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**The psychological wellbeing of carers of people with dementia: What role does knowledge play on carers' perception of dementia?**

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**The psychological wellbeing of carers of people with dementia: What role does  
knowledge play on carers' perception of dementia?**

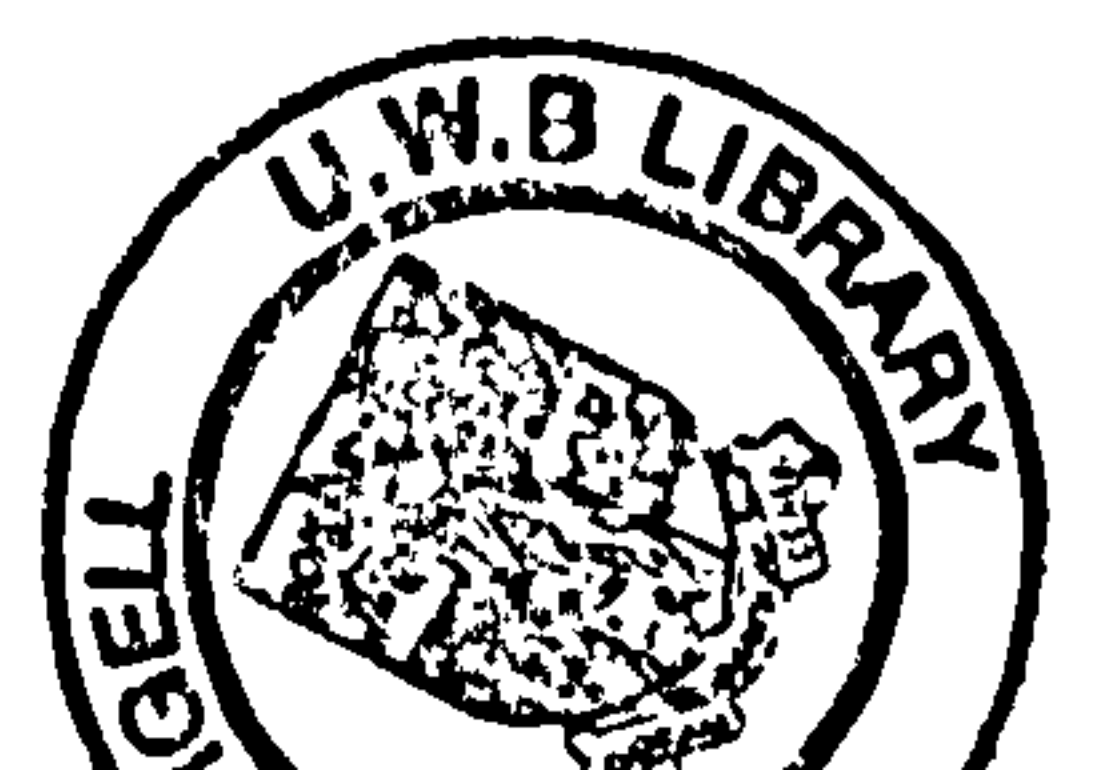
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**A thesis submitted in partial fulfilment for the Degree of Doctor of Clinical Psychology  
(D.ClinPsy).**

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## **Dedication**

I would like to dedicate this to my parents, who have supported me throughout the three years of my training. My mum's dedication in caring for my dad, without any thought for herself, inspired me to write about carers of people with dementia. My father's spirit and humour has motivated me through the 'challenging' past three years. Thank you mum and dad for all your love and support, this would not have been possible without you.

## **Acknowledgements**

**I would like to thank all the carers who took part in this research project for their time and effort in completing the questionnaires. My thanks and appreciation to all the participating health professionals and key workers from all the voluntary organisations who were involved in the recruitment process.**

**My deep appreciation to Drs. Carolien Lamers, Dr Robert Jones and Dr. Dave Daley who supported me throughout the past three years but in particularly over the past four weeks.**

**A big thank you to my friend Helen for keeping me sane over the past few months, your support was much appreciated. Finally, a BIG thank you to Chris and Jasmine for putting up with such a busy mum.**



## Abstract

The following two papers focus on the psychological wellbeing of carers of people with dementia. The aim of the review paper was to gain an understanding of the barriers that British South Asian carers (BSAC) experience in accessing services. A review of past studies revealed several themes emerging from the literature and these included: limitations in health professionals' culture competence and linguistic abilities, a lack of dementia knowledge by South Asian carers, their perception of dementia and associated stigma. A model is proposed integrating these factors leading to a discussion of the implications of supporting and providing interventions for BSAC. The empirical paper focuses on the relationship between carers' knowledge of dementia, anxiety, preferred coping style (monitoring or blunting information) and competence levels. This questionnaire-based study recruited 51 participants from local health services and voluntary organisations. The results indicated a significant negative association between biomedical knowledge and anxiety, although this should be interpreted with caution due to a low Cronbach's  $\alpha$  Coefficient (.54) on the biomedical subscale. A further significant association was found between knowledge and age of carer. Anxiety and competence amongst younger carers was significantly negatively correlated, however there was no association between these two variables in older carers. These findings suggest that the perception and understanding of dementia may have changed over recent years, especially amongst younger carers, with positive implications in terms of carers' psychological wellbeing. Although knowledge about dementia appears to have positive implications in terms of (younger) carers' psychological well-being, when providing support and interventions

health professionals should not ignore the emotional aspects of caring for a person with dementia.

**Key words:** dementia, caregivers, knowledge, perception, South Asian, culture

# **Ethical Approval**

## **Section 1 (part 1)**

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## **Appendix 1a**

**Participant's information sheets**

**(Welsh & English versions).**

**Consent forms Welsh & English versions**

**Team members' information**

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## **Appendix 1b**

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## **Section 1 (part 2)**

### **Reflections on the process of research**

## **Reflections on the process of research**

### **Process issues**

#### *Welsh links with both studies*

Being a Welsh speaking Trainee Clinical Psychologist and a daughter of a man with dementia led me to my initial thoughts about conducting a piece of research involving Welsh carers of people with dementia. This interest stemmed from my clinical experience as an Assistant Psychologist and as a Trainee Clinical Psychologist, working with Welsh and non-Welsh families. My interest in learning more about the perception of dementia, the stigma attached to it, and looking at the possibly different experiences of Welsh and non-Welsh carers inspired me to write both the review and empirical papers. As my initial thoughts were to look specifically at Welsh carers, I was reminded of the difficulties in recruiting an adequate sample size, due to the nature of the participants required and the time frame available to me. This deterred me from continuing with this line of research and initially left me feeling frustrated and disappointed; however, on reflection this was the right decision.

Although my research project targeted carers from a predominantly Welsh speaking geographical location, only 18% of Welsh speaking carers took part in my empirical study. The initial attempt to review the literature on Welsh speaking carers of people with dementia only yielded a couple of articles relating to neurological testing of Welsh speaking dementia clients. This led me to consider other groups within the United Kingdom (UK), perhaps minority groups, who were under-researched and who may bring a different cultural perspective to dementia and the services provided to dementia sufferers, and who consequently 'cope' with dementia in a different way.

This resulted in my review paper, looking at the literature on South Asian carers of people with dementia. However, this has strengthened my interest and determination to conduct future (possible qualitative) research on the Welsh speaking population, possibly focussing specifically on the perception of dementia and the cultural influences on caring.

### *Personal issues*

As my father has received a dementia diagnosis, this gave me a more personal insight into the difficulties that a person with dementia and their carer may experience on a daily basis. Having the personal involvement with dementia has inspired and motivated me to conduct this piece of research. At times, I was reminded of this emotional involvement when participants included a personal note attached with the returned measures, either to wish me all the best with my research or with more personal sentiments. In order to obtain clarity regarding the time-scale of data-collection, a small number of carers phoned and left messages for me. The poignancy of these notes and messages reminded me of the daily struggle and stresses involved in caring for people with dementia and also of the time and effort required to complete and return the questionnaires.

### *Participant's implicit feedback*

The time-scale needed to complete the measures (65-85 minutes) was, in comparison with many other research projects, not unduly long or laborious, and I suggested that carers completed the measures over a period of a few days. However, finding 65-85 minutes can be quite a challenge for carers who feel stressed and are pressed for any free time. Therefore, lack of free time may have been a barrier for some carers in

taking part in the research, especially those who experience high levels of burden and who may be unsupported. Therefore, the possibility of a skewed sample is discussed in the Discussion Section.

## **Professional issues**

### *Recruitment process*

Participant recruitment proved to be one the biggest challenges for this project, and a number of possible explanations can be considered for the lower than anticipated uptake. Carers of people with dementia currently living within the community can feel extremely stressed or pressured for time, and the possibility of a low uptake was recognised prior to starting this project. The timing of this research project was also unfortunate as a number of other local studies were being conducted targeting carers and care recipients of people with dementia. However, despite these initial concerns a total of 474 questionnaire packs were sent out, with 51 packs returned (31 packs were returned from a support group in England).

The recruitment process involved a number of presentations within the North West Wales and Conwy & Denbighshire NHS Trusts, and to representatives from local charities and support groups. A total of 16 presentations took place, which varied in time-scale from 20-25 minutes to two hours . Significant team members, who were unable to attend presentations, were also followed up. Travelling to and from some presentation venues took 1 and a half to 2 hours each way, and given the short time scale available for recruitment this inevitably impacted on the number of presentations. I presented at various Multidisciplinary Team (MDT) meetings and, in turn, MDT members handed out questionnaire packs to carers that they were currently

working with or had worked with in the past, and therefore had established a professional relationship with. Although this method of recruitment was very time consuming, compared with randomly sending questionnaire packs in the post to carers, this appeared to be a much more personal and person-centred way of recruiting participants. I may use this method of recruitment again in future research projects, with some changes, which might include co-ordinating my research with other research projects, liaising closely with other fellow researchers, and focussing more on charities and support groups.

During presentations, the feedback from many of the teams was one of genuine interest, as MDT members are often involved in sharing information about dementia with carers post-diagnosis, and I was invited to give a further presentation on the outcome of this study. Interestingly, a number of professionals who had been working locally with Welsh speaking families reported that, in the past, they felt that some carers appeared to “manage better” when their knowledge base of dementia was “basic”, as they did not anticipate the difficulties ahead of them. These comments fitted in neatly with my hypothesis, that carers who have a high knowledge base of dementia might demonstrate higher anxiety levels.

### *Measures*

Amongst the measures administered in this study, the Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992) was used to assess care recipients’ behavioural difficulties and carers’ reaction to these difficulties. The format of this scale proved quite complex for some carers to complete, and in hindsight perhaps a more ‘user-friendly’ scale may have been more appropriate.

The Monitoring and Blunting Scale (Miller, 1987) was used to assess carers' coping style and in order to obtain a copy of this measure a number of emails were exchanged with the author, and I was asked to sign an agreement before receiving a copy of the measure. Shortly before I was due to present to the Ethics Committee I received a copy of the measure, and felt compelled, because of time-constraints, to use this scale. In comparison to the RMBPC, this scale has a simple, easy to use format. However, a few participants appeared to have some difficulties with completing this measure, and the Dementia Quiz scale, appropriately. Although the number of participants who did not complete these measures correctly was low, due to a relatively small sample size, erroneous responses or missing data may have had some impact on data analysis. These issues are discussed in more detail in the Extended Discussion section.

### *Ethical issues*

Detaching myself from my clinical obligations and focussing on my role as a researcher was, at times, challenging. This was particularly difficult when presenting the research to carers who attended support groups, as some carers would ask for general advice or information about managing specific difficulties. During these meetings I introduced myself and gave a brief description of my research project before handing out my questionnaire packs. During the two hour sessions, carers openly shared experiences with each other, and during one of these sessions a carer specifically described a worrying scenario, which I considered to be an "ethical issue". At the end of the session, I advised the carer to repeat what she had shared with the group to her General Practitioner, Community Psychiatric Nurse or relevant

health professional. I also checked with my research supervisor that I had followed the correct procedure. However, switching role from being a Trainee Clinical Psychologist to being a Researcher proved more difficult than anticipated.

On a more positive note, I feel that both the review and empirical papers are clinically relevant and useful in terms of future research into carers of people with dementia. The process of writing a review paper and completing a large-scale research project has indeed been a challenging one as well as involving a huge learning curve. However, I also feel an immense sense of achievement and satisfaction in having being able to research and write about a topic of genuine interest to me.

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**Understanding the needs of British South Asian carers of people with dementia:**

**A review of the literature**

**Catherine Davies (proposed second author Drs. Carolien Lamers)**

**Aging & Mental Health**

## Abstract

**Objectives:** To review the literature on British South Asian carers (BSAC) of people with dementia and the barriers to their use of services.

**Method:** Databases were searched for studies looking at BSAC living within the U.K and South Asian carers within their country of origin.

**Results:** A number of themes were highlighted, which may enable health professionals to understand the complexities experienced by BSAC wishing to engage with services. These included limitations in health professionals' culture competence and linguistic abilities, South Asian carers' lack of dementia knowledge, their perception of dementia, and stigma.

**Conclusion:**By proposing a model that integrates these factors, insights can be derived as to how some of these individual factors together act as barriers to service uptake. The interplay between these factors with implications for the psychological wellbeing of the carer are explored, as well as the implications for health professionals' approach in exploring innovative ways of engaging BSAC of people with dementia in services.

**Key Words:**South Asian, knowledge, stigma, barrier, services

## Introduction

Within the UK, South Asian communities account for 3.6% of the population and due to the influx of South Asian immigrants into the UK in the 1940's, 1950's and 1960's, a considerable increase in the number of older South Asian adults will be witnessed over the next 10-20 years. It is estimated that there will be almost 1.8 million ethnic minority elders living in the UK by 2016 (Milne, 2004). As age is the greatest risk factor for developing Alzheimer's disease (Milne & Chryssanthopoulou, 2005), a significant increase in the number of older South Asian adults who develop dementia syndromes and associated disorders, such as depression, can be anticipated in the near future. The South Asian population have a high incidence of physical health problems such as diabetes, cardiovascular problems, stroke and hypertension (Balarajan, 1996; Smaje, 1995), which increases their vulnerability to developing vascular dementia.

It is estimated that around 700,000 people within the UK may have dementia (although far fewer have received a diagnosis), and approximately 11,500 are from black and minority ethnic groups (BME). The prevalence for those with a young onset (<65 years) dementia is almost three times higher within BME groups compared with the general UK population (Alzheimer's Society, 2007).

Two-thirds of people with dementia are currently living within the community and the majority are cared for by their spouse, partners or family-members. Although there are

some studies who have reported on the positive aspects of caring for a person with dementia, for example, carers report feelings of satisfaction, mastery and a sense of well-being (Connel et al., 2001; Farran, 1997), the evidence suggests that carers of people with dementia often experience high levels of burden, stress and poor psychological wellbeing, and the literature on carer's morbidity is well established (Pinquart & Sorensen, 2003; Mahoney et al, 2005; Brodaty & Hadzi-Pavlovic, 1990).

Numerous studies highlight the benefit of formal support and intervention for carers of people with dementia (Jarrott et al., 2005), which may enable carers to continue their care-giving role at home (Brodaty et al., 2003). For example, encouraging results were yielded in a study targeting physical and social difficulties within the home environment, with carers reporting an increase in self-efficacy (Gitlin et al., 2001). In further studies, individual counselling was reported as having a positive impact on carer's psychological wellbeing; psychoeducational interventions have shown to be effective (Bourgeois et al., 2002). An increase in carers' knowledge of dementia showed lower levels of depression in carers of people with dementia (Graham, Ballard & Sham, 1997). However, a limited amount of research has been conducted on BSAC (Purandare, et al., 2007; Turner Christie & Haworth, 2005) and most of the studies reviewed were qualitative in nature with no long-term outcome studies looking at BSAC' psychological wellbeing (Milne & Chryssanthopoulou, 2005). The literature suggests that, at present, a limited number of BSAC are currently accessing the services available to caregivers (Mackenzie, 2006; Adamson, 1999).

Gaining an understanding of the barriers to service uptake is a crucial first step in appreciating the complexities faced by BSAC. Their reluctance and inability to receive, or perhaps, the reluctance and inability of health professionals to successfully promote services to BSAC needs to be explored. This paper will review the literature and highlight factors that may have direct implications relating to supporting BSAC within the UK.

## Methods

The following search terms were used as key words: Dementia AND Care\* AND culture; Dementia AND Care\* AND Ethnic\*. An Astrix (\*) denotes various word endings. The search covered the period between 1995 and present. The following databases were used: Web of Knowledge, Web of Science, Science Direct and PsychINFO. Further searches were conducted on specific Journals (for example, *Dementia* by Sage Publishers), while other articles were obtained through a cross-referencing process. The inclusion criteria included peer-reviewed articles looking specifically at British South Asian carers living within the U.K. Articles looking at Asian carers outside the U.K, for example within the United States (U.S), Korea and China were excluded. Studies of South Asian carers within their country of origin (Bangladesh, India and Pakistan) were also reviewed. However, due to the limited research available on South Asian carers within their country of origin, only studies from India were found. Therefore, this review paper will focus on studies of British South Asian carers living within the U.K and studies of carers from India.

Within this review paper, British South Asian carers of people with dementia living

within the U.K will be referred to as BSAC and South Asian carers of people with dementia within their country of origin will be referred to as SACCO.

## Cultural differences

### The changing role of family units

Traditionally in India, primary carers of people with dementia include family and friends (Chandra, 1996). However, factors such as dual career families and migration are significant in impacting on the way older South Asian adults are now cared for within the community in India (Irudaya Rajan, 2000). The extended family model is gradually being replaced by the nuclearisation of families, and this is especially true within urban areas (Emmatty, Bhatti, & Mukalel, 2006). This is particularly worrying as there is a lack of formal services for people with dementia in India (Prince, 1997) with residential care being accessed as a last resort (Ematty, Bhatti & Mukalet, 2006). This suggests that, in India, carers provide long-term care for people with dementia, often with no expectation of respite, formal support or intervention.

The shift from the traditional extended family model is also being witnessed within South Asian communities in the U.K. (Katbamna et al., 2002), although many families still live within extended households (Bowes & Dar, 2000; Owen, 1994). Studies looking at British South Asian carers (not exclusively dementia carer-givers), reported that living within an extended-family unit does not always guarantee increased emotional and practical support for primary carers (Ahmad & Atkin, 2000; Chamba et al., 1998; Katbamna et al., 2004). In Ahmad & Atkin's qualitative study (1996) daughters-in-law,

who are often the main carers, reported receiving a limited amount of emotional support from other family members. Male support was described as “unreliable” (Katbamna, 2004) and due to the stigma attached to dementia, the diagnosis was often hidden from the rest of the community and thus little formal support was received (Mackenzie, 2006).

### Carers' experiences

Within extended-family households in India and the UK, the spouse, daughter or daughter-in-law typically undertakes the role of caregiver (Shaji et al., 2003; Townsend & Godfrey, 2001; Ismail & Mackenzie, 2003; Mackenzie, 2006.) Many South Asian carers of people with dementia within their country of origin (SACCO) are severely criticised by family members, with accusations of neglect of the care recipient. In Shaji et al's (2003) qualitative study, condemnation of SACCO was reported as being particularly high when the care recipient exhibited specific behaviour difficulties related to dementia, such as incontinence or wandering, adding to the stress experienced by carers.

SACCO and BSAC described a range of different reasons for taking up their role as primary caregivers, including caring out of duty, because it was their responsibility to do so, because it was their fate, or was part of a penance (Emmatty et al., 2006; Shaji et al., 2003; Mackenzie, 2006). Studies described religion as playing a central role in the lives of BSAC and as having a strong influence on the caring role. For example, Muslims described their caring role as being a duty and a way of obtaining blessings, while Sikh and Hindu carers described their caring roles in terms of repaying the care recipient (Mackenzie, 2006).

As with SACCO, similar stresses are experienced by BSAC, with reports of condemnation and criticism of carers from family members or religious leaders, especially when BSAC have difficulties in managing behavioural difficulties associated with dementia (Mackenzie, 2006; Ismail & Mackenzie, 2003; Katbamna, 1998). Mackenzie's (2006) study, which is part of a three-year project set out to support carers' of dementia from South Asian and Eastern European communities living in the U.K, focused on the impact of stigma on BSAC. Findings from this study revealed that a dementia diagnosis would result in higher levels of condemnation from within their communities in comparison with the majority white British population, perhaps highlighting how the perception of dementia may differ within diverse cultural backgrounds. Unsurprisingly, many BSAC do not seek professional help in the form of assessment, support or intervention, with care recipients being kept away from social situations (Milne & Chryssanthopoulou, 2005). The lack of formal and informal support often results in BSAC feeling isolated, stressed and vulnerable to depression.

### Services available

In comparison with BSAC, SACCO may face many practical difficulties in relation to accessing services. Geographic location and a lack of government funding have an immediate impact on carers wishing to access services (McCabe, 2006). Some SACCO travel long distances for clinic or hospital appointments and a limited number of people with dementia have contact with doctors (Patel & Prince, 2001). SACCO who managed to attend outpatient clinics received a limited amount of information or advice by health



professionals in relation to managing behavioural difficulties associated with dementia, which was of prime concern to many of them; none of the carers were in regular contact with health services (Shaji et al., 2003). Interestingly, in Shaji et al's qualitative study involving 17 carers, many voiced their interest in gaining more information about dementia care or joining support groups indicating a need for help and advice in caring for a person with dementia.

In contrast, here within the U.K., a range of services are generally available to carers of people with dementia from Asian and non-Asian backgrounds, however service uptake is low within the South Asian community (Lindesay et al., 1997; Seabrooke & Milne, 2004). Throughout the literature reviewed, similar themes emerged as barriers to service uptake for BSAC and these factors are reviewed below.

### **Barriers to service uptake**

#### **Communication**

Some older BSAC may have difficulties in expressing themselves in English and communicating with health professionals may be a barrier to service uptake. Even through translation, word meaning can often be misinterpreted or lost; for example, the same word can be used to describe both physical and emotional pain in Asian languages (Rait & Burns, 1997). Even the term 'care-giver' can be unfamiliar to BSAC who may struggle to distinguish between the typical caregivers' responsibilities and those provided in kinship (Townsend & Godfrey, 2001). There appears to be no equivalent word for dementia in any of the South Asian community languages (Mackenzie, 2006), with 'mad'

being one interpretation (Alzheimer's Society, 2007).

Even when exploring or 'measuring' carers' burden, expressing negative feelings and emotions about caring for a loved one with dementia can be a very uncomfortable thought for many carers from any background. In a study within the United States, the whole concept of reporting care-giving as being a burden was seen as an unacceptable notion for many Black and Asian carers (Dilworth-Anderson et al., 2002). Therefore, it may not be enough to be able to 'understand the language' or communicate using visual aids. The need to obtain a more holistic understanding of the South Asian community, their languages, cultural practices, beliefs (beliefs about dementia), values and traditions is vital. This may also incorporate an awareness of stigma on multiple levels.

Norman (1985) discussed the concept of 'Triple Jeopardy', which looks at the simultaneous disadvantages experienced by minority groups living within the U.K. These disadvantages include the impact of age, physical/social conditions such as poor housing conditions - which may lead to discrimination, and also a significant third factor of inaccessible services. Many of the studies reviewed reported on the concept of 'Triple Jeopardy' (Gilliard et al., 2005; Rait & Burns, 1997; Turner, Christie & Haworth, 2005), while others remain more cautious, suggesting that this theory may be lacking in empirical evidence (Iliffe & Manthorpe, 2004). However, a broad understanding of BSAC' beliefs and practices will also have implications in terms of how health professionals share information about dementia with BSAC.

### Health professionals' knowledge

Within the UK, minority groups are often treated as homogenous (Rait and Burns, 1997) and many South Asian service users expressed dissatisfaction with the current services (Bowl, 2007; Seabrook & Milne; 2004, Adamson, 1999), stated their lack of awareness of the services available (Lindesay et al., 1997), or reported not being 'listened to' (Bowl, 2007). Data for the above studies were derived from qualitative studies using focus groups, qualitative interviews, or structured interviews administered in their own language. Health professionals' lack of knowledge regarding service users' language, religious beliefs and cultural practices - including those relating to food and personal care, were seen as a major barrier to service uptake by South Asian service users (Ilfie & Manthrove, 2004; Milne, 2004; ). For example, a BSAC reported on the culturally inappropriate advice given by a nurse, in response to difficulties with dressing and undressing a care recipient with dementia, where it was suggested that the care recipient wear a jogging suit instead of a sari (Katbamna et al., 2002).

### Carers' limited knowledge of dementia

SACCO have limited access to information about dementia and none of the 17 carers interviewed in Shaji et al's (2003) qualitative study were unfamiliar with the terms dementia or Alzheimer's disease. However, all were familiar with a colloquial term 'Chinnan' which is used to describe a person with dementia. Literally translated 'Chinnan' is a reference to the child-like presentation of a person with dementia. Carers often described the behaviours that accompany dementia as deliberate misbehaviour and few of the 12 BSAC who took part in Adamson's (2001) qualitative study were reported

to be able to separate dementia from ageing (Adamson, 2001).

Despite media coverage on dementia and services available to carers within the U.K, BSAC appear to have a limited amount of awareness and knowledge about dementia (Ayalon & Arean, 2004; Turner, Christie & Haworth, 2005; Ismail & Mackenzie, 2003). Purandare et al., (2007) conducted a quantitative piece of research comparing dementia knowledge of 196 British South Asian older adults with 59 white older adults attending three different day centers. Both groups completed the Dementia Knowledge Questionnaire (DKQ; Graham et al., 1997) in the language of their choice (English, Gujarati or Urdu). Both groups were found to have a limited knowledge base of dementia, with the Indian group achieving particularly low scores on 'Basic Knowledge'.

BSAC, who had contact with General Practitioners (GPs), described a lack of information given to them about dementia, and a lack of clarity regarding the differences between depression and dementia. Many carers perceived this as the same condition (Ismail & Mackenzie, 2003). In a further qualitative study, involving 96 (British) South Asian and 96 white older adults matched for age, sex and area of residence, knowledge of dementia was examined using semi-structured interviews in a choice of four languages. The normal ageing process was seen by 47 South Asian participants as the most likely cause of dementia in comparison to 22 participants from the white older adult group (Turner, Christie & Haworth, 2005). Findings from this study were consistent with previous studies (Adamson, 2001) in reporting that South Asian older adults had a lower knowledge base of dementia compared with white older adults.

## Perception and attitudes of carers towards dementia

Perceptions, attitudes and the understanding of dementia vary amongst the South Asian population both within their country of origin and here in the UK, and there appears to be two contrasting approaches to viewing dementia (Milne & Chrissanthopoulou, 2005).

### Normalising view

The first approach includes the normalising view, that dementia is a normal part of the aging process (Aylon & Arean, 2004; Chandra, 1996; Milne, 2004). This view is reflected in the language used to describe cognitive impairment; the literal translation for cognitive impairment' is 'turned 60' (Chandra, 1996). This phrase has been used for centuries as part of the Indian language, supporting the notion that cognitive impairment or dementia is seen as a normal part of the aging process. The concept of the deterioration in cognitive functioning with age may result in the absence of a need for medical attention, and this view may be held by some professionals, as well as lay people, in India (Chandra, 1996).

### Stigmatisation view

The second approach includes the stigmatisation view of dementia (syndromes), with reports of Alzheimer's Dementia as being contagious or a form of insanity (Aylon & Arean, 2004). Stigma was reported as stemming from religious beliefs (Mackenzie, 2006) and the concept of reincarnation is an important belief for some South Asian carers, within their country of origin as well as within the U.K and therefore, when a person develops dementia this may be seen as punishment for bad deeds in a previous life.

Religious models often incorporate stories of black magic or evil spirits, such as the view that dementia is a punishment from God. For example, in a qualitative piece of research conducted with SACCO, one carer believed that her husband's cognitive decline was due to 'black magic' (Shaji et al., 2003). Folk models are often used to understand dementia, and were highlighted in a number of studies reviewed within minority groups living in Western countries (Dilworth-Anderson & Gibson, 2002; Mackenzie, 2006).

The stigmatisation view of dementia is a further barrier for BSAC wishing to access services. Stigma plays such an integral role in how dementia is viewed by the family and the community, and has implications in terms of how a person with dementia is cared for. BSAC adapt their coping strategies, in an attempt to manage dementia, by playing down the functional and cognitive difficulties of the care recipient, hiding the person with dementia (Goffman, 1963), and by not accessing the services that both the carer and care recipient require, thus avoiding rejection by others (Mackenzie, 2006) and protecting the family name and honour (Katbamna et al., 2002).

### Summary of themes

To summarise, a lack of knowledge by health professionals regarding service users' language, ethnicity, cultures and traditions may be a barrier to service uptake for many BSAC. Gaining a broader understanding of the South Asian way of life, in terms of their culture and beliefs, will result in enriching communications between health professionals and BSAC. This in turn may increase service uptake and enable health professionals to gain further knowledge and understanding of BSAC.

It is hypothesised that engaging with health professionals from a range of different services (GP, nursing, occupation, health, psychiatry, psychology) may facilitate BSAC' knowledge of dementia. Studies indicate that an increased knowledge of Alzheimer's Dementia is associated with help seeking behaviour (Werner, 2003); therefore, this may further increase BSAC' service uptake. A broader understanding of dementia will have implications in terms of BSAC' perception of dementia, perhaps questioning both the normalisation and the stigmatisation view. Challenging the stigma associated with dementia may lead to a further increase in service uptake, and may impact on the care recipient's level and quality of care.

All of these factors may have implications for the psychological health of BSAC as well as having implications for health professionals in terms of engaging BSAC. A diagrammatical representation of BSAC' barriers to service uptake and the implications of these barriers is presented below (see Figure 1.).

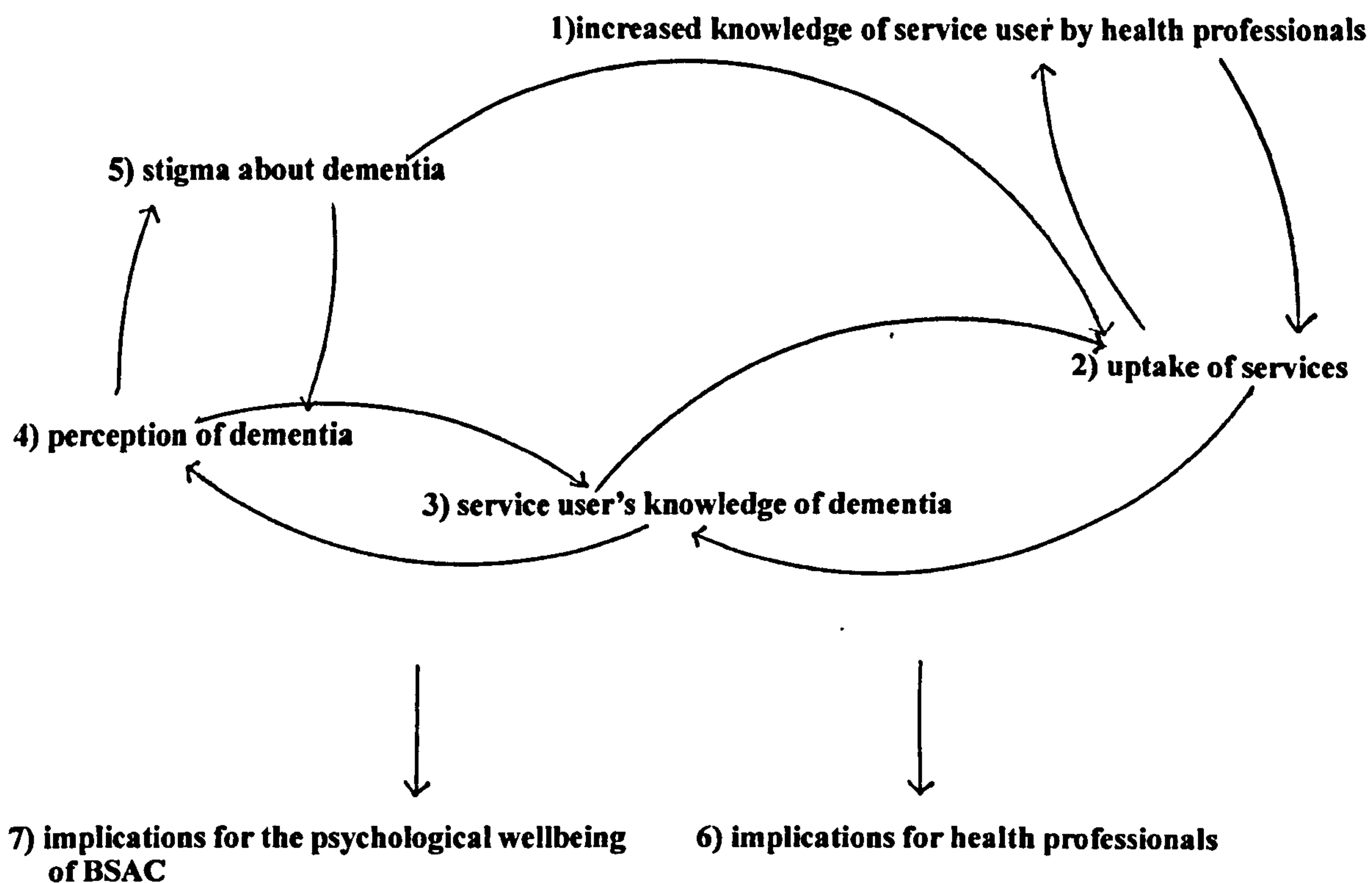


Figure 1. Understanding British South Asian Carers' (BSAC') barriers to service uptake

## Discussion

In reviewing the limited literature on the BSAC' experience of caring for a person with dementia, it has become apparent that there are a range of cultural challenges that need to be overcome.

## Methodology

In comparison to the indigenous population of the UK, a limited number of studies have



been conducted looking at the BSAC' psychological wellbeing. The majority of these studies have been qualitative, therefore making it difficult to directly measure BSAC' morbidity levels, although qualitative research allows for comparisons between different populations.

In many of the studies reviewed, BSAC were able to take part in (semi-) structured interviews or focus groups in their own choice of language, with other studies reporting using transcripts that were later translated. This process allowed carers to freely voice their opinions. However, when the interaction between researcher and carer involved a three way interaction (researcher, interpreter and carer), the quality of data may have been compromised, thus further increasing the complexity of data analysis.

The studies reviewed were diverse in terms of the aims and outcomes. For example, some studies focussed specifically on knowledge of dementia within British South Asian older adults compared to a majority, white, older adults group (Purandare et al., 2007), while other studies looked at convening and facilitating support groups for British South Asian families of people with dementia (Ismail & Mackenzie, 2003), or looked at the specific impact of stigma on BSAC (Mackenzie, 2006). Studies also highlighted the need for validated tools in South Asian languages, such as in Punjabis, Gujeratis and Bengalis. Measures need to be sensitive to cultural variations and educational bias whilst evaluating psychological wellbeing, cognitive decline and activities of daily living as part of a dementia assessment (Bowl, 2007).

A common theme throughout many of the studies included the significant preparatory outreach work conducted in order to engage participants with taking part in research, surveys and support groups, (Ismail & Mackenzie, 2003; Adamson, 2001). This highlights the need to build and further develop the present relationship between health professionals and the British South Asian people, within the community, prior to attempting to engage in services; this may be facilitated by employing more South Asian health professionals.

### **Implications for health professionals**

#### **Training**

Based on the literature reviewed, there appears to be similarities in South Asian carers' beliefs and experiences of dementia, both within their country of origin and within the U.K, suggesting that these beliefs are not only deep rooted but a way of life. A clear understanding of this basic factor may enable health professionals to adapt approaches and become more creative and flexible in developing different ways to engage BSAC. As cultural variations and beliefs (religious or folk models) about dementia have such a strong influence on shaping the meaning of dementia, health professionals may need to gain an understanding of the factors that shape these beliefs. This will have significant implications on how health professionals share information about dementia with BSAC.

Culture competence and linguistic ability was reported as extremely advantageous in engaging South Asian immigrants (Bhatnagar & Frank, 1997) and these qualities may have positive implications in terms of forging closer relationship between health

professionals and BSAC. Errors such as misspelling a person's name can be construed as disrespectful adding to the barriers to service uptake as well as resulting in further complexities of tracing clients (Bhatnagar & Frank, 1997).

### Accessing services

Older adults from ethnic minority groups have high general practice (G.P.) registration rates (Shah, Oommen & Toteja, 2006; Lindesay et al., (1997). G.P. attendance amongst Asian Gujarati was recorded at 70.1% compared with 40.1% amongst white older adults. However, annual G.P. check-ups were only offered to 22% of the Asian Gujarati older adults population, compared to 61.3% of white older adults (Lindesay et al., 1997). Further consultations with psychiatry services, post G.P. consultation, are limited. This suggests that the G.P. may be an excellent starting point in terms of working closely with older adults from South Asian communities especially if G.Ps liaise closely with primary care services, thereby establishing a solid framework to build on, prior to clients developing dementia and other related disorders. This may encourage prospective carers and care recipients to feel less apprehensive about approaching services.

### Support groups

Setting up support groups for BSAC is not an easy task, however, many carers highlighted the need for information relating to the management of behavioural difficulties related to dementia. The fear of being identified as a carer of a person with dementia can be a difficult barrier to overcome for many BSAC and therefore the recruitment of carers for support groups needs careful consideration. The fear of

condemnation from within the community was identified as a significant factor in recruiting BSAC into support groups. This highlights the tremendous amount of groundwork that is required prior to setting up formal support groups for BSAC (Ismail & Mackenzie, 2003). Simple steps such as choosing a suitable venue can have a huge impact on uptake (Ismail & Mackenzie, 2003). Practical advice and information regarding managing day-to-day difficulties may help to facilitate the coping process and reduce carers' burden, as well as challenge the stigma associated with dementia.

### **Building of current successes**

Ismail & Mackenzie (2003) describe the importance of “building up a relationship” with BSAC prior to setting up their support group. Setting up a sitting service and providing culturally appropriate food for group members all contributed to building a positive relation with the carers. BSAC were encouraged to think of the type of support that they might require and focus was placed on “empowering” carers who attended the support group. Contact between carers and facilitators between sessions was reported as crucial as it clearly showed carers that the facilitators were interested in supporting the carers, thus reinforcing the positive relationship between them.

### **Implications for British South Asian Carers of people with dementia**

#### **Perception of dementia**

Two very diverse approaches to viewing dementia have significant implications in terms of accessing support and intervention for BSAC. As dementia is seen as a normal part of the aging process, carers are less likely to seek intervention or formal support (Turner,

Christie & Haworth, 2005). The strong stigma attached to dementia has implications in terms of accessing both formal and informal support of friends and family members. This is particularly worrying as the modernisation of family units and dual careers place more pressure on the primary caregiver. As a result of the stigma attached to dementia, a limited number of BSAC and care recipients seek assessment and support, resulting in a reduced number of BSAC being offered interventions.

### Increasing knowledge of dementia

As carers of people with dementia become more knowledgeable and more competent this may have positive implications in terms of reducing carers' burden and increasing carers' psychological wellbeing. Increased knowledge has also shown to impact on carers' coping style, with carers exhibiting a monitoring style of coping, that is, carers actively seeking out information about the dementia (Proctor, Martin & Hewison, 2002). As a carer becomes more knowledgeable about the aetiology and management of dementia, it is perceived that this may have a positive impact on the relationship between the carer and care recipient, allowing for a more person-centred approach to caring. Therefore, an increased knowledge of dementia may help the carer to extend their caring role at home.

### Assessment and Diagnosis

Culturally appropriate assessments will help the diagnostic process of distinguishing dementia from the typical cognitive difficulties experienced with aging. Receiving a diagnosis can have positive implications for carers, in terms of feeling a sense of relief, and by providing an explanation of what's happening, for instance why care recipients

demonstrate behavioural difficulties such as incontinence, aggressive behaviour or low mood. This can remove the blame from carer and care recipient, and allow the carers to respond differently towards the care recipient. A diagnosis may have implications in terms of how the family and the wider community relate to the carer and care recipient in general. As vascular dementia appears to be more prevalent within the Asian population, gaining knowledge about the vulnerability factors associated with vascular dementia is important.

### Summary

The psychological impact of caring for people with dementia is well documented and accessing services could potentially alleviate some of the stresses associated with carers' strain and burden. Culture and ethnicity have been highlighted as defining factors in dementia caregiving and in influencing the experiences of Asian carers (Milne & Chrissanthopoulou, 2005). Based on the studies reviewed, it appears that BSAC are a minority group who experience a number of significant barriers to accessing the services available.

The proposed model (figure 1) represents the main themes emerging from the literature as barriers for BSAC of people with dementia to engaging in services. It is clear that, although BSAC may experience certain worries and stresses that may be similar to those experienced by non-BSAC carers (difficulties in managing care recipients' behavioural problems, financial worries, concerns for future management), there are specific factors that prevent BSAC from accessing appropriate services. These factors include a lack of

knowledge by health professionals regarding South Asian culture and beliefs, BSAC's lack of knowledge about dementia, BSAC's perception of dementia, and the stigma associated with dementia syndromes. Other factors, which have not been discussed in detail in this paper and therefore have not been included in the model, include: the general experiences of being in a minority group and how this may impact on accessing services, and the significant role that religion may have on caregiving. It is also important not to assume that interventions that may be effective for one group of people will have the same impact on other groups, this may or may not be the case. Further research is required to establish the effectiveness of evidence-based interventions on carers from the South Asian community, however the first step would be to engage BSAC of people with dementia with appropriate service.

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**Carers' Knowledge of Dementia: What is the relationship between carers' knowledge of dementia, their anxiety levels, coping style and perceived competence levels?**

**Catherine Davies (proposed second author Drs. Carolien Lamers)**

**Key Words: dementia knowledge, carers' of people with dementia, psychological well-being**

## Abstract

**Objectives:** This study set out to explore the relationship between knowledge of dementia, anxiety levels, coping style and perceived competence levels in carers of people with dementia currently living in the community.

**Method:** A total of fifty-one primary carers, recruited through local services and voluntary organisations, took part in the study, which involved completing a set of questionnaires. Information was collected on carers' knowledge of dementia, anxiety and depression, coping style of either monitoring or blunting for information, and competence. Information relating to care recipients' level of cognitive functioning, and memory and behavioural difficulties associated with dementia was also collected.

**Results:** A significant negative association between biomedical knowledge and anxiety levels was found, although this should be interpreted with caution due to the low Cronbach's  $\alpha$  coefficient on the biomedical subscale (.54). Younger carers showed higher dementia knowledge compared with older carers, with younger carers exhibiting lower anxiety and higher competence levels. Interestingly, duration of difficulties was negatively associated with scores on the coping subscale of the knowledge measure. No associations were found between style of coping and knowledge, anxiety or competence levels.

**Conclusion:** Perception and understanding of dementia, especially amongst younger carers, may have changed over the past decade. The educational component of interventions may be successful in terms of sharing dementia knowledge with younger carers although the emotional element of caring may still need be addressed.

**Key Words:** information, carers, anxiety, coping, competence,

## Introduction

It is well documented that carers of people with dementia often experience high levels of stress and burden (Cooper et al., 2006; Pinquart & Sorensen, 2006; Pusey & Richards, 2001; Sorensen et al., 2006), and in an attempt to promote the psychological wellbeing of carers, a range of interventions have been developed and carried out with carers of people with dementia (Challis et al., 1997; Gendron et al., 1986; McCurry et al., 1998) with many of the interventions specifically targeting carers' anxiety and/or depression (Gendron et al., 1986). In a systematic review of the literature, Cooper et al. (2006) revealed that around 25% of carers exhibit clinically significant anxiety levels and that carers' coping styles were found to be strongly associated with their anxiety levels. It has also been suggested that knowledge of dementia is associated with carers' anxiety levels (Proctor et al., 2002), and carers who had more knowledge of dementia also presented with lower depression levels, and were described as being more competent (Graham et al., 1997).

Education has played an integral part in many interventions offered to carers, and should be delivered at the pace of the carer (Sorensen et al., 2006; Burgener et al., 1998). Today carers are able to access information about dementia from a range of different sources including the media, library, Internet, support groups and voluntary organisations. A lack of knowledge about dementia may lead carers to misattribute care recipient's behaviour, for example, as being non-compliant or as "just being awkward". During the diagnostic process and post-diagnosis, professionals often provide carers with a body of information both verbally and/or in the form of leaflets and articles to provide them with adequate information about dementia. Indeed studies have indicated that knowledge on any aspect of dementia is generally

considered beneficial to carers (Dieckmann et al., 1988). However, only two main studies have looked specifically at carers' knowledge of dementia and carers' morbidity.

In addition to the acquisition of knowledge, carers' coping style has been found to be a major factor in how individuals relate to information given to them, and this has been documented in health psychology (Miller et al., 1996). Studies have highlighted that patients are often better able to cope with their illness when information they receive about their condition and treatment is tailored to meet the individual's coping style (Miller, 1995). An individual may actively seek out information (monitors) or conversely they may prefer to avoid information (blunters).

A monitoring style of coping has also been associated with carers who have elevated levels of anxiety and also have high dementia knowledge (Proctor et al., 2002). That is, carers actively seek out information about dementia as opposed to blunting information (avoiding information).

The aim of the present study is to build on the findings of Graham et al. (1997) and Proctor et al. (2002), in exploring the relationship between carers' knowledge of dementia, their anxiety levels, coping style, and perceived competence levels. This study intends to assess which areas of dementia knowledge are linked to anxiety and gain a better understanding of the mechanisms involved in processing information about dementia. This study may have clinical implications as regards to working closely with carers throughout the diagnostic process as well as pre and post diagnosis. Findings of the present study may help to establish effective ways of

working with carers by sharing information about dementia congruently with carers' coping style, and exploring carers' concerns and their understanding of dementia.

It is hypothesised that there will be an association between carers' level of knowledge about dementia, carers' anxiety levels and a monitoring style of coping. It is also anticipated that there will be an association between knowledge of dementia, a monitoring style of coping and perceived competence levels. The study will look at the relationship between the four main variables, (knowledge, anxiety, coping and competence), and providing the criteria for mediation are met proceed to analyse these factors using the mediation model of analysis.

## Materials and Methods

### Participants

Participants included primary carers of people with dementia currently living in the community. A primary caregiver was defined as someone who provides the majority of care and support to a person who has received a diagnosis of dementia and is currently living in the community. A primary carer could be a spouse, adult child carer, relative, friend or neighbour. A total of 52 participants agreed to take part in the study, one was excluded as they had only completed the demographic questionnaire. Further demographic information about the primary carer and care recipient can be found in the Result Section.

## Measures

Packs containing seven measures were handed out to participants and these included a demographic questionnaire, to collect information about the carer and care recipient, and six other measures, which are discussed below. The primary caregiver completed all the measures and it was anticipated that this would take 60-85 minutes.

*The Revised Memory and Behavior Problem Checklist* (RMBPC; Teri, et al., 1992) was used to establish the care recipients' level of functioning. This measure includes three separate subscale scores (memory related, disruptive behaviour, and depression), and assesses both the frequency of behaviour and the caregiver reactions to the behaviour. The carer rated the frequency of the behaviour over the past week, on a scale from 0 = 'never occurred' to 4 = 'daily or more often'. The option of 9 = 'don't know' or 'not applicable' was also available. Carers' reaction to the behaviour were also rated on a scale of between 0 = 'not at all' to 4 = 'extremely'. Again, the option of 9 = 'don't know/not applicable' was available. For consistency purposes, it was decided that for carers who had scored a '0 never occurred' for frequency of behaviour, and had not rated a reaction score, a '0 not at all' would be recorded for reaction. Similarly, for carers who scored a '9 don't know/not applicable' for frequency of behaviour, and had not rated a reaction score, it was decided that '9 don't know/ not applicable' would be recorded. For the purpose of this study, total frequency and total reaction scores were analysed and not subscale scores.

The RMBPC is reported to have high internal consistency, with a reported Cronbach's  $\alpha$  coefficient of .84 for total Frequency score and .90 for total Reaction score (Teri et

al., 1992). A Cronbach's  $\alpha$  coefficient of .84 for total Reaction and .86 for total Frequency was indicated with this population sample.

*The Informant Questionnaire on Cognitive Decline in the Elderly* (IQCODE; Jorm & Jacomb, 1989) was used to establish stage of dementia. The IQCODE draws parallels with the Mini Mental State Examination (MMSE; Folstein et al., 1975) in terms of reporting on changes in the everyday cognitive functioning of the care recipient, thus providing the author with information regarding the stage of dementia. This questionnaire (short-form) includes 16 items, which look at changes to the care recipients' cognitive functioning over the past 10 years. Each item was scored on a scale of between 1 = 'much improved' to 5 = 'much worse'. A Cronbach's  $\alpha$  coefficient ranging from .93 to .97, based on several studies, which included a wide range of populations and languages, was reported for this scale (Jorm, 2004). The reliability of IQCODE with the present sample was high (Cronbach's  $\alpha$  coefficients .94).

*The Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1994) was administered to establish carers' anxiety levels; depression measures were also provided. The HADS is a well-established scale consisting of 7 Anxiety and 7 Depression items, and is scored using a four-point scale. It is used extensively, both clinically and within the research field, and has demonstrated high internal consistency both for residential populations and the general population aged 18+. A Cronbach's  $\alpha$  coefficient of .80 for the anxiety scale, and .76 for the depression scale, has been reported (Zigmond & Snaith, 1994), and for the present study a Cronbach's  $\alpha$  coefficient score of .84 for anxiety, and .81 for the depression scale, was

demonstrated.

*The Dementia Quiz* (Gilleard & Groom, 1994) was administered in order to establish carers' knowledge of dementia,. This is a multiple-choice questionnaire and measures three different domains (biomedical, coping and services); a total score is also calculated. Carers were asked to choose one correct option out of five and a 'don't know' option is included, therefore reducing the possibility of carers' randomly guessing the correct responses. Carers who chose more than one option received a score of zero for that item. A Cronbach's  $\alpha$  coefficient of .70 for the total Dementia Quiz score indicates high internal consistency for the present sample of participants; a Cronbach's  $\alpha$  coefficient of .88 was reported in other published studies (Gilleard & Groom, 1994).

*The Miller Behaviour Style Scale* (MBSS; Miller, 1987) was used to assess coping style. This measure focuses on two styles of coping, firstly a Monitoring coping style, which refers to individuals who actively seek out information, and secondly the Blunting style, which refers to individuals who avoid information. The measure includes four scenarios, with a choice of eight action statements for each. More than one answer could be given. A total monitoring and a total blunting score was achieved. In previous published studies this measure has shown high internal consistency (Cronbach's  $\alpha$  coefficient = .79 for monitoring and .69 for the blunting scale; Miller, 1987). In the current sample, a Cronbach's  $\alpha$  coefficient of .78 for the total Monitoring subscale, and .63 for the total Blunting subscale, was reported.

*The Short Sense of Competence Scales* (Vernooij-Dassen et al., 1999) was used to



measure carers' competence. This shortened version comprises of a 7 item questionnaire, which provides seven statements, and is scored on a scale from 1='agree very much' to 5 = 'disagree very strongly'. The measure looks at three domains and these include, i) carers' satisfaction with the person who has dementia (items 1-3) ii) carers' satisfaction with his/her own performance (items 4-5), and iii) the consequences, or impact, of caring on the carers' personal life (items 6-7). A Cronbach's  $\alpha$  coefficient of .76 suggests good reliability (Vernooij-Dassen et al., 1999) and this is consistent with the present study, which reports a Cronbach's  $\alpha$  coefficient of .80.

## Design

This was a cross-sectional, questionnaire-based study looking at primary carers of people with dementia currently living in the community. T-Tests and Correlations were used to look at the relationship between knowledge, anxiety levels, coping styles, and perceived competence levels, with the aim of using a mediation model of analysis.

## Procedure

Carers of people with dementia were identified from Memory Services, Community Mental Health Teams (CMHT), charities and support groups. The recruitment process involved providing key professionals within the voluntary sector (Alzheimer's Society, Carer's Outreach and Age Concern) and health professionals within North-West Wales and Conwy & Denbighshire NHS Trusts with a broad description of the research via an initial telephone conversation or email. This was followed by presentations in a total of 16 team meetings (referral, allocation) and support

group/Alzheimer's Cafes within both Trusts. Separate informal presentations targeting primary figures who were unable to attend team meetings were also arranged, for example, meetings were held with Occupational Therapists and local Clinical Psychologists. Carers from a support group in England were also invited to take part in the study.

An outline of the procedure and a description of the inclusion/exclusion criteria for participant recruitment were provided at team-meeting presentations. Ethical implications of the study were also discussed, for example, not targeting carers that were unduly stressed, or carers and care recipients who were just coming to terms with a dementia diagnosis. Questionnaire packs were handed over to team members (for example, Social Worker, Psychologist, Psychiatrist) working closely with carers of people with dementia, who, in turn reviewed their caseload for potential participants. Each team-member handed the packs out to appropriate carers and these were subsequently posted back to the author. A total of 473 questionnaire packs were sent out and a total of 52 were returned (one participant was excluded from the study).

### Data preparation and analysis

The data were examined for outliers greater than 2 standard deviations from the mean: no outliers were found. A one-sample Kolmogorov-Smirnov test was used to analyse the distribution of the data and assess the suitability of the data for parametric analysis. Apart from the IQCODE ( $Z = 2.10$ ,  $p < .01$ ) and the Monitoring scale ( $Z = 1.44$ ,  $p < .05$ ), all other variables were not significantly different from a normal distribution, and therefore parametric tests were used to analyse all other variables. The distribution of the IQCODE suggests that, for the current sample, the distribution

of care recipients' cognitive functioning lay at the moderate to severe end of the scale. This is consistent with the expected presentation of care recipients in this study. As the distribution of the data was also significantly different from a normal distribution in the Monitoring scale, non-parametric tests were used for analysis.

## Analysis strategy

The results section is in four parts and includes:

- i) Descriptive statistics to briefly present the main demographic variables.
- ii) Mean scores and Standard Deviations (S.D) are compared with those from published studies in order to establish whether the samples are similar.
- iii) Correlational analysis to look at the relationship between the main variables and to establish the criteria for mediation.
- iv) Independent-Samples T-tests tests were conducted to look at the differences between the mean scores of differences variables.

## Results

### i) Demographic information

Participants comprised of 51 carers with an age range between 46 and 88 years, with an average age of 66 years. The majority (78%) of the carers resided with the care recipients. A large proportion (63%) of the participants were members of local charities/support groups, and less than half reported that they attended support groups. In terms of participant's physical health, 67% reported their health to be good or above, with just over half of the carers describing themselves as religious or spiritual. Three quarters of the participants had been caring for a person with dementia for a period of over 2 years, with just over a third of care recipients receiving no formal

help or support. Care recipients' age ranged from 59 to 91 years, with an average age of 77 years. In comparison with the demographic characteristics of Proctor et al's study (2002), participants' age, care recipients' age, and living arrangements were similar. However, a greater number of wives (71%) participated in the present study compared with Proctor's study (24% ), and in addition there were a larger number of female participants in the present study compared with Proctor's study (54%). Further demographic information about the carers and care recipients who took part in the study is presented in Table 1.

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insert Table 1 here  
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ii) Mean scores and Standard Deviations

The RMBPC Frequency and Reaction mean scores and standard deviations are comparable with those in Teri et al.'s study (1992), where 201 care recipients and caregivers took part in a comprehensive assessment of cognitive impairment. The IQCODE mean and standard deviation scores were .05 Standard Deviation higher in the present sample compared with scores from a previous study looking at clients who attended Memory Clinics (Logiudice et al., 1999). This reflects a slightly higher level of cognitive impairment in the present sample and is confirmed by the distribution of the data, suggesting that the care recipients were functioning towards the moderately to severe end of the scale. However, care recipients in Proctor et al's study (2002) also exhibited a high level of cognitive impairment (MMSE = 7.8, SD = 6.1).

The HADS mean scores and standard deviation for anxiety and depression were at the mild (or borderline) range. These scores were consistent with anxiety and depression scores in Proctor et al's (2002) study.

The Dementia Quiz total and subscale scores (especially service knowledge) were higher in the present study, in comparison with Proctor et al's (2002) study. Proctor et al. (2002) reported that the mean subscale scores in their study were comparable with a group of carers referred to in Gilleard and Groom's (1994) study, who had no contact with charities and carers' organisation, and cared for care recipients who were at the early stages of dementia. Therefore, when comparing knowledge of dementia scores in the present sample with those presented in Proctor et al's sample, it would be expected that the current sample would show a higher knowledge base, especially carers who are not in the early stages of care-giving, and those who had contact with services and charities. Carers in Gilleard and Groom's study, who were members of a charity organisation, scored slightly higher on the Dementia quiz subscales, with service knowledge scores being fairly consistent to scores in the present study.

The Monitoring and Blunting total scores in the present study were lower than those presented in Proctor et al's study and the most likely explanation for this is that there may have been some confusion as to how to complete this measure appropriately. Carers may have ticked just one of the options presented to them for each scenario instead of ticking all the options that applied to them. In Proctor et al's study, carers were interviewed before being left with questionnaires to complete; carers who had not completed the measures correctly were also 'chased up'.

The Short Sense of Competence total scores were reported as somewhat lower in the present sample in comparison with the Vernooy-Dassen et al. (1999) study. Analysis of the three domains on the Short Sense of Competence Scale, (satisfaction with the person who has dementia, satisfaction with own performance as a carer, and the consequences of caring in terms of carers' personal life) revealed that no pattern of association was established between any of the domains on the competence scale and knowledge of dementia.

The means and Standard Deviation scores are presented in Table 2.

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insert Table 2 here  
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iii) *Correlational analysis test for the criteria for mediation.*

A correlational analysis looked at the association between the main variables, and the criteria for mediation were not met.

A correlational analysis failed to show a relationship between carer's total dementia knowledge scores and anxiety levels, but a negative correlation was found between biomedical knowledge and anxiety levels, however it should be noted that the Cronbach's  $\alpha$  coefficient for the biomedical subtest for the current sample was

slightly low at .54. Therefore this finding should be interpreted with caution.

No relationship was found between anxiety levels and coping style, dementia knowledge and coping style, or competence levels and coping style. Therefore, the hypothesis that carers' anxiety levels were associated with a monitoring style of coping cannot be supported.

However, in looking at the four main variables (knowledge, anxiety, coping and competence), results showed that anxiety and competence were negatively correlated and that depression and competence were also negatively correlated. This suggests that carers with lower levels of psychopathology reported higher levels of perceived competence.

Interestingly, RMBPC Frequency and Reaction subscales showed a strong association with a number of other variables. Anxiety was associated with RMBPC Frequency and RMBPC Reaction, and depression was associated with RMBPC Frequency and Reaction, suggesting that memory and behaviour difficulties associated with dementia impact on carers' anxiety and depression levels. Competence was negatively associated with RMBPC Frequency and Reaction, also suggesting that an increase in memory and behavioural difficulties result in lower perceived competence levels. Scores on the RMBPC Frequency and Reaction subscales were strongly correlated with care recipients' IQCODE scores, which is indicative of the increased memory and behaviour difficulties associated with a progressive stage of dementia and an increased reaction to these behaviours by the caregiver.

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insert Table 3. here  
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A Correlational analysis was also used to explore the association between demographic factors and other variables. Duration of difficulties and scores on the Dementia Quiz coping subscale were significantly negatively correlated, possibly suggesting that dementia coping knowledge may not be such an important factor for carers who have been in the caring role for a significantly longer period of time. However, it is extremely important to consider the limitations of the Dementia Quiz coping subscale in terms of being a reliable measure of carers' coping knowledge. The limitations of this measure, and particularly this subscale, are discussed in more detail in the discussion section.

A negative correlation was demonstrated between age and total knowledge, biomedical knowledge and coping knowledge of dementia, suggesting that younger carers had an increased knowledge base. No other significant associations were found between demographic factors and other variables, for example, hours of care and dementia knowledge, gender and knowledge, age and competence levels, hours of care and competence levels, or relationship to care recipient and competence levels. However, there was an association between gender (female) and the monitoring style of coping. Correlational analysis between demographic factors and the main variables



are presented in Table 4.

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*Insert Table 4. here*

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As an association between anxiety and competence has already been established, a further correlational analysis was conducted to look at the relationship between carers' age, knowledge of dementia, anxiety and competence levels. Age was separated into Group 1 (N = 30) carers aged between 46 and 66 years and Group 2 (N = 21) carers aged between 67 and 88 years. Separate correlations were conducted for each group, and results indicated that Group 1 showed a negative association between anxiety and competence levels ( $r = -.55, p < .01$ ); however, no relationship between these two variables was found in Group 2 ( $r = -.15, p > .01$ ). Therefore, the results showed a negative association between anxiety and competence within younger carers and this association was not present within older carers. Total knowledge scores were not correlated with anxiety or competence in either of the groups.

The lack of a significant association between the main variables suggested that it was not possible to proceed with the mediation model of analysis, which would have explored two models consisting of three factors (Model 1. knowledge, anxiety, coping

and Model 2. knowledge, coping and competence). It was anticipated that, in Model 1, the relationship between knowledge and coping would have been mediated by carers' anxiety levels, and in Model 2. the relationship between knowledge and competence would have been mediated by carers' coping style. However, due to the lack of a significant association between knowledge and coping style in Model 1. and knowledge and competence in Model 2. the author did not proceed with the mediation model of analysis.

Results indicated that the criteria for the mediation were not met.

#### iv) *Independent-Sample T-Test*

In order to further explore the relationship between age, anxiety, competence and biomedical knowledge, Independent-Sample T-Tests were conducted. Participants were separated into high and low competence groups, through a median split process, and the results revealed that the mean anxiety scores differed significantly between carers who were high in competence levels (N=20) compared to those who were low in competence levels (N=21). When carers were separated into two groups according to age, no differences were reported in the mean anxiety or mean competence scores. However, results revealed significant differences between the mean score of the two groups (younger versus older carers) for biomedical knowledge, with younger carers reporting higher mean scores. Independent-Sample T-Tests are presented in Table 5 a and 5b.

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insert Table 5 (a) here

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insert Table 5 (b) here

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## Discussion

The aim of the present study was to look at the relationship between four main variables, including knowledge of dementia, anxiety, coping style (monitoring or blunting), and perceived competence levels.

The main hypotheses of the study have not been confirmed and no relationship was found between dementia total knowledge scores, anxiety, coping style and competence, although results indicated a negative relationship between carers' biomedical knowledge and anxiety levels. However, due to a low Cronbach's  $\alpha$  coefficient on the biomedical subscale, this finding may need to be interpreted with

some caution. This finding is inconsistent with previous studies (Proctor et al., 2002; Graham et al., 1997) reporting a positive correlation between knowledge and carers' anxiety levels. The present study failed to establish any relationship between anxiety and coping style, with no relationship between competence and coping style was established, although female carers were associated with a monitoring style of coping.

The association between carers' psychopathology (anxiety, depression and competence) with RMBPC frequency and reaction scores suggests that it may be the behavioural element associated with dementia that carers find challenging. The association between the behavioural aspects of caring for a person with dementia has been highlighted in previous studies (Donaldson et al., 1998). It may be the *anticipation* of behavioural difficulties that is most distressing for carers, although this was not tested or established in the present study.

### Interpretation of findings

Younger carers were shown to have higher knowledge of dementia compared with older carers. Further analysis of the data comparing spouses (older carers) and adult children (younger carers) did not show that knowledge was higher in adult child carers, therefore knowledge differences between the two groups does not appear to be associated with the relationship between carer and care recipient (spouse versus adult-child carer). It may be that younger carers in general are more familiar with modern Information Technology, and an abundance of biomedical information is available and easily accessed via the Internet or similar sources. A further explanation for an increased knowledge base may be in the way dementia is perceived by younger carers compared with older carers, in terms of dementia being less stigmatised. Perhaps

being more open with others about the diagnosis enables younger carers to seek out the information about dementia. Studies have highlighted the impact that stigma has on carers, in terms of carers not sharing the diagnosis with others, not engaging in services, and having lower a knowledge base of dementia (Mackenzie, 2006; Purandare et al., 2007). Younger carers had an increased knowledge base regarding the aetiology of dementia, lower anxiety and higher competence levels. Graham et al., (1997) also reported a positive association between higher knowledge and higher competence levels of carers in their study.

The lack of a significant association between carers' coping style and knowledge may be explained by some participants not completing this measure appropriately.

The negative association between duration of (cognitive) difficulties and coping knowledge may possibly suggest that as time goes by, 'knowledge' may not be a priority to carers, but that an emotional element of understanding of what is happening, especially as the caring role progresses, is more important. However, it is also important to consider the limitations of the Dementia Quiz coping subscale, in terms of defining and accurately measuring carers' coping knowledge of dementia.

## Limitations of the study

### Sampling issues

Some of the possible reasons for the difference in this study's findings compared with Proctor et al's (2002) study may be due to the sample characteristics. Due to the small number of participants obtained for this research project, the sample may not be

representative of all carers of people with dementia. Carers who had recently received a diagnosis of dementia were not approached. Out of the 51 participants who took part in the study, between 30 and 40 were carers who either attended support groups or were members of various charities. It is possible that carers who were particularly stressed may not have taken part in the study; however, a large proportion (78%) of the carers had been in the caring role for over two-years, and the IQCODE scores suggested that care recipients' cognitive functioning fell at the moderate to severe end of scale. This suggests that at least a fair proportion of the carers may have been 'long-term' carers of people with dementia.

## Measures

The Monitoring and Blunting Scale may not have been a suitable measure for the present sample due to the unsuitability of the scenarios and participants may also have been unclear as to how to complete this measure. Similarly the RMBPC in particular proved quite challenging for participants to complete, resulting in some missing data.

The Dementia Knowledge Quiz provides a quantitative measure of carers' knowledge in three different domains (biomedical, coping and service knowledge). However, it should be noted that the correct answer for several of the items on this scale may need to be updated. It is also important to highlight the difficulty in measuring carers' coping knowledge, based on choosing the 'correct' answer from each scenario presented in the coping subscale, as coping knowledge will vary greatly according to each individual carer and care recipient's presenting difficulties. High scores on this subscale may reflect carers' knowledge of the conventional view of dementia care, but may not typically reflect carers' in-depth knowledge of the care recipient.

Conversely, carers who scored poorly on this scale, may have a lower level of agreement with the conventional view of dementia care but have an in-depth knowledge of the care recipient and their presenting difficulties.

It should also be noted that, as this study is a preliminary replication of a previous study (using  $p < 0.05$ ) and in the interest of generating future hypotheses, the author did not correct for multiple significance testing.

### Summary and conclusion

This study set out to replicate the findings of Proctor et al. (2002) and Graham et al's (1997) studies, but was unable to confirm the associations between total knowledge scores, anxiety, coping style and competence levels in carers of people with dementia, although, a significant negative association was found between biomedical knowledge and anxiety; a significant negative association between anxiety and competence levels was established in younger carers. Previous studies (Graham et al., 1997; and Proctor et al., 2002) were conducted between 6 and 10 years ago, and this may indicate how services have developed in urban and rural areas in the way carers of people with dementia are now supported. Younger carers appear to be more knowledgeable, less anxious and feel more competent. This might suggest that perhaps the educational component of interventions is successful in terms of sharing knowledge with carers. There may also have been a slight shift, over the past decade, in terms of the attitudes, perceptions and the understanding of dementia. Replications of this study are worthwhile in order to further investigate the relationship between knowledge about dementia, anxiety, coping style and competence. There is a need for further research to investigate the relationship between knowledge of dementia and carers'

psychological wellbeing. Intervention focussing more on the emotional aspects of caring might be another approach to develop when dealing with the anxiety triggered by caring for someone with dementia.



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# **Tables**

## **Section 3**

**Table 1. Participants' characteristics**

**Table 1. Demographic information of carers and care-recipients**

		<i>N</i>	%
Gender	Female	36	(71%)
	Male	15	(29%)
Carers' age 46-88 years	Mean 66.3 (SD 10.7)		
Resides with carer	All of the time	40	(78%)
	Some of the time	0	
	Not at all	11	(22%)
Relationship to care-recipient	missing data	1	(2%)
	close friend	1	(2%)
	daughter	12	(24%)
	daughter-in law	1	(2%)
	husband	10	(19%)
	son	2	(4%)
	wife	24	(47%)
Hours of care	0-5 hrs	11	(22%)
	5-10 hrs	2	(4%)
	10-15 hrs	3	(6%)
	15-20 hrs	3	(6%)
	20-24 hrs	32	(62%)
Member Support group/charity	missing data	1	(2%)
	Yes	32	(63%)
	No	18	(35%)
Attends support groups	missing data	1	(2%)
	Yes	22	(43%)
	No	28	(55%)
Carers' physical health	Excellent	7	(14%)
	Very good	12	(24%)
	Good	15	(29%)
	Fair	17	(33%)
Religious/spirituality	missing data	4	(8%)
	Yes	27	(53%)
	No	20	(39%)
Carers' Ethnicity	English	40	(78%)
	Welsh	9	(18%)
	Other	2	(4%)
Care-recipient's age	Mean 77.05 (SD 9.0)		
Duration of difficulties	0 - 6 months	0	
	0 - 12 months	1	(2%)
	12 - 18 months	0	
	18 - 24 months	10	(20%)
	> 2 years	40	(78%)
Hours of support/week (hrs)	Range 0-58 hrs	mean 9.2	
	0 hrs	16 carers	(31%)

Table 2. Means and Standard Deviation scores for the present study and for published studies

Measures	Mean (S.D)	
	Present study	Published study
RMBPC total frequency	1.7 (0.63)	1.4 (1.3) (Teri et al., 1992)
RMBPC total reaction	2.1 (0.79)	2.0 (1.2) (Teri et al., 1992)
IQCODE	4.7 (0.4)	4.2 (0.4) (Logiudice et al., 1999)
HADS Anxiety	8.6 (4.4)	8.7 (4.0) (Proctor et al., 2002)
HADS depression	6.7 (3.8)	6.1 (3.9) (Proctor et al., 2002)
Total dementia quiz	16.6 (4.7)	14.5 (3.6) (Proctor et al., 2002)
Dementia biomedical	4.6 (1.6)	4.1 (1.5) (Proctor et al., 2002)
Dementia coping	5.7 (2.7)	5.1 (1.6) (Proctor et al., 2002)
Dementia service	6.2 (1.4)	5.3 (1.5) (Proctor et al., 2002)
Dementia biomedical	4.6 (1.6)	5.6 (1.7) (Gilleard & Groom, 1994)
Dementia coping	5.7 (2.7)	6.4 (1.1) (Gilleard & Groom, 1994)
Dementia service	6.2 (1.4)	6.5 (1.8) (Gilleard & Groom, 1994)
Total monitoring	7.1 (3.2)	10.0 (3.2) (Proctor et al., 2002)
Total blunting	2.9 (2.0)	4.9 (2.3) (Proctor et al., 2002)
Competence	3.5 (0.7)	4.4 (1.9) (Vernooy-Dassen, 1999)

Table 3. Correlational analysis of the main variables RMBPC, IQCODE, HADS, Dementia Quiz, Monitoring & Blunting Scale and Short Sense of Competence Scale.

	Total Knowledge	Biomedical	Coping	Service	RMBPC (F)	RMBPC (R)	IQCODE	Anxiety	Depression	Monitoring	Blunting	Competence
Total Knowledge												
Biomedical	.79***											
Coping	.87***	.43***										
Service	.64***	.41***	.34***									
RMBPC (F)	.06	.04	-.04									
RMBPC (R)	.14	-.10	-.11									
IQCODE	.16	-.02	.26									
Anxiety	-.07	-.33*	.16									
Depression	-.16	-.19	-.17									
Monitoring	.08	.08	.20									
Blunting	.07	.00	.25									
Competence	-.16	-.03	-.16									
				.64***	.13	.16	-.07	-.16	-.16	.09	.07	-.16
			.43***	.41***	-.10	-.02	-.33*	-.19	-.19	.08	.00	-.03
			.34***	.34*	.23	.11	.16	.16	.17	.20	.25	-.16
			.06	-.04	-.11	.26	-.19	-.12	-.12	-.01	-.10	-.05
			.06	-.04	.56***	.36**	.37**	.41***	.41***	.15	.01	-.40***
			.14	-.11		.32*	.52***	.47***	.47***	.14	-.07	-.39***
			.16	.26	.32*		.19	.25	.25	.02	-.09	-.13
			-.07	-.19	.52***	.19	.47***	.47***	.47***	.23	.05	-.45***
			-.16	-.12	.47***	.25	.23	.06	.06	.06	-.09	-.37**
			.08	-.01	.14	.02	.23	-.09	-.09	.46***	.46***	-.23
			.07	-.10	-.07	-.09	.05	-.45***	-.37**	-.23	-.23	.03
			-.16	-.05	-.39***	-.13	-.45***	-.37**	-.37**	-.23	-.23	.03

p < .05\*

p < .01\*\*

p < .00\*\*\*

Non-parametric data in bold



Table. 4 Correlation table looking at the interaction of demographic variables and outcome measures

	Total D.Q	Biomedical	Coping	Service	Anxiety	Depression	Monitoring	Blunting	Competence	IQCODE	RMBPC(F)	RMBPC(R)
Carers' gender	-.03	.02	.07	.01	.15	.01	<b>.36***</b>	.11	.00	<b>-.11</b>	.09	.18
Carers' age	<b>-.35*</b>	<b>-.33*</b>	<b>-.34*</b>	-.24	-.05	.18	.01	-.11	-.11	<b>-.05</b>	-.07	-.22
Resides with	.08	.16	.06	-.05	-.10	<b>-.39***</b>	.00	.02	-.02	.00	.03	.11
Relationship	.05	.17	-.06	.05	-.10	-.15	-.18	.00	.12	.16	.02	.02
Hours of care	.01	-.12	-.01	.14	.04	<b>.35*</b>	-.18	-.12	-.03	<b>.03</b>	-.07	-.04
Member of charities	-.00	.05	-.05	-.16	-.23	-.28	-.16	.02	.08	<b>-.23</b>	-.05	-.16
Attends support group	-.10	.01	-.18	-.15	-.30*	-.07	-.21	.09	.19	<b>-.04</b>	.08	-.13
Carers' physical health	<b>-.32*</b>	-.13	<b>-.31*</b>	<b>-.33*</b>	<b>.35*</b>	<b>.32*</b>	-.01	-.09	-.28	<b>-.02</b>	.12	.09
Religious/spirituality	.00	.05	.02	-.17	-.11	-.18	-.23	-.11	.14	<b>.13</b>	-.22	-.04
Care-recipients age	-.16	-.06	-.24	-.28	-.13	.02	-.11	.01	.06	<b>.21</b>	.16	.05
Duration of difficulties	-.21	-.24	<b>-.45***</b>	-.10	-.04	.22	-.02	.01	.18	<b>.11</b>	.01	-.02
Hours of support	-.05	-.12	-.14	.25	.05	.07	<b>.02</b>	-.16	.30	<b>.44***</b>	.16	.21

P<.05\*

P<.01\*\*

P<.00\*\*\*

Non-parametric data in bold

Table 5 (a). Independent Sample T-Tests Mean score differences according to carers' age

Variable	Younger carers	Older carers	t value	p
Biomedical knowledge	4.96 (1.57)	3.69 (1.70)	2.32*	p < .05
Anxiety	8.44 (4.42)	9.0 (4.73)	-39	p > .05
Competence	3.64	3.21	1.75	p > .05

Table 5 (b) Independent Sample T-Tests Mean scores differences according to carers' competence levels

Variable	Low competence	High competence	t value	p
Anxiety	10.42 (4.14)	7.10 (4.65)	2.32	p < .05

# **Contributions to clinical practice, theory and learning**

## **Section 4**

## Contributions to clinical practice, theory and learning

### Implications for clinical practice

#### Knowledge of dementia

The present study was unable to replicate Graham et al (1997) and Proctor et al.'s (2002) findings relating to knowledge of dementia, carers' coping style, and psychological wellbeing. However, results suggested an association between carers' anxiety levels and biomedical knowledge. Despite a fairly small sample size and some methodological difficulties relating to completion of the questionnaires, the current sample showed higher levels of dementia knowledge compared with Proctor et al's study (2002). This may be due, in part, to a high proportion of the carers (78%) having been in the caring role for over 2 years. Also 63% of carers reported to be members of charitable organisations or support groups, thus enabling carers to access information and support on a regular basis. This is in contrast to Proctor's study where the carers had received a diagnosis more recently and they were not yet linked into support or voluntary groups.

Knowledge of dementia may play a major role in enabling carers to understand more about the care recipients' journey through dementia, and may help to support carers to maintain their role as carers for longer. Knowledge of dementia may also challenge the stigma and stereotypical preconceptions associated with dementia (Mackenzie, 2006). This study acknowledges that education is an important factor in multi-component interventions for carers. However, this study also highlights that, apart from education and knowledge alone, there is a need for supporting carers with the emotional processing involved in caring for people with dementia. Indeed providing

emotional support may be equally as important as promoting knowledge and understanding in maintaining carers' psychological wellbeing, and may address a number of issues, such as loss of self identity, stigma and the emotional turmoil of being faced with a dementia diagnosis.

Nationally, charitable organisations and support groups are able to provide information and support to carers, and locally a number of support groups meet on a monthly basis. Group members collaboratively decide on the monthly agenda and establish what information would be useful to them. Informally, carers provide emotional support to each other. For some carers, a group format may not suit and their needs may need to be addressed on an individual basis. While charitable organisations appear to be well established in many areas in Wales and the UK, few or no resources are available in more rural parts of North Wales, with no support groups specifically targeting first language Welsh carers and care recipients, who may struggle to come to terms with the concept of dementia and with the stigma associated with the diagnosis. It is often the case that if non-Welsh speakers are present in a gathering, the group language becomes English. For first-language Welsh-speakers, the requirement to express emotional issues through a language that is not their mother tongue can be challenging and perhaps not inviting. This experience might not be too dissimilar to that of British South Asian Carers of people with dementia living within the UK.

### Sharing information

Although this study did not investigate how the diagnosis of dementia was shared with younger and older carers and carer recipients, the following hypothesis may need

to be considered as to why younger carers (46-66 years) in this study exhibited lower anxiety and higher competence levels.

The relationship between the knowledge and anxiety of younger carers established in the present study is indeed an interesting one, and may indicate how younger carers acquire information about dementia. In contrast to working with older carers, health professionals may adopt a different working model when supporting younger carers and care recipients through the diagnostic process; perhaps a model that is more client-led.

The manner in which a dementia diagnosis is shared with carers is crucial, and studies have highlighted the challenges that professionals face in sharing a diagnosis with (all) carers and care recipients. Carers and care recipients often face a lengthy process of dementia assessment, and often experience delays in obtaining a clear diagnosis (Luscome et al., 1998). This prolonged process of 'searching' for a diagnosis may contribute to the higher anxiety levels especially if the carer and care recipients' knowledge of dementia is low. Health professionals may struggle in sharing a diagnosis and studies show that younger carers of dementia may require a slightly different level of support from services (Loscombe et al., 1998). Health professionals may be more open and forthcoming with information about dementia when working with younger carers, perhaps assuming that a 'younger' carer will cope better with a dementia diagnosis than an 'older' carer. Whereas, in reality, carers' psychological wellbeing should be assessed and information should be shared, based on the individual needs of both carer and care recipient. Therefore, although this study showed that younger carers displayed lower levels of anxiety and higher competence

levels, it is important not to assume that younger and older carers differ in the way they may respond to information about dementia.

The fact that younger carers in the present study showed higher knowledge of dementia, might be related to their perception of a dementia syndrome as less stigmatising compared to older carers. This may result in younger carers openly seeking out more information and sharing information about dementia with others. Due to modern technology, an abundance of information about the aetiology of dementia may be easily accessed via the Internet, and this method of obtaining information may be more accessible to younger carers compared with older carers. Hence, carers' anxiety levels may decrease when information about dementia can be accessed at the pace required by the carers and this may result in an increase in competence levels. It is also important that the perception of dementia, in all carers and care recipients, be explored during the diagnostic process.

### Implications of measures

The measures used in this study gave an insight as to the knowledge base and psychological wellbeing of carers of people with dementia currently living in the community, and therefore provided information as to which areas services may need to target their interventions. Carers' knowledge of dementia was higher than in previous studies (Graham et al., 1997, Proctor et al., 2002) and this may be due to a shift in services over the past decade and changes in the way carers are supported. High media coverage over recent years may also increase carers' motivation to join charitable organisations such as the Alzheimer's Society and higher knowledge of dementia has also been associated with more help-seeking behaviour (Werner, 2003).

Mean anxiety scores of this sample were reported to be within the mild to moderate range, with depression scores slightly lower. However, anxiety, depression and competence were associated with care recipients' behaviour difficulties, suggesting that services may need to target interventions aimed specifically at supporting carers in managing the behavioural aspects associated with dementia care. This is important, as behavioural difficulties, such as incontinence, are often cited by carers as primary reasons for seeking residential care for the care recipient.

The Short Sense of Competence questionnaire was used to assess carers' perceived competence levels and appears to be an excellent tool to use when looking at providing intervention. Health professionals can target interventions based on how the carers have completed this simple measure. This scale is separated into three domains looking at: satisfaction with the person who has dementia, the carers' satisfaction with own performance as a caregiver, and the consequences of caring on the carer's own personal life. Therefore, focus can be placed on a specific domain that requires attention.

### Implications for future research and theory development

#### Knowledge of dementia

A limitation of the present study is that it included measures which had not been completed appropriately. The Dementia Quiz (Gilleard & Groom; 1994) was chosen as it includes an assessment of knowledge of three separate domains of dementia, and has a multiple-choice format, requiring the carer to choose just one statement out of five choices; it had also been used in Proctor et al's (2002) study. A number of carers



chose more than one statement for each statement, indicating that they had, possibly, misunderstood the instructions on how to complete this measure. Alternatively, there may be more than one 'correct answer', especially in relation to the (Dementia Quiz) coping subscale. A number of carers had written down a couple of other suggestions that might be useful in their own personal circumstances. This highlights the individual differences between care recipients' presentations and the individual differences in how carers manage difficult situations. This also supports the notion that psychological interventions should be tailored to meet the individual carer and care recipient (Brodaty et al., 2003).

In terms of modifying or designing new measures to look at dementia knowledge, measures should be broad, in terms of being appropriate for carers from different cultures and background. Quality of knowledge and perceptions of dementia should be regularly updated and be reflected in the scoring of the scale; this could then be used to tailor interventions for carers and care recipients.

### Sharing information

Further research is needed to explore the relationship between sharing information about dementia and psychopathology. Qualitative studies are often useful in exploring the perception of dementia and in establishing effective ways of sharing information that is culturally appropriate, less intrusive and more client-centred compared with completing packs of diverse questionnaires. Qualitative research, using focus groups, can be used to establish carers' perception of dementia within diverse groups of people, such as individuals from minority groups, such as South Asian carers, or groups of young (or older) carers. This method of data collection can provide a rich

source of data information that can in turn influence quantitative research and interventions.

Further research is needed to establish appropriate ways of sharing information with carers, and services may need to be creative in the way that they deliver these services. For example, accessing services through the use of Information Technology might be useful and convenient for some carers, where they might be able to contact specific health professionals via email. This may be a cost effective way of accessing help and support, provided it is managed appropriately. For example, the carer has contact with their individual health professional on a regular basis and the health professional has a good understanding of the care recipient's needs and the difficulties that they are experiencing. This may also be appropriate for individuals from minority backgrounds, who fear the stigma associated with dementia, and are cautious about openly seeking help from services. A similar pilot study was reported in Norway looking at older adults who cared for a spouse. Although the study was unable to conclude that carers' stress or mental health problems were reduced, participants had valued support from other carers (Torp et al., 2008). This method of accessing support would enable carers to contact relevant health professionals quickly, without the additional stress of possibly having to organise alternative care for the care recipient, or be seen in public places, using services associated with dementia, or stigmatised services, such as psychiatry.

The current models used to share information about dementia may need to be modified and possibly modernised. Services need to establish further evidence-based

interventions that are both client-centred and provide a creative approach to supporting carers.

### Implications of measures

A common theme that ran through this project was the difficulty sustained by participants in completing the measures. The seven measures included in the pack were very diverse, in terms of the information they provided the author, and the format of each measure.

The Monitoring & Blunting Coping Scale (Miller, 1987) required carers to select as many of the statements that applied to them for each of the four scenarios presented. Some carers ticked just one choice on each item and this may have been because carers felt that just one of the statements reflected their coping style, or they may have misunderstood the instructions. The Monitoring & Blunting Coping Scale (Miller, 2004) is an unusual scale in terms of the four scenarios that it presents, and may not have been suitable for the present sample. For example, the second and fourth scenarios related to being held hostage by a group of armed terrorists and being in an aeroplane, which loses control. In addition, the third scenario relates to being in employment, and, as a large proportion of the participants in the present study may be either approaching, or have reached, retirement, perhaps this scenario may not have been ideal for the current sample.

The Revised Memory and Behavior Problem Checklist (Teri et al., 1992) RMBPC has been used extensively in many studies. However, it proved challenging for some carers to complete and resulted in some missing data. For the purpose of this study,

the total RMBPC subscale scores were analysed, and although it would have been interesting to establish which subscale (memory, depression, disruption) correlated with carers' morbidity, this was not the specific purpose of this research project and was outside the remit of this study. Totalling up the frequency and reaction scores proved difficult, partly due to the challenges of missing data, and it was therefore decided that the two subscales would be totalled manually.

Future research with this client group may need to be structured quite differently; for example, method of recruitment, completion of questionnaires and choice of questionnaires would need to be researched carefully. A pilot study would highlight any potential difficulties similar to those experienced in the present study, and therefore would be a crucial first step in any future research projects.

This study highlights the importance of working closely with carers of people with dementia, and is very relevant regarding the clinical implications of supporting carers before and after diagnosis. The replication of these findings might lead to a review in our understanding of how information and knowledge aids (or hinders) carers, and which routes to pursue in terms of interventions, for example, reminiscence groups, emotion based and practical interventions.

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## **Section 5**

**Word count**

## **Word Count**

**Overall abstract 236**

**Reflections 1,485**

**Review abstract 162**

**Review paper 4,696**

**References 1,369**

**Empirical abstract 276**

**Empirical paper 4,703**

**References 976**

**Extended discussion 2,370**

**References 293**

**Tables 732**

**Total word count 19, 408 (including P.I.S, C.F & Ethics)**

**Appendix word count 5,110**