. ___
23. I’ve been trying to get advice or help from other people about what to do. ___
24. I've been learning to live with it. ___
25. I've been thinking hard about what steps to take. ___
26. I’ve been blaming myself for things that happened. ___
27. I've been praying or meditating. ___
28. I've been making fun of the situation. ___

Please turn to section six

Section six Social Support Questionnaire

The following question asks about people in your environment who provide you with help or support. The question has two parts:

For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described, (both at home and at work). Please give a description of the person (e.g. neighbour) and their relationship to you.

For the second part, circle how satisfied you are with the overall support you have.

If you have no support check the words “no one”, but still rate your level of satisfaction.

1. = Very dissatisfied

2 = fairly dissatisfied

3 = a little dissatisfied

4. = a little satisfied

5. = fairly satisfied

6. = very satisfied

1. Who can you really count on to be dependable when you need help?

	very satisfied very dissatisfied
a) No one	6 5 4 3 2 1
b) ………………………….	6 5 4 3 2 1
c) ………………………….	6 5 4 3 2 1
d) ………………………….	6 5 4 3 2 1
e) ………………………….	6 5 4 3 2 1

Section seven Willingness to Care Scale

Caregivers may differ in the tasks they feel able and/or willing to perform.
Being able to perform a task means that you believe you could do it if necessary.
Being willing to perform a task means that you feel you would do it if it had to be done.

- For example: *I am able to change soiled sheets but I would not be completely willing to do so.*

As you read the statements below, think about the person who is in need of support.

- FIRST, place an “X” by each one of the tasks you currently carry out and in the second box write how many times a week you do the task. If you do not currently perform the task you can skip the questions but return to them during the second set of questions.
- SECOND, Re-read the items, and write a number which best shows how able you are to do each one, and how willing you are for **all** tasks (even if you do not do the task), where:

1 = completely unable/unwilling
2 = somewhat unable/unwilling
3 = not sure
4 = somewhat able/willing
5 = completely able/willing

Task you do	No times/week	Task	Able (1-5)	Willing (1-5)
		Listen when the recipient is sad.		
		Comfort when the recipient is upset		
		Help the recipient deal with anxiety about the future		
		Hold hands when the recipient is afraid		
		Encourage when the recipient feels hopeless		
		Listen to the recipients concerns about death or dying		
		Help keep the recipients spirits up		
		Hold the recipient when he or she is crying		
		Listen to the recipient when he or she is angry		
		Be patient when the recipient is disorientated or confused		
		Take the recipient to a medical appointment		
		Bring home the groceries for the recipient		
		Clean the recipients room or home		
		Prepare meals for the recipient		
		Help pay for the recipients medicine		

PLEASE RATE ALL ITEMS

Tasks you do	No time/week	Tasks	Able (1-5)	Willing (1-5)
		Wash the recipients dishes		
		Do the recipients laundry		
		Help pay for the recipients food or housing		
		Have the recipient live in your home		
		Negotiate the recipients health care options with a doctor		
		Help the recipient take medication		
		Change the recipient’s dirty bed sheets		
		Help the recipient take a bath		
		Clean up after the recipient who has lost bowel or bladder control		
		Help the recipient eat a meal		
		Clean up when the recipient has thrown up		
		Turn the recipient in bed		
		Change dressings on the recipient’s sores		
		Help the recipient in the bathroom		
		Help the recipient move in and out of bed		

PLEASE RATE ALL ITEMS

Section eight Caregiver GAINS

As a result of providing care, to what extent did you…

(Please tick the appropriate box)

	A lot	Somewhat	A little	Not at all
Become more sensitive to persons with disabilities?				
Get a better idea of what's important in life?				
Become aware of inner strengths?				
Become closer to God?				
Grow as a person?				
Become closer to family?				
Gain a sense of fulfilling duty?				
Become more self confident?				
Learn to do new things?				
Make new friends?				

Please turn to section nine

Section nine Hospital Anxiety and Depression Scale

The next questions are related to how you have been feeling in the last seven days. As before there are no ‘correct’ or ‘Incorrect’ answers. Please answer according to your **own feelings,** rather than how you think ‘most people’ would answer.

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

3. **I get 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 so 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 ☐
   - From time to time but not too often ☐
   - Only occasionally ☐

6. **I feel cheerful:**

Not at all ☐
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 often ☐
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 TV programme:**
Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

Please turn to section ten

Section ten Brief WHO QOL

The following questions ask how you feel about your quality of life. Please choose the answer that appears the most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Whilst answering the questions please think about your **life in the last four weeks.**
Please circle the appropriate answer.

1) How would you rate your quality of life?

1	2	3	4	5
Very poor	Poor	Neither	Good	Very good

2) How satisfied are you with your health?

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

3) **To what extent do you feel that physical pain prevents you from doing what you need to do.**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	An extreme amount

4) **How much do you need any medical treatment to function in your daily life?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	An extreme amount

5) **How much do you enjoy life?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	An extreme amount

6) **To what extent do you feel your life to be meaningful?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	An extreme amount

7) **How well are you able to concentrate?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	Extremely

8) **How safe do you feel in your daily life?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	Extremely

9) **How healthy is your physical environment?**

1	2	3	4	5
Not at all	A little	Moderate amount	Very much	Extremely

10) **Do you have enough energy for everyday life?**

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

11) **Are you able to accept your bodily appearance?**

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

12) **Have you enough money to meet your needs?**

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

13) **How available to you is the information you need in your day-to-day life?**

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

14) **To what extent do you have the opportunity for leisure activities?**

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely

15) **How well are you able to get around?**

1	2	3	4	5
Very poor	Poor	Neither	Good	Very good

16) **How satisfied are you with your sleep?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

17) **How satisfied are you with your ability to perform your daily living activities?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

18) **How satisfied are you with your capacity for work?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

19) **How satisfied are you with yourself?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

20) **How satisfied are you with your personal relationships?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

21) **How satisfied are you with your sex life?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

22) **How satisfied are you with the support you get from your friends?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

23) **How satisfied are you with the conditions of your living place?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

24) **How satisfied are you with your access to health services?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

25) **How satisfied are you with your transport?**

1	2	3	4	5
Very dissatisfied	dissatisfied	Neither	Satisfied	Very satisfied

26) **How often do you have negative feelings such as blue mood, despair, anxiety, depression?**

1	2	3	4	5
Always	Very often	Quite often	Seldom	Never

Do you have any comments about the questionnaire?

____

____

____

____

Thank you for taking the time to complete this questionnaire. Please return the questionnaire in the enclosed pre-paid envelope. If any of the issues raised in the questionnaire have caused any distress or if you require information about support services please see the information sheet, which contains a list of services available for carers. **Thank you again!**

Return address: Miss Sahdia Parveen, School of Psychology, Bangor University,
Freepost BG35, Brigantia, Penrallt Road, Bangor, Gwynedd, LL57 2AS.

Debrief Sheet

Culture and the carer role

Thank you very much for participating in this study. The questionnaire you have completed explored a range of factors including:

- Family values
- Perception of illness
- Coping
- Use of support
- Willingness to care
- Carer experience
- Carer mood
- Carer quality of life

The aim of this study is to investigate the process by which the above factors influence each other and whether this process remains stable over time. We are also interested in examining how the carer role is influenced by demographic factors including:

- Ethnicity
- Gender
- Age and
- Care recipient's illness type

The findings of this study will help us develop a more detailed understanding of the caregiver role. This will hopefully aid the development of more services, which are sensitive to the needs of carers. Once data analysis has taken place you will receive a summary of the results. If you have not already indicated that you wish to receive a summary of the results, please contact the researchers using the details provided below. We hope that participating in this study has been an enjoyable experience, however if any undue distress has been caused during the study please contact:

Dr Oliver Turnbull, Head of School, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2DG

If you have any further questions and comments about the study or would like a summary of the results please contact the researcher or supervisor:

Sahdia Parveen: psp419@bangor.ac.uk 01248 388723

Dr Val Morrison (supervisor): v.morrison@bangor.ac.uk

Dr Catherine Robinson (supervisor): catherine.robinson@awardresearch.org.uk

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R.E: Culture and Caregiving Questionnaire

Dear ________________________

I am writing to confirm that I have received your completed questionnaire and consent form. I would also like to thank you for taking the time to complete the questionnaire and also for returning it so promptly.

I will ring you in _________________ to find out whether you would be willing to complete the second part of the questionnaire. You are under no obligation to complete another questionnaire and can withdraw from the study at any time. Carers who complete all three questionnaires will be entered into a free prize draw where they will have the chance to win £100 worth of vouchers of their choice.

Once again thank you for taking part in this study and I look forward to hearing from you in the future.

Best Wishes

Miss Sahdia Parveen

Table 1. Period 2 IVs predicting absolute anxiety at time 3.

Predictor (P2)	*b*	*SE*	*beta*
Ethnicity	-1.83	0.93	-0.17
Gender	1.08	0.79	0.11
Age	0.004	0.03	0.01
Diagnosis	-0.69	0.28	-0.19
r^2 Change		0.19	
F Change		6.29***	
Anxiety (P1)	0.33	0.36	0.29
r^2 Change		0.14	
F Change		21.72***	
IPQ Consequence	0.54	0.37	0.12
IPQ Identity	0.56	0.42	0.12
IPQ Concern	0.28	0.39	0.06
IPQ Emotional representation	0.38	0.36	0.08
r^2 Change		0.07	
F Change		3.00*	
No of emotional tasks	0.53	0.36	0.12
r^2 Change		0.04	
F Change		6.22**	
Self distraction	0.31	0.35	0.07
Denial	0.29	0.41	0.06
Instrumental support	0.37	0.40	0.08
Behavioural disengagement	0.72	0.39	0.16
Venting	0.56	0.4	0.12
Planning	0.10	0.39	0.02
Self blame	0.34	0.37	0.07
r^2 Change		0.10	
F Change		2.89**	
Mean satisfaction	-0.13	0.38	-0.03
r^2 Change		0.001	
F Change		0.12	
Final r^2		0.54	

Note

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

Table 2. Period 2 IVs predicting absolute depression at time 3.

Predictors (P2)	*b*	*SE*	*Beta*
Ethnicity	-1.57	0.97	-0.15
Gender	0.24	0.81	0.03
Age	0.02	0.03	0.05
Diagnosis	-0.39	0.30	-0.11
r^2 Change		0.10	
F Change		2.84*	
Depression (P1)	0.80	0.38	0.18
r^2 Change		0.09	
F Change		11.59***	
IPQ Consequence	0.75	0.38	0.17
IPQ Identity	0.74	0.43	0.16
IPQ6 Concern	0.23	0.41	0.05
IPQ Emotional representation	0.05	0.38	0.01
r^2 Change		0.08	
F Change		2.80*	
Emotional tasks	0.57	0.37	0.13
r^2 Change		0.03	
F Change		4.49*	
Denial	-0.08	0.40	-0.02
Behavioural disengagement	0.86	0.41	0.19
Venting	1.03	0.40	0.23
Positive reframing	0.61	0.39	0.14
Planning	0.31	0.40	0.07
r^2 Change		0.15	
F Change		5.34***	
Total Support	-0.25	0.40	-0.06
r^2 Change		0.002	
F Change		0.41	
Final r^2		0.45	

Note

* p < .05   ** p < .01   *** p < .001

Table 3. Period 2 IVs predicting time 3 **Physical** QoL.

Predictor (P2)	*b*	*SE*	*Beta*
Ethnicity	2.39	0.93	0.21
Gender	-0.41	0.79	-0.04
Diagnosis	0.69	0.31	0.18
Hours	-0.01	0.01	-0.07
Years	-0.22	0.05	-0.35
r^2 Change		0.29	
F Change		8.98***	
Physical QoL (P1)	-0.95	0.40	-0.20
r^2 Change		0.002	
F Change		0.35	
IPQ Concern	-0.83	0.36	-0.17
r^2 Change		0.03	
F Change		4.48*	
Denial	-1.06	0.41	-0.22
Instrumental support	-0.63	0.41	-0.13
Behavioral disengagement	-0.85	0.41	-0.18
Planning	0.08	0.41	0.02
Self blame	-0.52	0.38	-0.11
r^2 Change		0.16	
F Change		6.02***	
Total support	0.29	0.38	0.06
r^2 Change		0.003	
F Change		0.59	
Final r^2		0.48	

Note

* p < .05 *** p < .001

Table 4. Period 2 IVs predicting time 3 **Psychological** QoL.

Predictor (P2)	*b*	*SE*	*Beta*
Ethnicity	0.51	0.53	0.07
Gender	0.76	0.47	0.12
Diagnosis	0.32	0.17	0.13
r^2 Change		0.04	
F Change		1.76	
Psychological QoL (P1)	1.32	0.23	0.43
r^2 Change		0.33	
F Change		59.03***	
IPQ Identity	-0.57	0.24	-0.19
IPQ6 Concern	-0.13	0.24	-0.04
r^2 Change		0.05	
F Change		4.51**	
Denial	-0.23	0.24	-0.08
Instrumental support	-0.28	0.24	-0.09
Behavioural disengagement	-0.42	0.24	-0.14
Venting	-0.48	0.24	-0.16
Planning	-0.09	0.24	-0.03
Self blame	-0.21	0.23	-0.07
r^2 Change		0.11	
F Change		4.09***	
Final r^2		0.53	

Note

** p < .01 *** p < .001

Table 5. Period 2 IVs predicting time 3 **Social** QoL.

Predictor (P2)	*b*	*SE*	*Beta*
Ethnicity	-0.33	0.3	-0.07
Gender	0.10	0.26	0.03
Diagnosis	0.02	0.10	0.01
r^2 Change		0.03	
F Change		1.35	
Social QoL (P1)	1.23	0.13	0.64
r^2 Change		0.52	
F Change		133.13***	
Extrinsic motivations	-0.24	0.12	-0.13
r^2 Change		0.01	
F Change		3.24	
IPQ Identity	-0.05	0.14	-0.02
IPQ Concern	-0.20	0.14	-0.11
r^2 Change		0.01	
F Change		1.71	
Active coping	-0.07	0.15	-0.04
Instrumental support	-0.12	0.13	-0.06
Behavioural disengagement	-0.29	0.12	-0.15
Positive reframing	-0.07	0.13	-0.03
Planning	-0.07	0.15	-0.04
r^2 Change		0.04	
F Change		2.34*	
Final r^2		0.61	

Note

* $p < .05$ *** $p < .001$

Table 6. Period 2 IVs predicting time 3 **Environmental** QoL.

Predictors (P2)	*b*	*SE*	*Beta*
Ethnicity	2.74	0.68	0.29
Gender	-0.25	0.57	-0.03
Age	0.03	0.02	0.10
Diagnosis	0.08	0.21	0.03
r^2 Change		0.21	
F Change		7.71***	
Environmental Qol (P1)	2.15	0.25	0.54
r^2 Change		0.33	
F Change		79.30***	
Extrinsic motivations	-0.41	0.26	-0.10
r^2 Change		0.01	
F Change		2.44	
IPQ Concern	-0.19	0.26	-0.04
r^2 Change		0.003	
F Change		0.69	
Planning	-0.67	0.25	-0.17
r^2 Change		0.03	
F Change		8.35**	
Total support	0.32	0.26	0.08
r^2 Change		0.01	
F Change		1.53	
Final r^2		0.59	

Note

* p < .05 ** p < .01 *** p < .001