

**Manuscript Title:****Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence****Authors:**

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## **Abstract**

**Background:** Despite a growing elderly South Asian (SA) population, little is known about the experience of diagnosis and care for those living with dementia. There have been a number of individual qualitative studies exploring the experiences of SA people living with dementia and their carers across different contexts. There has also been a growing interest in synthesizing qualitative research to systematically integrate qualitative evidence from multiple studies to tell us more about a topic at a more abstract level than single studies alone. The aim of this qualitative synthesis was to clearly identify the gaps in the literature and produce new insights regarding the knowledge and understanding of the attitudes, perceptions, and beliefs of the SA community about dementia.

**Methods:** Following a systematic search of the literature, included qualitative studies were assessed by two independent reviewers for methodological quality. Data were extracted and pooled using the Joanna Briggs Institute (JBI) Qualitative Assessment and Review Instrument (QARI). Findings were synthesized using the JBI approach to qualitative synthesis by meta-aggregation.

**Results:** Seventeen papers were critically appraised, with 13 meeting the inclusion criteria. Participants were mostly of SAs of Indian background; followed by Pakistani with a few Sri Lankans. Missing SA countries from the current evidence base included those from Bangladesh, Bhutan, Maldives, and Nepal. Three meta-synthesis themes emerged from the analysis: (1) a poor awareness and understanding of dementia, (2) the experience of caregiving, and (3) the attitudes toward dementia care provision.

**Conclusions:** A consistent message from this qualitative synthesis was the limited knowledge and understanding of dementia among the SAs. While symptoms of dementia such as 'memory loss' were believed to be a part of a normal ageing process, some SA carers viewed dementia as demons or God's punishments. Most studies reported that many SAs were explicit in associating stigmas with dementia.

## **Keywords**

Dementia, ageing, family carer, ethnicity, South Asia, meta-aggregation, qualitative synthesis

## **Introduction**

There are an estimated 36 million people worldwide living with dementia, and this number is expected to increase to 66 million in 2030, rising by 71% to 115 million in 2050 (Prince, Bryce, & Ferri, 2011). The number of people with dementia in the UK is estimated to be 821,884 representing 1.3% of the population (Luengo-Fernandez, Leal, & Gary, 2010) with about 670,000 family and friends acting as primary carers (Lakey, Chandaria, Quince, Kane, & Saunders, 2012). Dementia is not a disease in itself, but a collection of symptoms that exist when brain cells die and stop working properly (Alzheimer's Research UK, 2013). Dementia is a syndrome where a group of symptoms gradually get worse over time with age. The symptoms are likely to include memory loss, confusion, inappropriate behaviour, getting lost, problems with communication or difficulties with finding the right words, faulty reasoning, sleep disturbance, hallucination, fainting, and agitation. However, the symptoms of dementia increase over time and everyone may experience the changes at different stages. There are many types of dementia, but Alzheimer's disease is the most common. Other types of dementia include vascular dementia which is the second most common cause of dementia that occurs after a series of strokes, dementia with Lewy bodies, and frontotemporal dementia. There is a lot of research about potential treatments for dementia. However, to date there is no cure but there are drugs available that can help with dementia's symptoms. Moreover, dementia can be debilitating with mild to moderate behavioural symptoms not only for the person living with dementia, but also for family members (Wang, 2012).

## **Dementia in South Asians**

Despite increasing numbers, there is little research on dementia in South Asian groups, whether looking into their country of settlement or their country of origin. There are no exact figures regarding the prevalence of dementia in Black and Asian Minority Ethnic (BAME) groups in the UK. The estimates range from under 20,000 in 2011 to 25,000 in 2013 (APPG, 2013) of people from BAME groups with dementia. However, this figure is predicted to grow to 160,000 by 2051 (Khan, 2015; Truswell, 2014). It is also acknowledged that any figure is likely to be a considerable under-representation as dementia has been characterized as a 'hidden problem' for South Asian people (Brownlie, 1991; Wilkinson, 2002). The South Asian people with dementia is a considerably marginalized group who remains excluded from literature commenting on service use or on the experience of living with dementia. However, the number of South Asian people with dementia will rise significantly, because age is the most significant known risk factor for dementia and the large number of South Asian migrants who came to the UK between 1950 and 1970 for work are now ageing.

Estimates on how many live with dementia vary and are likely to be unreliable as the high incidence of diabetes, smoking, heart disease, and stroke in these communities impact on prevalence. A recent study from *Lancet Neurology* revealed that seven potentially variable dementia risk factors such as: diabetes, mid-life hypertension, mid-life obesity, smoking, depression, low educational attainment, and physical inactivity (Barnes & Yaffe, 2011). More evidence suggests that people with diabetes have an increased risk of developing dementia in later life (Bruce, Harrington, Davis, & Davis, 2001; Peila, Rodriguez, & Launer, 2002; Stewart & Liolitsa, 1999a). These principal risks factors (4 out of 7) such as diabetes, smoking, depression, and low education attainment have been identified as important associations of developing dementia, which are disturbingly common in BAME communities. Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common among people of African and African-Caribbean origin (Diabetes UK, 2012). Moreover, doctor-diagnosed diabetes is almost four times as prevalent in Bangladeshi men, and almost three times as prevalent in Pakistani and Indian men compared with men in the general population (Health and Social Care Information Centre, 2006). Among women, diabetes is more than five times as likely among Pakistani women, at least three times as likely in Bangladeshi women. In addition, according to the Health Survey for England 2004, also South Asian origin children were more than 13 times more likely to have Type 2 diabetes than white children. Nonetheless, Pakistanis and Bangladeshis have the highest rates of self-reported smoking, whereas Bangladeshis have the highest rate of chewing tobacco compare to the national average and other ethnicities. Despite the high prevalence of diabetes and smoking rates among South Asian older population in the UK which may cause cognitive deterioration, the role of diabetes mellitus (DM) and smoking as risk factors for cognitive decline in later life has received little epidemiological attention in the UK (Stewart & Liolitsa, 1999b). Therefore, it is suggested that the above estimated number of people with dementia does not accurately represent the South Asian and other BAME communities.

There is little information on dementia research in the UK specifically looking at BAME groups. However, what research has been carried out to date has been predominately in the USA. Thorough search of the literature has revealed that few previous primary studies have been conducted and majority of these are US based studies mainly focused on African American, Hispanic, Black Caregivers, Chinese, Chinese Americans, Koreans, Korean Americans, Latinos, Whites and European Union carers of people with dementia (Botsford, Clarke, & Gibb, 2011; Connell & Gibson, 1997; Connell, Janevic, & Gallant, 2001; Daker-White, Beattie, Gilliard, & Means, 2002; Milne & Chryssanthopoulou, 2005; Mukadam, Cooper, & Livingston, 2011; Regan, Bhattacharyya, Kevern, & Rana, 2012). One systematic review comprising a mixture of both qualitative and quantitative international literature looked at dementia from the

patients perspectives was conducted by de Boer et al. (2007) in Netherlands, which, although fifty international studies met inclusion criteria, yet none of these represented the South Asian patients' perspectives.

In the light of all of this, in the UK and elsewhere, there has been little quantitative research done on the prevalence of dementia in South Asian ethnic minority communities. First, a prevalence study conducted among ethnic elders of South Asian origin in the inner city of Liverpool of UK and used the Hindi translation of the community version of the Geriatric Mental State schedule (GMS-A) diagnostic tool to identify a diagnosis of dementia (Bhatnagar & Frank, 1997). Their study suggested that vascular dementia is much more common among South Asian people than dementia of the Alzheimer type. A decade later, another quantitative study conducted among the Indian population in Manchester, UK focussed on the knowledge about some basic aspects of dementia such as prevalence, risk factors and symptomatology (Purandare, Luthra, Swarbrick, & Burns, 2007). This study found that Indian people as South Asians have poor knowledge about dementia. In addition, another quantitative study also conducted in Leicester, UK among the Indian Gujrati population (Shah, Lindsay, & Jagger, 1998) and a few more quantitative studies conducted in India (Pinto & Seethalakshmi, 2006; Shaji, Promodu, Abraham, Roy, & Verghese, 1996) have concentrated on survey methods as well as depended on local modified versions of Mini Mental State Examination (MMSE) method for diagnosis of dementia. A few studies have been conducted that deliver some understandings into migration and its following experiences for BAME communities (Ballard, 1999; Bhachu, 1985; Garbin, 2005). However, little attention has been paid to the minority ethnic migrants' experiences of dementia in their country of origin. Therefore, conducting a qualitative synthesis among South Asian carers' and their relatives with dementia's experiences not only makes this study unique, but also allows the researchers to summarize and compare the evidence between their country of origin and their country of settlement.

## **Objectives**

The objective of this review was to appraise and synthesise the best available qualitative evidence to provide a better understanding of the experiences of South Asian people with dementia and their family carers.

## **Methods**

A qualitative synthesis of primary studies was conducted using a meta-aggregation method guided by the JBI approach. The meta-aggregation method of qualitative synthesis is one of the first to provide a robust framework for qualitative synthesis designed to model Cochrane's

process for systematic reviews whilst being sensitive to the nature of qualitative research and its traditions (Pearson, 2004). The JBI approach comprises a number of set stages: a comprehensive search of the literature, a critical appraisal of potential studies using a suitable criteria-selection tool, synthesis of the findings from the included studies (meta-aggregation), and finally, creating a “line of argument” output that can serve as a basis for evidence-based practice. The meta-aggregation procedure involves the following three steps (Figure 1).

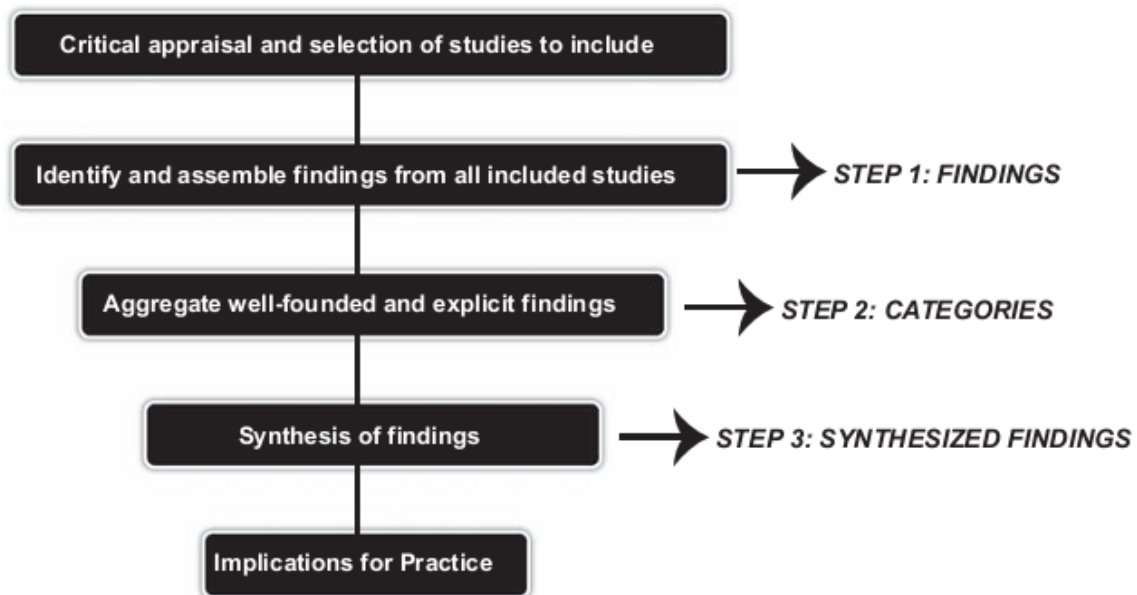


Figure 1 - Steps in meta-aggregation

Source: Pearson, Robertson-Malt, & Rittenmeyer, 2011

### Search strategy

The considered qualitative interpretive studies drawing on the experiences of South Asian people with dementia included, but were not limited to, methodological approaches such as phenomenology, grounded theory, ethnography, action research, and feminist research. The search strategy aimed to find both published and unpublished studies. The three-step search strategy depicted above was adopted. An initial limited search of MEDLINE and CINAHL was undertaken, which included searching for words contained in the title and abstract, as well as for the index terms used to describe the article. A second search using all identified keywords (Table 1) and index terms across all relevant databases was then undertaken, covering the period between 1970 and 2014, such as the Web of Science, MEDLINE (Web of Knowledge),

CINAHL, E-Journals, SocINDEX, eBook Collection, PsycINFO, MEDLINE (ProQuest), British Library EThos, JSTOR, Social Care Online, and Science Direct. Auto alerts were set up on key databases so that the reviewer could learn about new relevant material as it became available. An additional search was also carried out via relevant websites and gateways (e.g., Age UK, Alzheimer Europe, Alzheimer Scotland, Alzheimer's Research UK, Alzheimer's Society, Alzheimer's Association, Alzheimer's Disease International, British Medical Association, Dementia Friends, MIND, Rethink Mental Illness, and Time to Change). Thirdly, a search of the reference lists of all identified reports was also carried out to incorporate additional studies. The search was not limited to nationality or language, as the search strategy aimed to find international qualitative studies written in English and in other languages. Non-English studies would be subsequently translated into full-text articles, if it was possible to do so using translation tools, such as Google Translate. If translation was not possible, the primary authors were contacted to provide additional details about their study. If the author could not be reached, and if the document could not be translated, the article was subsequently excluded from the study. In addition, grey literature was sought, and a hand search of relevant journals was also conducted. Attempts were made to contact the authors, experts, and groups that might have access to relevant data (both published and unpublished). Some, however, did not respond to these emails.

### **The initial search terms included**

#### **Keywords:**

The initial search was not limited by the methodology to assure the maximum article retrieval from the databases. The keywords were organised into six groups, as follows (Table 1):

**Table 1- Keywords used in the search**

<b>Keyword groups</b>	<b>Keywords/terms</b>
Keyword group 1: Phenomenon of interest	Attitudes, barriers, experience*, impacts, issues, opportunit*, understanding
Keyword group 2: Dementia	Alzheimer’s disease, creutzfeldt-jakob disease, delirium, dementia, dementia diagnos*, dementia with lewy bodies, early onset dementia, fronto-temporal dementia, cognitive impairment, huntington’s disease, korsakoff’s syndrome, memory loss, parkinson’s disease, vascular dementia
Keyword group 3: Older people	Age*, elder* geriatric, later life, older adults, patients, pensioners, seniors
Keyword group 4: Carers in context	Care*, carer, community care, family members, formal care, informal care, primary care, service, spouse, support,
Keyword group 5: South Asians	Asian, Bangladesh*, Bhutan, black and minority ethnic groups, bme, ethnic*, immigrants, India*, Maldives, migrants, Nepal*, Pakistan*, south Asia, Sri Lanka
Keyword group 6: Qualitative approaches	Action research, conversational analysis, descriptive qualitative research study, discourse analysis, ethnograph*, exploratory stud*, focus groups, grounded theory, interview*, narrative* observational method*, participant observation, phenomenology*, qualitative, qualitative research method, qualitative study, qualitative synthesis, thematic analysis

**Inclusion criteria**

The PICO mnemonic was used to construct clear and meaningful questions for this systematic review protocol of qualitative evidence (Booth, 2004).

Population: (1) South Asian people with a diagnosis of any type of dementia; and (2) family carers.

Phenomenon of interest: the range of knowledge, views about dementia, perceptions, beliefs, and experiences of older people from the South Asian communities living with dementia, as well as their family carers.

Context: communities and primary care settings, both in South Asians’ country of origin and the country of settlement.

Outcome: it was hoped that the outcomes of this synthesis would help to identify the various themes embedded in the qualitative studies that fully describe the primary outcomes of South Asian people with dementia and their family carers in their countries of settlement and in their countries of origin. Secondary outcomes for family carers would be included as carers’ burden, dementia-associated stress as well their health experiences and quality of life.



## **Data screening**

Following the search, 2,515 papers were identified. After removing the duplicates, 1,267 papers were entered into the EPPI-Reviewer database. The screening process was conducted in three stages, as studies were included or excluded based on the following: (1) the titles alone, (2) the abstracts, and (3) reading of the full texts. The reasons for each article's inclusion or exclusion were documented to include descriptive and evaluative codes, descriptions of each included study, and the data used and produced during synthesis (Rees, Oliver, Woodman, & Thomas, 2011). Each stage was independently assessed by two reviewers. Where an agreement could not be reached, a third reviewer was involved.

## **Data extraction**

### **Study details**

A total of 187 papers were examined in depth. Seventeen studies were selected for retrieval for this review. Four of these studies were then excluded based on the assessment of their methodological quality, which meant that thirteen studies met the inclusion criteria (Figure 2). All included studies were published between 2001 and 2013, and all were scientific research papers apart from one (Jutlla, 2011), which was a PhD thesis. The analytical methods of all thirteen studies that were finally included in this analysis were described as grounded theory (n=4), thematic analysis (n=4), content analysis (n=2), and ethnographic analysis (n=2); one study's adopted methodology was generic qualitative or unclear (n=1). Most studies (n=10) used interviews as the primary method of data collection, while two studies combined both interviews and non-participant observation methods, and one study combined both interviews and focus group discussions. The qualitative papers selected for retrieval were assessed by two independent reviewers for methodological validity.

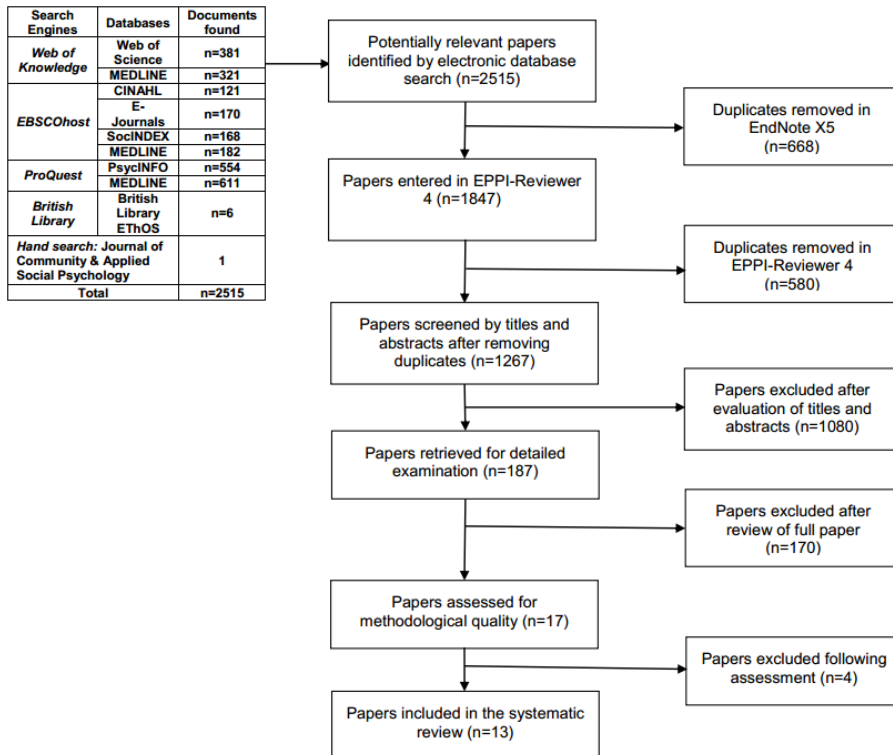


Figure 2 - A flowchart of search results

### Assessment of methodological quality

An assessment of the methodological quality of each paper was performed prior to inclusion in the qualitative synthesis; the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI QARI), a standardised critical appraisal instrument tool was used to achieve this aim (JBI, 2011), as shown in Table 2 below. Data were then extracted from the included studies using the standardised data extraction tool, JBI QARI.

**Table 2 - JBI QARI Critical Appraisal Checklist for Interpretive and Critical Research**

Reviewer \_\_\_\_\_ Date \_\_\_\_\_  
 Author \_\_\_\_\_ Year \_\_\_\_\_ Record number \_\_\_\_\_

	Criteria	Yes	No	Unclear
1	There is congruity between the stated philosophical perspective and the research methodology.			
2	There is congruity between the research methodology and the research question or objectives.			
3	There is congruity between the research methodology and the methods used to collect data.			
4	There is congruity between the research methodology and the representation and analysis of data.			
5	There is congruity between the research methodology and the interpretation of results.			
6	There is a statement locating the researcher culturally or theoretically.			
7	The influence of the researcher on the research, and vice-versa, is addressed.			
8	Participants and their voices are adequately represented.			
9	The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval an appropriate body.			
10	Conclusions drawn in the research report appear to flow from the analysis or interpretation of the			
	Total			

Overall appraisal:                      Include:                      Exclude:                      Seek further info.

Comments (Reasons for inclusion or exclusion)

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Source: JBI, 2011

### **Study setting and participants**

The included studies were conducted in a variety of countries: the UK (n=9); India (n=2); Canada (n=1); and Pakistan (n=1). Most studies (n=8) were part of a broader BAME investigation and included African-Caribbean, Irish, Eastern European, and White British populations. The South Asian studies relied on fairly small sample sizes, but they reported that most of their participants were from the general region of 'South Asia'. Across the thirteen studies included in the analysis, there were 214 participants, most of which were family carers (n=145, in 12 studies). Importantly, no formal carers were identified in those included studies, although the perspectives of service providers (n=53) were assessed in three studies, and three studies examined the experiences of people with dementia (n=16). Those studies that examined one's perspectives between his or her country of origin or his or her country of settlement concentrated on two countries (India and Pakistan). The majority of participants

across the thirteen studies were of Indian background, followed by those of Pakistani background, while very few were Sri Lankans. Missing were the perspectives of those from Bangladesh, Bhutan, the Maldives, and Nepal. A small number of studies (n=2) referred to specific religious groups, such as Sikhs, or to people from particular geographical areas, such as the Punjab. Moreover, nine UK studies included participants from India and Pakistan; there was also one Canadian study that included participants from India and Sri Lanka alone. As part of the large BAME groups, two UK studies also included participants (n=5) from Bangladeshi communities (1 participant and 4 participants, respectively). However, Bangladeshi participants and their voices were not adequately represented in those two studies. Further details are provided in Table 3 below. Furthermore, despite their inclusion, the voices of the people with dementia were also not satisfactorily characterised in either of the two reviewed articles. Nevertheless, it seemed due to the complexity in measuring the immigrant generations and ethnic attrition, information about generation status was not formally documented. Perhaps the authors of those included studies tried to encourage a maximum participation and convince confidentiality, hence, identifying generation possibly confirmed through early discussion at the interviews rather than details being formally recorded. As a result, three UK studies disclosed participants' generation status, such as only four carers were British born.

**Table 3- Summary of reviewed articles**

**Studies conducted in South Asians' countries of settlement**

References	Methods	Phenomenon of Interest (Purpose)	Setting (Country)	Cultural	Participants
Adamson, J. 2001	Exploratory; in-depth, semi-structured interviews; thematic analysis and coding	Awareness, recognition and understanding of dementia	Primary care based settings, informants' homes (England)	SA and African/Caribbean heritage in the UK	N=30 carers of a person with dementia, 18 African/Caribbean and 12 SA (Pakistan, India and East Africa)
Adamson, J and Donovan, J. 2004	Exploratory; in-depth, semi-structured interviews; constant comparison methods, analytical headings and topic guides coding	Experience of African/Caribbean and SA carers caring for older family members with dementia	Primary care based setting; research participants' own homes (England)	African/Caribbean and SA heritage in the UK	N=36 carers; 21 African/Caribbean and 15 SAs/ older family members
Bowes, A. Wilkinson, H. 2003	Exploratory; semi-structured interviews, case studies; thematic analysis	Understanding the dementia experiences	Primary and community based (Scotland)	SA	15; 11 service providers and 4 case studies with people with dementia and their families
Godfrey, M & Townsend, J. 2001	Exploratory; In-depth interviews, individual and focus group interviews; nothing mentioned about the data analysis	Understanding of the barriers to respite care services experienced by SA families caring for a relative with dementia	Local offices and day centres; home-based respite services (England)	SA, East African Asian	N=12 carers; Pakistani 7, Indian 3, Bangladeshi 1 & East-African Asian 1
Jutla. K. 2011	Constructed grounded theory; in-depth narrative interviews; conceptual framework analysis	This study highlights the importance of the migration experiences and personal histories of carers, and the extent to which those experiences influence the perceptions and experiences of formal and informal care services amongst Sikh carers in Wolverhampton, particularly among those caring for an older person with dementia	Primary care settings at carers' homes (England)	Sikhs, Indian	N=12 Sikh carers
Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., Murray, J. 2010	Grounded theory; in-depth individual interviews; thematic analysis	Individual experience or subjective reality of living with dementia	Primary care based settings, such as participants' homes or community based settings e.g. at day centres (England)	Three of the largest ethnic groups; Black Caribbean, South Asian and White British	N=30 people with dementia; 11 Black Caribbean (3 male and 8 female), 9 SA (5 male and 4 female), and 10 White British (5 male and 5 female)
Lawrence, V., Murray, J., Samsi, K., Banerjee, S. 2008	Grounded theory; in-depth individual interviews; thematic analysis	Attitudes, experiences, and needs of family carers of people with dementia	Primary care based settings as participants' homes (England)	Three of the largest ethnic groups; Black Caribbean, South Asian and White British	N=32 carers of people with dementia (10 Black Caribbean, 10 SA, 12 White British)
Mackenzie, J. 2006	Phenomenology; semi-structured interviews; thematic content analysis	Stigma and care giving experiences of dementia among carers	Primary and community care-based settings (England)	East European and SA	N=21 carers; Pakistani carers 11, Indian carers 5, Polish carers 4 and Ukrainian carer 1
McCleary et al. 2012	Descriptive research methodology; in-depth, semi-structured, and face-to-face to interviews; qualitative content analysis	Experiences of a diagnosis of dementia	Primary and community care-based settings (Canada)	SA; Indian and Sri Lankan	N=14; 6 people with dementia (3 Indian and 3 Sri Lankan) and 8 carers
Mukadam, N., Cooper, C., Basit, B., Livingston, G. 2011	Demographic study; semi-structured interviews; thematic analysis	Attitudes towards dementia diagnosis pathways	Home and healthcare settings (England)	White, SA and Black Caribbean cultures	N=18 carers; 4 White UK carers, 5 SA, 5 Black African/Caribbean, 1 White Irish, 1 White other, 1 Asian other, and 1 Chinese
<b>Studies conducted in South Asians' countries of origin</b>					
References	Methods	Phenomenon of Interest (Purpose)	Setting (Country)	Cultural	Participants
Brijnath, B. 2011	Ethnography; semi-structured interviews, observation; field notes, deductive and inductive coding, thematic coding, NVivo 9	Examine how care is understood cross-culturally by providing different types of food and how food can maintain positive relationships	Home and institutional settings (India)	Indian/ SA	N=20 carers 9; 3 men and 17 women; 21 key service providers
Brijnath, B & Manderson, L. 2011	Ethnography; in-depth, semi-structured interviews, observation; data were transcribed and coded thematically, inductive and deductive, NVivo	Biomedical technologies, MRI scans for dementia diagnosis	Home, hospital, and community (India)	Indian, SA	N=20 carers; spouses n=10, daughters n=6, daughters-in-law n=4. And 21 Key Service Providers
Qadir, Gulzar, Haqqani, & Khalid. 2013	Exploratory; in-depth, semi-structured interviews; thematic analysis	This study explores awareness among carers, their attitudes toward family members suffering from dementia, and their experience of burden	Hospital settings (Pakistan)	Pakistani	N=12 Carers

### **Quality of included studies**

The methodological quality of the included studies was assessed by two reviewers using the assessment tool from the JBI, known as QARI (Table 2). The quality scores for the included studies were calculated by weighing the studies according to the QARI assessment tool's 'yes', 'no', or 'unclear' values. The studies were appraised according to each QARI question and they were given a score of 1 for one satisfactory 'yes' answer, and a score of 0 was given for a 'no' or an 'unclear' answer. The final score was obtained after adding the values assigned to each question. A cut-off points of answering 'yes' to six out of the 10 questions was agreed upon and implemented by all reviewers. Only one study had a maximum score of 10, while four studies failed to make the cut-off point of six 'yes' responses; these four studies were then excluded from the synthesis. The qualitative studies that scored lower than six points typically did not provide enough information on QARI questions 6, 7, 8, and 9. For example, some of these studies lacked clarity regarding the researchers' values, beliefs, and their potential influence on the research. In addition, an absence of participant validation of the research findings (by providing verbatim quotations of participants' voices, for instance) was apparent in the study. Therefore, the reviewer searched for and included participants' direct quotations from the studies. This was a significant step when assessing the study quality during data extraction, as it helped the reviewer to establish the degree to which the findings were genuinely characteristic of the data (Pearson, Robertson-Malt, & Rittenmeyer, 2011). Also, studies from South Asians' countries of settlement suffered from an unclear sampling strategy and difficulties with recruitment; hence, these works failed to represent the individual target South Asian populations.

### **Synthesis of findings**

The meta-synthesis of studies included in the review generated three meta-synthesized findings; furthermore, this synthesis was derived from 186 study findings that were subsequently aggregated into seven categories, as shown in Figure 3 below.

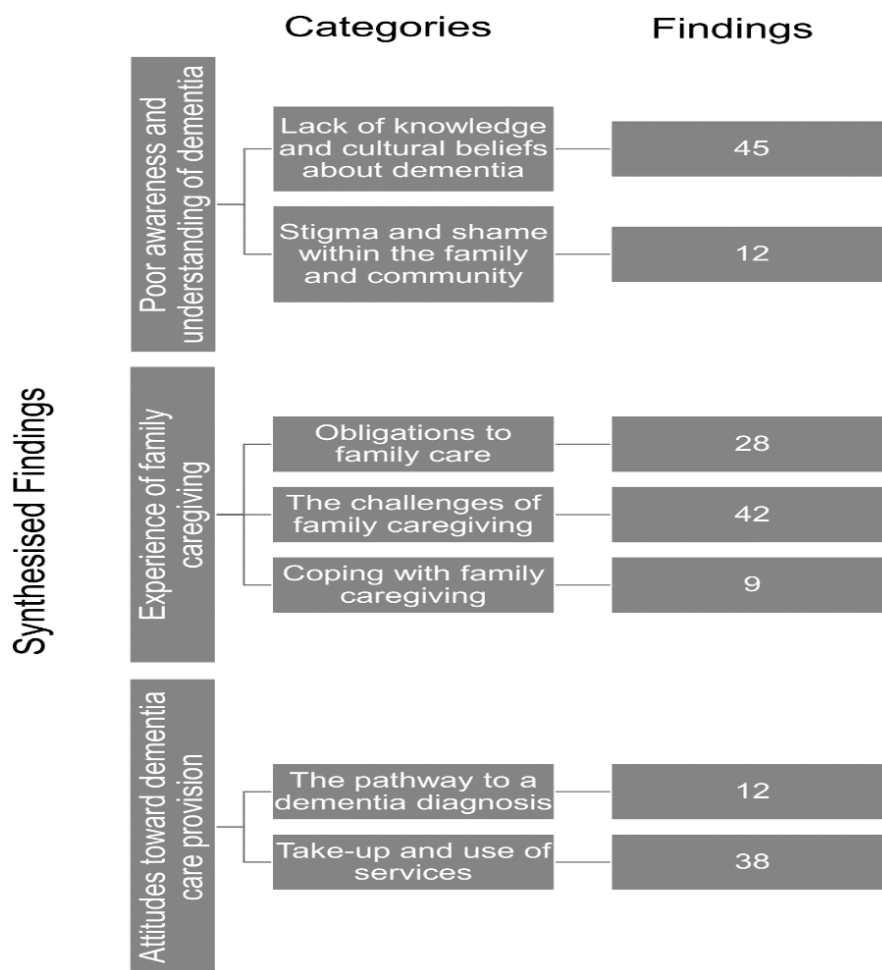


Figure 3 - Relations of synthesis topics, categories, and findings

### Meta-synthesis 1. Poor awareness and understanding of dementia

One of the most significant synthesis findings of this review was the lack of knowledge and understanding of dementia among South Asian family carers who were taking care of their relatives with dementia. Eleven of the 13 included studies highlighted this issue. Within this first meta-synthesis theme, two categories emerged: lack of knowledge and cultural beliefs about dementia, and stigma and shame within the family and community.

#### Category 1.1. Lack of knowledge and cultural beliefs about dementia

Across the groups, most people with dementia and their family carers consistently acknowledged their lack of knowledge about dementia. Moreover, various studies assessing the differences between South Asians in their countries of origin or countries of settlement

generally revealed that family carers had difficulty recognizing dementia symptoms. Even when the symptoms of dementia were detected, they were not seen as problematic; rather, they were regarded as consistent with the normal ageing process. The studies conducted about South Asian people with dementia in England and Canada demonstrated that memory loss and dementia were seen as part of the normal ageing process rather than symptoms of a degenerative disease of the brain that becomes worse over time (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2010; McCleary et al., 2012). In particular, those people with dementia in the UK and Canada were unaware about their earlier cognitive changes, and those fluctuations did not warrant alarm until a family member drew attention to them.

Adamson (2001) interviewed 12 South Asian family carers of relatives with dementia in the UK. She found that most of the family carers lacked knowledge about the signs and symptoms of dementia before their relative was diagnosed. Family carers linked dementia to a wide range of psychosocial, physical, and mental problems including diabetes, excessive tension or depression, sadness, anxiety, fear, social withdrawal, isolation, and loneliness (Brijnath & Manderson, 2011; Jutlla, 2011; McCleary et al., 2012; Mukadam, Cooper, Basit, & Livingston, 2011). Family carers' religious beliefs also informed their understandings, and some believed that dementia was a punishment resulting from something the individual had done wrong (Adamson, 2001; McCleary et al., 2012).

*Rather, he referred to his mother as 'mad' and said his mother was paying for something bad she had done earlier in her life. Nasreen explained that the lack of understanding about dementia results in family members bringing their own beliefs, for example, on religion, into their explanation for the symptoms. In this case her father felt, from his interpretation of the Koran, God was making his mother pay for punishing his sister for running away from an abusive marriage his mother had encouraged. (Case study 2: p. 394 in Adamson, 2001)*

However, family carers in Pakistan described that dementia was a medium through which one's relationship with God deepened, and not a punishment from God (Qadir, Gulzar, Haqqani, & Khalid, 2013). Most studies conducted in the South Asians' settlement countries reported that dementia was regarded as 'madness', and that understanding of this disease was not just an individual issue, but it was also important within families and the wider community (Adamson, 2001; Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Godfrey & Townsend, 2001; Lawrence et al., 2010; Mackenzie, 2006). In India, Brijnath and Manderson (2011) found that the symptoms of dementia were seen as part of the normal ageing process rather than mental illness, until the people with dementia suffered from incontinence and also developed paranoia and delusions, and showed violent behaviours. Moreover, given that



service providers often use jargon, and since there are no meaningful words for dementia in their own languages, family carers sometimes confused their understanding of dementia with other diseases, such as cancer, acquired immunodeficiency syndrome (AIDS), depression, or schizophrenia.

Most importantly, research conducted in Scotland and Canada reported that a visit to a general practitioner (GP) or any trauma-related hospital admission or any other acute medical problem for people with dementia were regarded as the first tangible signs of a dementia diagnosis among South Asian family carers (Bowes & Wilkinson, 2003; McCleary et al., 2012). Family carers did not recognise the symptoms of dementia prior to the traumatic events, as the presence of these symptoms only became clear when doctors referred people with dementia for cognitive testing. Before these traumatic events and early dementia symptoms, the family carers attributed any physical or psychosocial problems to the normal ageing process; these were not considered serious by them.

In addition, a study conducted in India by Brijnath and Manderson (2011) showed that family carers had a little knowledge about the support and treatment available for people with dementia, which was not confined to members of the public. Of the eleven key service providers (GP, community psychiatric nurses, and consultants) in Scotland who participated in the research, three participants believed that there was no treatment available for people with dementia (Bowes & Wilkinson, 2003). Although family carers thought memory problems and dementia were a normal part of ageing, they felt that dementia-associated problems could be prevented by changing the lifestyles of the people with dementia (Brijnath & Manderson, 2011). There is a belief that the people with dementia may be deliberately difficult, rather than acknowledging that their memory problems might be caused by a disease process.

### **Category 1.2. Stigma and shame within the family and community**

Seven studies reported that various cultural and religious factors influenced the level of stigma associated with dementia among the South Asian communities. Mackenzie (2006) explored the causes of stigma among family carers of Indian and Pakistani origin living in England. The study discovered how the different perspectives of the stigma associated with dementia were rooted in both religious and supernatural explanations among Pakistani Muslim families. Family carers and their relatives with dementia were stigmatised through being perceived by the wider Muslim community members as being cursed or possessed by evil spirits. Perhaps they had not been strongly faithful Muslims, or they did not pray enough to keep the dementia away. Thus, dementia was regarded as a punishment from God that ultimately brought shame upon the entire family. Another study found that people with dementia felt stigmatised about

their deteriorating cognitive state (memory loss, speech impairment) and their declining ability to participate in activities with their families or in the broader community; they thus withdrew, which in turn affected their lives and led to a loss of self-esteem and loneliness (Lawrence et al., 2010).

*I can't talk well, I can't figure out the sums you see, taking 8 from 12 is difficult for me, changing, getting the change if I go to the shops, I don't go now. So it has affected my life very badly. I avoid going to people, especially former friends, unless I go to places where everyone has Alzheimer's. (p. 8)*

However, three UK studies demonstrated that the stigma about dementia in the South Asian community interferes with the willingness or ability of people with dementia and their family members to participate in the community (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutla, 2011). Two UK studies found that South Asian families felt socially excluded by having a relative with dementia, and they tried to hide the person from visitors (Adamson & Donovan, 2005; Mackenzie, 2006).

*Before we used to invite people for dinner and I had to do a lot of cooking. We were going to other people's houses for parties and dinner before. But now we have to stop that and I can't go in the evening because I can't leave my husband home and I can't take him – nobody invites us anymore. Two years back, some people were inviting us even still but now everybody has stopped inviting us because he can't... So they don't invite us anymore. (p. 44 in Adamson & Donovan, 2005)*

Brijnath and Manderson's (2011) study conducted in India produced results contrary to those reported by the above studies (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutla, 2011), as family carers were more likely to report stigma associated with managing incontinence among people with dementia, rather than experiencing stigma with any of the other symptoms. The tendency to associate the symptoms of dementia with mental illness was also considered as a barrier to arranged marriages within some South Asian communities, as reported in one study (Bowes & Wilkinson, 2003). Specifically, if there was dementia in the family, it was kept secret for fear that a marriage would not take place if this information was disclosed. Thus, notions of stigma permeate cultural and religious perceptions of dementia in South Asian populations at every stage of this disease, starting from the initial recognition of memory problems and extending to an official diagnosis and beyond.

On the other hand, not being able to care for a person with dementia within the family was another potential source of stigma in the South Asian communities. Regardless of any physical or mental illnesses, caring for an ageing parent at home, rather than putting them in a care home, is traditionally considered a strong cultural and religious duty (Adamson & Donovan,

2005; Godfrey & Townsend, 2001; Juttla, 2011). The moral obligation to care for an ageing or disabled elder is strictly and solemnly observed by the wider South Asian community. Some UK studies reported that family carers felt they were under pressure from various community members to look after the people with dementia within the family because of the stigma associated with not meeting family obligations to provide care (Juttla, 2011; Adamson & Donovan, 2005; Godfrey & Townsend, 2001). Seeking external help or sending the people with dementia to a day centre or care home was reported as bringing shame upon the family.

The South Asian groups varied in their understanding and experiences of the social stigma related to dementia. However, social stigma was also associated with contemptuous attitudes and misconceptions among service providers. Bowes & Wilkinson (2003) found that service providers made generalisations about the stigma faced by the South Asian communities, believing that families did not want to disclose dementia problems outside the family. However, case study findings revealed that family carers actually wanted to receive help from service providers in order to cope with their loved one's dementia, but they rarely asked for this assistance (Bowes & Wilkinson, 2003). Participants felt that none of the existing services were responsive enough to people's needs and that the needs of South Asian people were particularly neglected.

## **Meta-synthesis 2. Experience of family caregiving**

This theme refers to the family carers' experiences of caring for their relatives with dementia. Eight of the 13 studies included herein reported the obligation to provide care, the practical and emotional challenges of family caregiving, and how these carers managed their situations.

### **Category 2.1. Obligations to family care**

This category explored the key factors that were associated with the constructs of one's obligation to provide care for a person with dementia. Family carers described a mix of filial and moral obligation, as well as reciprocal love and respect toward their older parents. Some expressed a belief that if adult children cared for their elderly parents, then one day, their children would also look after them when they were old (Godfrey & Townsend, 2001). While there was a tendency to focus on the problems associated with family care, the analysis showed that caring for an elder with dementia was often seen in a positive light. In India, Brijnath & Manderson (2011) found that once a relative received a diagnosis of dementia, it served as an opportunity for family carers to prepare themselves for care rather than to seek treatment. Conversely, in England, Godfrey and Townsend (2001) reported that grandchildren caring for a grandmother with dementia described reciprocity, love, respect, and duty as the

main reasons for providing care. Furthermore, a wife believed that caring for her husband with dementia made her a good wife, and she was thus happy to undertake this role (Godfrey & Townsend, 2001). Likewise, daughters' or sons' attitudes toward caregiving were reciprocal, as they stated they were giving back to their older parents who gave them life and provided care when they were younger; now it was the children's time to provide care for their parents (Lawrence, Murray, Samsi, & Banerjee, 2008).

*You know as Indians, we always look after our parents. Yes, I am the sole carer, I have no brothers and I just... my father he looked after me when I was young and he has done lots and lots of things for me so it's my turn to look after him. (p. 241)*

In the studies, all family carers living in the UK did not seem to perceive caring for one's parents or grandparents as a pleasant task, but rather as a religious duty or cultural obligation (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011; Lawrence et al., 2008; Mackenzie, 2006). Religious and cultural obligations to provide care are highly influential among the South Asian communities. Religious beliefs offer family carers a sense of internal personal support and peace of mind throughout the difficult journey of caring for their loved ones with dementia (Adamson & Donovan, 2005; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Lawrence et al., 2008; Lawrence et al., 2010; Mackenzie, 2006; Qadir et al., 2013). One study showed that living with and caring for ill husbands constituted one of the core teachings of, and an established practice in Hinduism. A South Asian Hindu wife in England, who was the family carer of her husband with dementia, stressed her religious duty to provide care for her husband (Adamson & Donovan, 2005). Similar research was conducted in both the South Asians' country of origin and in their country of settlement in Pakistan and England, respectively (Adamson & Donovan, 2005; Qadir et al., 2013). These studies revealed that while Pakistani Muslim family carers feared retribution from Allah for not providing care, they regarded providing care for their parents with dementia as virtuous deeds and as a blessing to be rewarded in the afterlife. Family carers believed that by providing care, they were fulfilling their religious duties toward their elderly relatives, as well as toward God, which was expected from a truly religious person. Where there were strong religious and cultural pressures to care for people with dementia, there was a persistent faith in God that supported families when caring became difficult. Thus, there was an expectation that adult children would provide care for the people with dementia. However, parents sometimes felt that the care they received from their children was less than their contribution to their children (Lawrence et al., 2010). If they received good care, it was seen as the children paying them back.

## **Category 2.2. The challenges of family caregiving**

Although the previous category highlighted the cultural, religious, and filial obligations to provide care, ten out thirteen studies in this category reported that the caregiving situation created greater challenges for the family carers. Most studies stated that caring for people with dementia was mostly a family-based task, and that the majority of the family carers were daughters-in-law or unmarried daughters, who engaged in intense hard work on a daily basis (Adamson & Donovan, 2005; Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001; Lawrence et al., 2008; Mukadam et al., 2011). The reviewed studies described how the symptoms of dementia affected people with dementia, and how this severely impacted the family carers' psychological and physical health, as well as their finances, employment, and practical daily living.

The lack of knowledge about how a person may change as a direct result of dementia impacted every family member, including children. Family carers were worried about their children, as they did not understand the features of dementia and found it hard to accept the fact that the person with dementia was exhibiting unusual behaviour (Godfrey & Townsend, 2001). Another study found that living with a person with dementia also had a negative effect on one son's mental health, as he was simultaneously coping with frustration and anger (Adamson & Donovan, 2005). A lack of knowledge about the symptoms of dementia made children perceive that the people with dementia were responsible for their illness. In addition, the stress of family care had a negative impact on family relationships, especially on marital satisfaction, as couples were often unable to spend time together (Godfrey & Townsend, 2001; Lawrence et al., 2008; Qadir et al., 2013). Several studies further found that husbands were complaining that their wives – who were acting as family carers for their parents – did not spend intimate time with them, as the wives were rather busy with their caregiving duties (Godfrey & Townsend, 2001; Qadir et al., 2013). Thus, in addition to the physical pressures of meeting the needs of a person with dementia, there were also psychological and emotional factors and consequences.

Godfrey & Townsend (2001) found that South Asian family carers commonly had to deal with the people with dementia's behavioural difficulties, sleep disturbances, as well as night-time waking. Some family carers were subjected to abusive or threatening behaviours by their relatives with dementia, including wives who described how on several occasions, their spouses (with dementia) became aggressive. Moreover, in Pakistan, Qadir et al., (2013) found that those family carers who were under intense emotional and physical pressure wanted to escape, and some even prayed for the person's death. Half of the male family carers reported that the caregiving burden triggered anger, resentment, and guilt as, on several occasions, they had used physical force on their relatives with dementia.

Behaviours such as sleeplessness, agitation, and incontinence caused severe disruptions to family life which, as shown in an Indian study, indicated that family carers' experience of depression and anxiety was strikingly evident when the people with dementia stopped eating (Brijnath, 2011). Particular difficulties that family carers faced included the struggle to manage the people with dementia's personal hygiene, which was very difficult and embarrassing for the family members to accomplish. Only a few studies discussed how carers dealt with the unpleasant and difficult experience of handling the issues associated with urinary or faecal incontinence. In fact, a few studies have reported that family carers' need to deal with the people with dementia's incontinence was the most upsetting and humiliating act for the people with dementia, and it was also stressful for the carers themselves (Bowes & Wilkinson, 2003; Brijnath, 2011; Godfrey & Townsend, 2001). In devout Muslim households, faecal incontinence meant that the people with dementia and the carers could not pray in the house, nor could they go to mosque (Bowes & Wilkinson, 2003). The whole house had to be washed for purity before praying. One family had to move to a bigger house so that the people with dementia could have a separate flat for this very reason.

Although family carers were the around-the-clock care providers for the people with dementia, they received little attention or support directed toward the needs associated with their vital role. The current review found that when family members had recognised the symptoms of dementia, and it was followed by an official diagnosis, the interests of the people with dementia came before those of the carers. For instance, in Godfrey & Townsend's (2001) study, a daughter-in-law described how it was her duty to look after her mother-in-law, as she did not have any other choice. The current review also revealed that the daughters-in-law in South Asian households played three different challenging caregiving roles, which placed heavy demands on them. They were expected to care for their husbands, their young children and, additionally, their parents-in-law (Godfrey & Townsend, 2001; Jutilla, 2011; Lawrence et al., 2008; Qadir et al., 2013).

*You don't put yourself first. In fact, sometimes you don't even put the children first. Looking after the children is done around that of caring for elderly parents. We have put our careers on hold to look after them. It is stressful. There is a stress on relationships. Like we can't go out like a normal couple when we want to. (p. 37 in Godfrey & Townsend, 2001)*

However, family carers described how their hard work was unnoticed and unappreciated, and they felt neglected despite their very hard work. The nature of the caregiving role changed due to the increasing demands within the family environment, and the family carers reported feeling 'invisible' in the family. As a result, those family carers caring for a person with dementia

neglected their own health and wellbeing (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011). Nonetheless, despite these findings, family carers also mentioned that they found it hard to express the details of their caregiving burden to health professionals and others in the community (Bowes & Wilkinson, 2003; Godfrey & Townsend, 2001).

### **Category 2.3. Coping with family caregiving**

Although most of the research reviewed in this report has focused on the knowledge of dementia and the burdens of being a family carer, only a few studies have focused on which coping strategies were used by family carers. To minimise the level of disruption to their own lives, family carers in India coped by consulting Ayurvedic, allopathic, and homeopathic doctors, as well as traditional practitioners and transcendental healers when seeking assistance for their relatives with dementia; family carers often received suggestions about different foods and lay remedies to use (Brijnath, 2011). On the other hand, regardless of their religious identities, the majority of family carers used prayers and continuous faith in God as religious coping mechanisms (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Mackenzie, 2006; Qadir et al., 2013). This was also the case for Pakistani family carers in their home country (Qadir et al., 2013).

*I satisfy myself by assuring time and again that troubles are from Allah (God) and he does not burden one more than his capacity. I cannot think of any other way out but to offer namaz (prayer) regularly. (p 236)*

Family carers generally believed that dementia was God given, and that He did not trouble anyone beyond their abilities. Despite the burdens and strains of caring, many family carers described the positive aspects of being a carer, such as the blessings that were bestowed upon them, which would provide them with earthly and heavenly feelings of satisfaction (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Mackenzie, 2006; Qadir et al., 2013). The participants explained that although caring was a stressful and burdensome role, they believed that it would bring rewards from God one day. Many also relied on their extended family to help with various activities, such as housework and emotional support, which helped relieve the family carers' stress (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Qadir et al., 2013).

### **Meta-synthesis 3. Attitudes toward dementia care provision**

This theme examined family carers' knowledge and attitude toward the current and future provision of dementia healthcare services. Despite limited evidence, the current review explored various cultural and religious issues that affected the accessibility of dementia care

services both in carers' country of origin and country of settlement. This theme included the two following categories:

### **Category 3.1. The pathway to a dementia diagnosis**

Overall, six studies reported on the process of achieving a dementia diagnosis (Bowes & Wilkinson, 2003; Brijnath & Manderson, 2011; Lawrence et al., 2010; Mackenzie, 2006; Mukadam et al., 2011) among the South Asian communities. Almost all carers recognised delays associated with seeking their relative's dementia diagnosis. Unlike White and Black African Caribbean groups, the main causes of delay among the South Asians included a lack of knowledge, confusion about the early signs, fear, and stigma. The numerous barriers to a prompt or accurate diagnosis of dementia prevented family carers and people with dementia from getting the best possible treatment; this influenced their attitudes toward seeking help from service providers.

*He is 75 years old, he has a few memory problems. It isn't anything that serious. So he goes out and forgets a bit, even I do. (p. 5 in Lawrence et al., 2010)*

Bowes and Wilkinson's (2003) study discussed that South Asian people with dementia were not getting a dementia diagnosis, due to such factors as poor medical communication or language issues. Moreover, a lack of dementia awareness was found among three out of eleven professionals. That study also reported that overall professionals' specific knowledge about dementia in the South Asian communities was essential to improving services. Similarly, family carers blamed the hospital staff for providing a delayed diagnosis of dementia (Mukadam et al., 2011). Family carers expressed several concerns, as hospital staff members appeared to be disorientated and failed to differentiate their older relative's significant physical health problems from the potential signs and symptoms of dementia. Another key issue that emerged from the study conducted by Mackenzie (2006) was that there was an overwhelming sense of fear and embarrassment among family carers and family members in the South Asian community. Family members were fearful of the stigma associated with being diagnosed with dementia, as a diagnosis of dementia could result in condemnation of the family.

In India, Brijnath & Manderson's (2011) study explained that poverty, structural weaknesses, and a lack of mental health professionals were the main reasons underlying the barriers faced when obtaining a dementia diagnosis. Other studies reported that a dementia diagnosis was often incidental, as it came about when visiting doctors for other physical problems (Bowes & Wilkinson, 2003; McCleary et al., 2012). McCleary et al. (2012) found that South Asian Canadians initially normalised the symptoms of dementia, attributing them to other causes and echoing the findings of Mukadam et al., (2011). The average length of time between



recognizing the early symptoms of dementia and finally seeking professional help was four years (Mukadam et al., 2011; McCleary et al., 2012). However, if families did recognise the symptoms of dementia, they often delayed seeking help for an official dementia diagnosis, which was another major problem. Cultural beliefs and expectations act as barriers to seeking and accepting help. The family carers initially sought help from friends and families instead of obtaining help from social services.

Finally, once the person was diagnosed with dementia, the family carers regretted blaming the person for his or her behaviours and symptoms, which would not have occurred if the diagnosis had been made earlier (Godfrey & Townsend, 2001). Moreover, an earlier diagnosis would have helped family carers to better prepare for and handle the situation. One of the most difficult and distressing challenges that family carers faced was to make decisions related to the dementia for their relatives with dementia. However, family carers were not always able to make these decisions for the people with dementia. A diagnosis of dementia meant that the people with dementia would rely on the individual or individuals who had decision-making power within the family unit. The family hierarchy clearly played a vital role, where male members had the authority over decision-making processes, including those related to healthcare (Godfrey & Townsend, 2001). As the head of the family, a son or husband plays a dominant role in healthcare decision-making. Godfrey & Townsend (2001) found that whilst the daughter-in-law primarily provided everyday caregiving for the people with dementia, it was the son who was the decision maker for the people with dementia's care, while ensuring the well-being of his ageing parents, whether with respect to dementia or any other sickness. Any requests for help to care for the people with dementia would need to be approved by the family carer's husband or father-in-law.

### **Category 3.2. Take-up and use of services**

Current review findings previously showed that female family members, such as daughters-in-law, provided most of the care in the South Asian communities. Several studies also revealed that South Asian women's significant caregiving obligations are well rooted in the traditional beliefs and practices in South Asian culture. Since the majority of family carers perceived potential dementia symptoms as part of the normal ageing process, carers continued their care duties as an extension of their current caregiving obligations for their relatives with dementia (Adamson & Donovan, 2005; Lawrence et al., 2008). Thus, following a diagnosis of dementia, family carers accepted their new roles and showed fewer expectations related to seeking and using external help.

*The eldest son is [responsible] and their daughter-in-law. It comes down to the daughter-in-law, not to the oldest son, it's very rare [that] you see an oldest son doing it, it's always his partner who takes over the role... it's the wife that does it. (p. 40 in Adamson & Donovan, 2005)*

Notwithstanding this, family carers were also unhappy with the services on offer, and access to services was particularly difficult, as there was a lack of information about these services provided in the family carers' respective languages. Furthermore, family carers were profoundly frustrated by the complicated and untrustworthy GP services, and they also reported that hospitals did not have enough facilities to provide the appropriate services for their relatives with dementia (Mukadam et al., 2011). Several family carers further expressed deep resentment, as they had experienced discrimination from the rigid service providers and blamed the government for ignoring the needs of South Asian groups in the UK (Jutlla, 2011).

Perhaps not surprisingly, almost all family carers in this review mentioned that their relatives with dementia preferred to remain at home. Due to the excessive caring responsibilities and the lack of support being provided by the extended family network in some cases, a few family carers wanted respite care at home. However, respite services were not fully understood by these family carers, and they were reluctant to receive care in their homes due to shame and privacy concerns. In addition, they did not wish to welcome strangers into their homes, and they were equally concerned about confidentiality even if the care workers were from the family carers' own communities (Jutlla, 2011; Godfrey & Townsend, 2001). Moreover, when help with personal care was needed, there were concerns about support being provided by younger people, particularly those of the opposite sex (Godfrey & Townsend, 2001).

*It is when Mum comes in and does the home care role. She bathes her and clears her room. Things like that I can't do for her in the Sikh culture, I cannot bathe her. (p. 41)*

The reviewed evidence concerning family carers' attitudes with respect to turning toward care home services for people with dementia were limited and conflicting. The South Asian communities appeared to be greatly concerned about the cultural appropriateness of care homes. They had concerns about language issues, the availability of South Asian care staff, access to South Asian food, and the level of respect for cultural and religious beliefs. However, many participants did not actively look for culturally appropriate services because they felt ashamed of doing so, or they feared that others in the community would think that the family members of people with dementia were unable to care for them (Adamson & Donovan, 2005; Godfrey & Townsend, 2001; Jutlla, 2011). Similar to what was noted for home respite services, another barrier to seeking out residential care was the issue of intimate care being undertaken by young health workers, particularly those of the opposite sex (Godfrey & Townsend, 2001).

To date, however, only Godfrey & Townsend's (2001) study has specifically investigated issues related to personal care being provided by opposite-sex health workers. Many major factors also compounded the reluctance of South Asian older people with dementia to seek care from their children at home, as well as to seek admission to mainstream care homes. Even though care is typically offered by the people with dementia's children, in Godfrey & Townsend's (2001) study, it appeared that some older people with dementia did not want any support from their children whatsoever. Older people realised that providing care is a very difficult undertaking; hence, they did not want to be a burden on their children, and they thus preferred to go to a care home. It is apparent that there is a need for more culturally appropriate healthcare services. Moreover, since few professionals are working with South Asian people with dementia and their family carers, it is important to incorporate various culturally-appropriate services within the currently available healthcare system (Bowes and Wilkinson, 2003).

## **Discussion**

This synthesis of the findings of the included studies that explored the experiences of South Asian people with dementia and their family carers revealed three meta-synthesis themes. First, the theme of "poor awareness and understanding of dementia" appeared to be central to the experiences of South Asian people with dementia and their family carers. The evidence reviewed in this synthesis showed that one's knowledge of dementia is of great importance; in fact, possessing knowledge about dementia ultimately shaped the quality of the course of care, and also affected the support provided to people with dementia and their carers across the journey of care. Since the participants' experiences of dementia and the caregiving journey were viewed through the lens of the South Asians' lack of knowledge about dementia and their cultural beliefs related the condition, the subsequent themes that emerged from these primary themes were thus interrelated. Obviously, knowledge is powerful because it controlled the South Asian settlers' or homeland family carers' intentions to seek and access help and support from care facilities.

Consistent with the findings of a previous review that focused on Black African, African Caribbean, Chinese, and South Asian populations (Milne & Chryssanthopoulou, 2005), the current synthesis also revealed that the majority of family carers regarded the early symptoms of dementia as part of the normal ageing process. The findings from the current synthesis were also in line with those of a previous study by Botsford, Clarke, and Gibb (2012), which found that potential early symptoms of dementia, such as memory impairment, were viewed as part of the normal ageing process, which subsequently affected help-seeking behaviours

among family carers. Their study only highlighted two ethnic minority communities in London: the Greek Cypriot and the African Caribbean. However, current study findings differed from most of the White populations who believe that dementia is caused by a physical, organic disease, yet signalling a much clearer understanding about dementia than the South Asian communities (Turner et al., 2005).

When examining the results of this synthesis in greater detail, similar themes emerged in a recent review that was conducted to examine the role of religion, spirituality, and culture in the understanding of dementia among the South Asian communities in the UK (Uppal & Bonas, 2014). However, in that review, some limitations were noted, including the fact that only five studies were included. Two of those five studies (Fontaine, Ahuja, Bradbury, Phillips, & Oyeboode, 2007; Turner et al., 2005) did not recruit any participants from either the people with dementia or family carer groups; hence, the findings of that review may be constrained by their limited sampling strategy. Moreover, that particular review combined both qualitative and quantitative studies, where the latter were not wholly capable of examining the complex nature of ethnicity and dementia issues (Botsford et al., 2011; Curry, Nembhard, & Bradley, 2009). Conversely, the current review adopted a purely qualitative method in an attempt to clarify the deeper meanings and understandings of dementia among South Asian people with dementia and their family carers. Perhaps qualitative methods have a greater capacity to elucidate the complex aspects of healthcare and ethnicity, to uncover participants' knowledge and beliefs about dementia, and to capture essential aspects of dementia caregiving from the perspective of South Asian communities (Berkwits & Inui, 1998; Malterud, 2001; Milne & Chryssanthopoulou, 2005).

The authors of the papers reviewed here have drawn the tentative conclusion that dementia awareness should be increased among South Asian communities in the UK and elsewhere. Without exception, all of the authors of the included studies acknowledge that dementia was under researched among South Asian communities (Milne & Chryssanthopoulou, 2005; Botsford et al., 2011). Knowledge and understanding of the various symptoms, causes, and treatments of dementia are more limited among the South Asian communities than they are among White British communities in the UK (Turner et al., 2005). South Asians' understanding, and knowledge of dementia is limited by the lack of an equivalent term for 'dementia' in their native languages. Knowledge and understanding of dementia, of course, is not constrained by language among the White British. Secondly, cultural norms, values and religious beliefs shape the meaning of dementia as well as influence the caregiving responsibilities among South Asian communities (Seabrooke & Milne, 2004). The White British population is more influenced by Western philosophical thoughts, where understanding of dementia is mostly dominated by biomedical models that consider dementia a pathological entity affected by

neuronal and neurotransmitter failure (Turner et al., 2005). It was clear from this synthesis that the experiences, diagnostics, treatment, and care management of dementia varied across the ageing South Asian populations due to physiological, psychosocial, religious, and culturally sensitive factors. There was a lack of understanding and a failure of the individuals or family members to seek a diagnosis, usually by failing to recognise or ignoring the symptoms of dementia (which were considered to be a part of the normal ageing process). This resulted in family members expressing their anger and frustration, and ultimately blaming the people with dementia for both the causes of dementia and for any related inappropriate behaviour.

Most of the studies focusing on South Asians found that many individuals have negative attitudes toward dementia, and that there is also a high degree of stigma associated with it. However, dementia-related stigma exists in all other communities as well (APPG, 2013), although South Asians' cultural and religious diversity means that this stigma manifests itself differently. For example, Mukadam et al. (2011) found lower levels of stigma among whites and South Asian in England, where McCleary et al. (2012) did not find any stigma at all associated with dementia among Indians and Sri Lankans in Canada. Unlike other studies, South Asian family carers in both McCleary et al.'s (2011) and Mukadam et al.'s (2011) studies did not conceal their relatives' symptoms of dementia from outsiders, and they enthusiastically shared their experiences with the researchers; however, in the latter study, the stigma associated with dementia and the negative experiences related to the available health services were only mentioned by Black and African family carers. Thus, notions of stigma permeate cultural and religious perceptions of dementia in South Asian populations at every stage, from the initial recognition of memory problems, to diagnosis and beyond.

Although levels of stigma were hard to gauge from the included studies, it could be argued that the stigma associated with dementia may not necessarily constitute stigma about the disease itself. It is possible that the stigma is rooted in prejudices involving migration, education, ageing, ethnicity, poverty, illnesses, gender, and language barriers (Fisher & Ragsdale, 2006). In fact, stigma may not solely be associated with dementia; South Asians may think that there is a stigma associated with being old in Britain, or that there is a stigma pertaining to their ethnic identities (Derose, Escarce, & Lurie, 2007). In addition, if dementia was to be understood as 'cognitive impairments' or 'a disease of the brain' rather than 'madness' or the 'effect of bad spirits', any of the associated stigmas would be reduced (Innes, 2002). The use of appropriate language can combat the misunderstandings and resultant stigmas associated with dementia. Stigma will probably persist among the South Asian and other BAME communities until proper education has been provided and an understanding of dementia has established (WHO, 2001). Therefore, family and community members need to be made aware of the various related consequences that stigma can have on the quality of

care that people with dementia and their family carers receive. Families, communities, and healthcare settings need to work together to tackle stigma by raising awareness about dementia. In order to raise this awareness to reduce stigma while maintaining successful communication between South Asian service users and service providers, emphasis should be placed on recruiting more culturally and linguistically trained staff or staff members from South Asian ethnic backgrounds. Furthermore, service providers should also work with South Asian religious leaders (e.g., imams from the mosques, Hindu temples, and Gurdwaras) in order to challenge this stigma and to maintain a better understanding and acceptance of the available services.

Existing research about the burden of caregiving comes from White and Afro-Caribbean backgrounds in the USA (Daker-White et al., 2002; Milne & Chryssanthopoulou, 2005; Botsford et al., 2011), but the caregiving experience in South Asian communities differs from this in many ways. The primary reasons for these huge differences in dementia caregiving experiences between White, Black, and South Asian backgrounds are socio-economic, cultural, and religious issues, which remain understudied. Despite the importance of caregiving roles in the South Asian communities and the scarcity of current knowledge about dementia, research has thus far provided little evidence to illuminate how caring for persons with dementia relates to burdens or blessings that underlie the obligation to care. Most studies to date have shown how families are the source of caregiving in the South Asian communities. Perhaps not surprisingly, one prominent theme that emerged from the reviewed studies was how the expectations of dementia care provision among the South Asian community mainly fell upon the daughters-in-law. These findings were also in line with those of previous reviews, which discovered that BAME carers were culturally obliged to provide care for the people with dementia in the family (Milne & Chryssanthopoulou, 2005; Botsford et al., 2011).

To date, most research on filial responsibility has specifically looked at Chinese communities (Chiu & Yu, 2001; Milne & Chryssanthopoulou, 2005). Not much research has discussed the filial obligation to care for elderly parents in the South Asian community. Further research is needed to examine various sensitive issues that remain unexplored, such as how there are many problems concerning the South Asian community that are not talked about, including the idea that older people believe that their families do not care, or that they are being treated harshly by their children. Evidence shows that numerous traditions, such as the strong sense of extended family, living with and looking after the elderly, and being cared for by relatives, are breaking down in South Asian communities because of numerous socio-economic and demographic changes (Evandrou, 2000). For example, the role of South Asian women in the family is changing as more women are participating in the labour market than ever before (Wilson, 2006). However, the realities faced by South Asian families include the fact that adult

children want to look after their older parents, but they have other priorities (Hossain, 2012) such as, balancing work and family commitments. Therefore, the older people's expectations and understandings are changing day by day as well. The adverse mental health impacts of poverty and poor housing, a lack of education, unemployment, and low income are not unusual problems. These are some of the issues that have not yet been addressed by research teams, and our understanding of these factors will benefit from an exploration of these issues.

Although daughters-in-law perform most of the caring duties in the family, today, few empirical data are available on how the carer's role is perceived, and on the relationship between daughters-in-law and mothers-in-law in South Asian communities. The relationship between a daughter-in-law and her mother-in-law in South Asian communities is not always perceived as a positive and pleasant one to discuss. A daughter-in-law is always regarded as one of the weakest members of the family, although she gains some empowerment when her children grow up. It is very important for South Asian families to make sure that the daughters-in-law serve their parents-in-law, irrespective of whether or not they have dementia (Godfrey & Townsend, 2001; Gupta & Pillai, 2002). When considering the status of women in the household, the distribution of power amongst them is very complex. A few studies have been conducted around how family carers are being motivated or forced to provide care for their parents-in-law (Dasgupta & Rudra, 2011; Godfrey & Townsend, 2001; Jutlla, 2011). There may be many reasons underlying this caregiving role within extended families, including moral, cultural, religious, or family pressures, especially pressure from the carer's husband or mother-in-law. However, their White counterparts may not experience such stressful caregiving roles (Dykstra et al., 2006). White groups may not be obliged to provide care to the same extent as is commonly associated with the South Asian community's expectations, and neither do they have to live in overcrowded, poorly maintained houses with their extended families as many South Asians do.

A dementia diagnosis is, of course, a paramount issue among all South Asian communities, which is why clear research on the barriers to a dementia diagnosis among the South Asian population is needed. Until there is a much better understanding of the obstacles to a dementia diagnosis among South Asian communities, it would be tough to understand South Asian individuals' experiences of dementia. Previous evidence has found that South Asian family carers tend to access various healthcare services, or they seek help in response to a major illness or, in some cases, to deal with other symptoms, such as those associated with stroke, diabetes, and heart disease. A dementia diagnosis is significantly uncommon not only among the South Asian communities in the UK, but also among the entire UK population, regardless of ethnicity. More than 800,000 people with dementia are currently living in the UK; however, it has been estimated that only 48% of those individuals ever receive a dementia diagnosis

(Alzheimer's Society, 2014). The financial cost of a timely diagnosis of dementia may be a significant barrier for those in developing countries like India, Pakistan, Sri Lanka, and other South Asian countries (Brijnath & Manderson, 2011; Patel, Joshi, Suthar, & Desai, 2014). However, why do South Asian older people remain under diagnosed when they live in England or Canada, and why are they instead labelled as a hidden population (Brownlie, 1991; Wilkinson, 2002)? In the UK and Canada, the available health services are adequately capable of diagnosing dementia. However, South Asian older people are frequently not diagnosed with dementia. None of the studies available thus far has addressed these issues. Inadequate English proficiency may render South Asian older people a hidden population, as majority of older people cannot communicate and express their problems in English. Language barriers and a low level of education can thus prevent South Asian individuals from seeking help for a dementia diagnosis (Alagiakrishnan, 2008; Schmand, Lindeboom, Hooijer, & Jonker, 1995; Schmand et al., 1997). Importantly, none of the published research has highlighted this issue as a barrier specific to South Asian communities. Moreover, researchers specifically identified that among this population, help-seeking behaviour is limited to friends and families. Again, Brijnath & Manderson (2011) found that when dementia-related healthcare problems arose, family members spoke to various doctors in India. This may be one of the reasons why this population did not experience any language or cultural barriers in India when seeking help. However, in the UK, language and cultural barriers are definitely present when South Asian people ask for help. Perhaps this is why they are more comfortable discussing their health problems with their families and friends, as there are no cultural or linguistic differences within these groups. The lack of appropriate cultural and linguistic support is a pertinent issue for South Asians in the UK, as this not only presents difficulties for South Asians when they seek help, but it is also very challenging for the GP and clinicians (Fazil, Bywaters, Ali, Wallace, & Singh, 2002). However, to date, no research data are available related to self-reported memory problems or changes prior to the dementia diagnosis.

Healthcare decision-making power is significantly important in South Asian families. However, only one study thus far has specifically focused on this issue in the UK; it shows that due to a lack of knowledge about dementia and its diagnosis, decision makers in South Asian families are typically unable to make any decisions on where to seek help (Godfrey & Townsend, 2001). Despite this, they put more pressure on family carers to look after the elderly. Further research that focuses on how personal caregiving provided by the opposite sex is a barrier to receiving institutional care will also be beneficial. Subsequent research initiatives need to focus on alternative solutions to help those in South Asian communities when seeking a diagnosis of dementia, as well as when receiving healthcare services. The South Asian communities sometimes obediently comply with the instructions given to them by their doctors



or mosques' imams. Therefore, perhaps the decision makers could be found from outside the family among experienced professionals, like GP, psychiatrists, mosques' imams, or other religious leaders.

## **Limitations**

There are some limitations of this systematic review. First, meta-aggregation is a new approach that has received little attention worldwide when compared with other systematic review methodologies. Despite using broad terms in the search strategy, it might be possible that the systematic searches still missed some sources due to methodological quality. For example, if there were no direct quotations from the participants, those studies were excluded from this synthesis. Secondly, the scope of this synthesis was limited in terms of its ability to compare South Asians' experiences of dementia in their countries of origin and in their countries of settlement, especially since the majority of studies included in this synthesis were conducted in the participants' countries of settlement. The current understanding of dementia within the South Asian countries of origin is, therefore, a relatively neglected area that remains to be explored.

## **Conclusion**

The findings of this synthesis highlighted the various characteristics associated with the understanding and experiences of South Asian people with dementia and their family carers. A consistent message that emerged from this qualitative synthesis was that there was a limited knowledge and understanding of dementia among the South Asian population. The themes mostly represented the family carers' experiences of caring for the people with dementia from the perspectives of the burdens or blessings of family caring, the family carers' coping mechanisms, and the family carers' attitudes to the current and future provision of dementia care services. These findings also illustrated the various causes and principles used by these family carers to cope with their stressful situations while they provided care to their loved ones. However, the South Asian culture and its associated religions are complex and unique in many ways, particularly as there are many sub-cultures within the South Asian population. These individuals have many different forms and levels of expression. Therefore, it would be a grave mistake to make any broad generalisations or assumptions about the South Asian communities and their culture. For example, the numerous and varied foods, religions, languages, educational systems, employment situations, gender rights, castes, and social statuses distinguish each South Asian community from the others, which poses a significant

challenge for any researchers or policymakers who wish to explore these issues in greater detail.

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