

# What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings

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What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings.

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## **Abstract**

This paper reviews recent literature on the experiences, attitudes and needs of caring for someone with dementia in Black and minority ethnic communities in the United Kingdom. Eight articles, which investigated carer experiences from Black and minority ethnic communities when caring for someone with dementia, were critically appraised. All eight studies used a qualitative methodology. The review identified several themes and issues across the qualitative studies. These included memory loss being viewed as a normal process of ageing, care being perceived as an extension of an existing responsibility, a poor understanding of what support services provide, the influence of migration, the impact of stigma, and increased female responsibility. Methodological limitations of the research literature studies are also highlighted and clinically relevant implications are discussed, alongside recommendations for future research in this area.

*Keywords:* black, ethnic, carer, dementia, minority

## **Introduction**

Dementia is a major cause of disability in modern day society with approximately 800,000 people with the disease in the United Kingdom (UK) (Department of Health, 2009). This number is projected to double over the next 30 years with a cost to the economy greater than that for heart disease and cancer combined, despite most of the care being provided by family and friends (Luengo-Fernandez, Leal, & Gray, 2010). This predicted increase in the number of people with dementia is expected to be greater in Black and minority ethnic (BME) communities, as first-generation African Caribbean and South Asian migrants enter the age groups with the highest incidence of dementia (Weimer & Sager, 2009).

A study by Knapp and Prince (2007) also suggests that although BME communities tend to have a relatively young age profile at present, this will change as a consequence of immigration patterns in the latter part of the 21st century, leading to significantly higher numbers of members from these communities with dementia. Furthermore, there is concern that mental health services are not well equipped to meet the needs of BME elders and their families (Lievesley, 2010).

## **Carers in the UK**

Policy initiatives found in many western countries prioritise early diagnosis of dementia in order to facilitate timely access to treatment, information and support for people with dementia and their families (Department of Health, 2009). In the UK, around two-thirds of older people with dementia are supported in the community, and family carers are the most important source of dementia care. A family carer is

an individual providing assistance to a relative who is experiencing difficulties due to physical, emotional or cognitive impairments, often without financial compensation (Bridges, 1995). There are approximately six million family carers in the UK, with as many as three in five people likely to become a carer in their lifetime.

African Caribbean and South Asian communities represent the largest BME communities in the UK, yet the evidence base regarding dementia care in these communities is extremely limited. People from BME communities comprise 15% of the English population and 39% of the London population (National Audit Office, 2007). Although they access primary care at a similar rate to the indigenous population, they are less likely to access mental health services (Livingston, Leavey, Kitchen, Manela, Sembhi, & Katona, 2001). Research also points to significant variation among BME communities with regard to their motivation to adopt the carer role, their willingness to care, the experience of being a carer, and the use of external support (Parveen, Morrison, & Robinson, 2011).

## **Rationale**

A previous review of literature into caring for individuals with dementia in Black and South Asian communities in the UK was carried out by Milne and Chryssanthopoulou in 2005. The review found that the consequences of care giving in Black and South Asian communities were significant but also different from those experienced by White carers. These consequences were seen to be mediated by factors including religion, conceptualisations of dementia and expectations of family duty. The review also highlighted an evidence base characterised by small scale studies and weak methodology which further undermined the validity of results.

Although the review by Milne and Chryssanthopoulou (2005) presented a series of findings in relation to the experiences of caring for a person with dementia in Black and South Asian communities in the UK, a number of limitations were apparent. Firstly, the review included studies conducted in the USA to supplement those found in the UK, thereby not focussing on Black and South Asian communities in the UK alone. Due to both cultural differences and variations in healthcare systems it is difficult to generalise findings from Black and South Asian communities in the USA and attribute these to the UK. A further limitation of the review is its focus upon the experiences of only two BME communities in the UK, namely Black and South Asian; thereby limiting the knowledge of caring experiences held in other BME communities which reside in the UK.

An updated review of literature is warranted in order to gain a better understanding of the experiences, attitudes and needs of caring for someone with dementia in Black and South Asian communities and to build upon the existing findings of Milne and Chryssanthopoulou (2005). The present literature review will build on these findings by exploring the experiences of all BME communities within the UK. This will allow for a more focussed critical evaluation of empirical findings from research into the experiences, attitudes and needs of caring for someone with dementia among BME communities.

## **Aims**

Given the paucity of literature about the experience of carers from BME communities, there is a need to understand the evidence base surrounding the experiences, attitudes and needs of these individuals. The profound effect of culture

and ethnicity on caregiving underlines the importance of addressing the cultural context of a carer experience.

The present literature review aims to provide a critical appraisal of empirical research into the attitudes, experiences, and needs of these individuals providing care for a person with dementia within BME communities in the UK.

## Method

A systematic literature search was conducted by using six internet databases (PsychARTICLES, PsychINFO, Medline, CINAHL, Web of Knowledge and Scopus) to find peer reviewed journal articles (between 2005 and 2013) which examined the experiences, attitudes and needs of people from BME communities caring for someone with dementia. The databases were searched using key terms (see Figure 1). The terms were searched in

**Figure 1.** Key search terms

<p>South Asian, Black, Muslim, Hindu, Sikh, Irish, African Caribbean, Eastern European, ethnic, minorit*, bme,</p> <p>And</p> <p>Carer, cargiv*,</p> <p>And</p> <p>Dementia, Alzheimer's,</p>
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**Table 1.** Summary of reviewed articles.

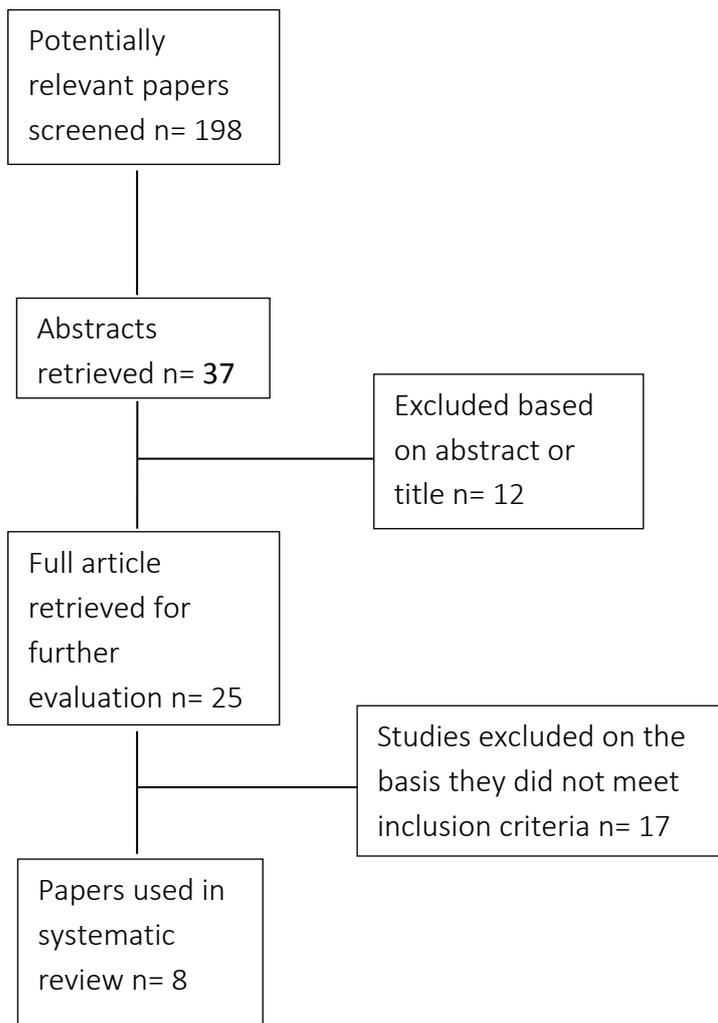
Study	Aim	Methodology	N	Sample	Design	Main findings	Limitations
Adamson and Donovan (2005)	Examining the experience of caring for an older family member, focusing on minority ethnic carers of a person with	Qualitative (grounded theory)	36	Age range - not stated  Gender - not stated  Ethnicity- 15 South Asian	In-depth semi-structured interviews	Experience of informal care has many similarities to the experience of chronic illness.  Carers describe their caring role in terms of:  A continuation of their previous relationship with the person being cared for.  The participants also describe highly disruptive elements to change in the	The majority of participants in the study were female.  The sample recruited were already accessing mental health services.  The study used different interpreters used throughout interview stage.
Botsford, Clarke and Gibb (2011)	Examining the experiences of partners of people with dementia in two BME groups.	Qualitative (grounded theory)	13	Age range- 60-80  Gender- 6 male 7 female  Ethnicity- 7 Greek Cypriot 6 African	43 In-depth interviews conducted over an 18 month period between 2007 and 2009	Participants engaged in an on-going process of “redefining relationships”.  Greek Cypriot partners tended to emphasise family relationships.  African Caribbean partners tended to view themselves primarily as an individual or as part of a couple.  Participants accommodated the changes associated with dementia into their lives rather than seeking help.  Participants saw their experience as an extension of their responsibilities	The study took place in only one city which limits generalising of results to other BME groups in other areas of the UK.  Only 1 <sup>st</sup> generation migrant carers were recruited in the study.  Only “partners” of dementia sufferers were recruited to take part in the study.

Study	Aim	Methodology	N	Sample	Design	Main findings	Limitations
Jolley, Moreland, Read, Kaur, Jutilla and Clark (2009)	To learn about dementia within BME groups and how to improve relevant services.	Qualitative (not stated)	30	Age range- not stated  Gender- not stated  Ethnicity- 10 African Caribbean 20 South Asian	Interviews conducted over a six year period between 2000 and 2006	There was a continuing lack of knowledge and understanding of dementia among carers.  Lack of understanding led to stigmatisation, mistaking symptoms of dementia with old age.  Carers remain isolated.  Variability in knowledge and attitudes between families and between generations.	The study was only conducted in one location.  In the second stage of the study, only Sikh carers of someone with dementia were interviewed and no Afro Caribbean carers were used.  The study only
Jutilla (2010)	Understanding migrant Sikh carers caring for an older person with dementia.	Qualitative (grounded theory)	12	Age range- not stated  Gender - 3 male 9 female  Ethnicity - Sikh	2-3 narrative interviews	Participants viewed their caring role as an extension of an existing obligation and identity.  Migration experiences did impact on experiences of carers.  Participants idealised their societies of origin, including type of support available to them in that society.	The study was only conducted in one city.  The study only focused on carers of someone with dementia from a Sikh community.  Therefore, findings can only be generalised to carers who have migrated

Study	Aim	Methodology	N	Sample	Design	Main findings	Limitations
Jutla and Moreland (2009)	Understanding Sikh carers caring for an older person with dementia	Qualitative (not stated)	5	Age range - not stated Gender - not stated Ethnicity - Sikh	Interview	Sikh community is not a homogeneous group. Diversity and differences within the Sikh community can have important implications for care. Factors to be considered include: carer's country of origin; migration route and	Due to the low sample size, results cannot be generalised to all BME carers of someone with dementia. The findings of only two interviews were presented and discussed in the study. The study only focussed on carers from a Sikh background
Lawrence, Murray, Samsi and Banerjee (2008)	To explore the caregiving attitudes, experiences and needs of family carers of people with dementia from the three largest BME groups in the UK.	Qualitative (grounded theory)	32	Age range - 33-87 Gender - 7 male 25 female Ethnicity - 10 African Caribbean 10 South Asian	In-depth individual interviews	Carers were identified as holding a 'traditional' or 'non-traditional' caregiver ideology. Participants conceptualised caregiving as natural, expected and virtuous. This informed feelings of fulfilment, strain, carers' fears and attitudes towards formal services.	The majority of participants were female which limits the results being generalised to male carers of someone with dementia. The study was only conducted in London. Only carers born in the UK were used in the study. The study recruited carers from just two BME groups. Namely South Asian and Afro Caribbean carers.

Study	Aim	Methodology	N	Sample	Design	Main Findings	Limitations
Mackenzie (2006)	To identify the support needs of family carers from Eastern European and South Asian groups	Qualitative (thematic analysis)	18	Age range - not stated Gender - not stated Ethnicity - 11 Pakistani 5 Indian 1 Polish	Semi-structured interviews	Understanding of dementia differed between Eastern European and South Asian carers. The understanding of dementia in different cultural contexts caused stigma. The management of stigma between eastern European and South Asian carers was similar. The experience of stigma influenced engagement with formal services.	The study was unclear if participants had migrated to the UK or were born in the UK. The carer's relationship to the dementia sufferer was not stated in the study. Unclear use of the term South Asian limited the generalisation of findings. A small sample size of Eastern European carers.
Mukadam, Cooper, Basit and Livingston (2011)	To explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in minority ethnic and indigenous groups.	Qualitative (grounded theory)	18	Age range - 27-85 Gender - 5 male 13 female Ethnicity - 4 White 5 Indian	Semi-structured interviews	Minority ethnic carers tended to delay help-seeking until they could no longer cope or until others commented on the problems. Dementia symptoms were seen as a normal part of ageing. Carers thought that families should look after their own elders. Minority ethnic carers held certain beliefs about the etiology of cognitive impairment, psychiatry and their sense of familial responsibility which affected their help-seeking.	The majority of participants were female. The study was conducted in only one city. The carers recruited for the study were already accessing formal health services in relation to their family member with dementia.

**Figure 2.** Literature review search flow diagram



journal article abstracts, titles and keywords. The overall search resulted in 25 peer reviewed articles, all of which were screened against the following criteria for inclusion in the present review:

### **Inclusion Criteria**

1. Papers published between 2005 and 2013.
2. The study explored the attitudes, experiences or needs of carers providing care for a family member living with dementia.
3. The carers were from a Black or minority ethnic community.
4. Participants were recruited within the UK.
5. The study was published in a peer-reviewed journal.

### **Exclusion criteria**

1. Unpublished dissertations or non-peer reviewed articles.
2. Articles published prior to 2005.
3. Non UK based studies.
4. Quantitative and survey based articles.

Once relevant articles were identified, their reference lists were searched using the same search terms for additional articles. The final search was conducted in March 2013 and no additional articles were identified. Eight articles were found to meet the required criteria for inclusion in the present review. Table 1 presents a summary of the studies, indicating the sample size, the characteristics of sample and the main findings. Figure 2 shows a flow diagram of the literature review article search process.

## **Results**

All eight peer reviewed articles included in the present review used a qualitative methodology, with five of the articles analysing their data using grounded theory. The majority of studies used semi-structured interviews to guide data collection. The age range of the carers included in the present literature review ranged from 27 to 86 years. Six of the articles focused on the experiences of more than one BME community, while two articles focused on only one BME community. The studies explored various psychological and social factors which influenced the experience of caring for a family member with dementia in the UK.

The findings from the present literature review will be framed in the following themes; perception of dementia as a normal process of ageing, caring seen as an extension of an existing responsibility, perception of existing mental health services, impact of migration on the caring role, impact of stigma on a carer's role, and female responsibility to provide care for a family member with dementia.

### **Perception of dementia as a normal process of ageing**

Evidence from the literature reviewed highlighted that a number of carers from BME communities had culturally based perceptions of dementia. Botsford, Clarke, and Gibb (2011) conducted 43 in-depth interviews with 13 Greek Cypriot and African Caribbean carers aged between 60 and 80 years, caring for a family member with dementia in London. The study took place over an 18 month period (2007-2009) and the data was analysed using a grounded theory approach. It was found that most of the participants had interpreted the changes associated with dementia as part of a

normal process of ageing. This was expressed through participants describing that memory problems were supposed to occur when a person became old. The majority of participants expressed a general belief that cognitive decline might be expected and therefore forgetfulness was part of the ageing process (Botsford et al., 2011).

Botsford et al., (2011) also found that the perception of memory problems being perceived as a normal process of ageing was associated with a delay between carers noticing a problem and seeking an explanation. The study highlighted a specific way in which dementia is construed in two BME communities. However, these findings are limited to only two discrete Greek Cypriot and African Caribbean communities in London.

This finding that carers viewed their family member's cognitive decline as a normal process of ageing was mirrored in a study by Jolley, Moreland, Read, Kaur, Jutlla, and Clark (2009) who conducted interviews over a six year period with 30 BME carers of people with dementia in Wolverhampton. The study highlighted that a lack of information and understanding held by African Caribbean and South Asian carers with regard to dementia led them to be unaware of its differentiation from normal ageing. Carers were found to not seek help or access mental health services due to being unaware that they were caring for someone with dementia (Jolley et al., 2009).

### **Caring as an extension of an existing responsibility**

As noted previously, a number of carers viewed cognitive decline as a normal process of ageing and therefore did not see their family member as suffering from a specific mental health disorder such as dementia. In addition to this, several studies

highlighted how carers from BME communities typically saw their role as an extension of an existing responsibility to care for their family member with dementia.

For example, Adamson and Donovan (2005) interviewed 36 carers from African Caribbean and South Asian communities who were caring for a family member with dementia across numerous geographical locations in the UK. Through the use of in-depth, semi-structured interviews, the study aimed to discover the meaning of being a carer for a family member. Using a grounded theory approach to analyse interview data, the study highlighted that participants viewed caring as a normal feature of their life which was often a continuation of their identity. It was found that participants did not view themselves as “carers”, but rather as fulfilling a natural role within the family (Adamson & Donovan, 2005).

The perception of caring as an extension of an existing responsibility was also evident in a qualitative study which compared the experiences of White, African Caribbean and South Asian carers, all caring for a relative with dementia. In-depth individual interviews with 32 carers, aged between 33 and 87 years from London, found that those carers with “traditional caregiver ideologies” saw caring as natural, expected and virtuous. Holding strong religious values motivated and shaped a carer’s desire to support a family member. In particular, daughter and son carers of South Asian origin were most likely to explain this in terms of caring as a cultural norm and as an opportunity to reciprocate parental support. This account was absent from the accounts of White British sons and daughters caring for their parents in the study (Lawrence, Murray, Samsi, & Banerjee, 2008).

The study also found that African Caribbean carers who were born in the UK, (second or third generation) held less traditional views of caring for an elder than first generation African Caribbean carers (Lawrence et al., 2008). This finding suggests that within BME communities, there are differences depending on the generation of the carer, although a limitation is that participants were only from the London region, and therefore, not necessarily representative of BME communities in other areas of the UK.

This finding of caring being a culture bound phenomenon was supported by research reporting that carers with strong family centred beliefs saw caring as a natural responsibility (Botsford et al., 2011). Similarly, previous research has also described a tendency of some carers to frame their role as a natural and expected facet of married life (Lawrence et al., 2008). In a similar vein, Adamson and Donovan (2005) found that carers often viewed the caring role as an accepted part of their relationship with the family member with dementia and viewed it as an extension of their family responsibilities. However, despite highlighting how carers situate their role as a cultural norm, Adamson and Donovan (2005) did not investigate what factors might account for this being the case.

### **Perception of existing mental health services**

As noted previously, research has found that carers from BME communities may see dementia as a normal process of ageing and appear to see their role as an extension of an existing responsibility. Research has also found that some carers had distinct perceptions of existing mental health services. Jolley et al. (2009) for example, conducted a number of interviews over a six year period (2000-2006) with 30 carers

from the African Caribbean and South Asian community in Wolverhampton. The main findings from these interviews revealed that carers perceived mental health services to lack the confidence and competence to address language barriers and cultural differences. This resulted in the carers feeling culturally stereotyped (Jolley et al., 2009).

In addition, the study by Jolley et al. (2009) captured the experiences of these carers whilst visiting their local General Practitioner. The majority of carers felt that the knowledge base of General Practitioners was variable, leading to some cases of initial misdiagnosis or a delay in reaching specialist care and support. Carers from the study also highlighted a distinct lack of clarity regarding the eligibility criteria for accessing mental health services. This resulted in carers feeling that they were not eligible to access such services (Jolley et al., 2009). Although this study was able to highlight the experiences of carers accessing mental health services for support, a limitation is that in the latter stages of the study, only South Asian carers were interviewed and no African Caribbean carers were involved as seen in the initial interviews conducted. This results in no comparable data available with regard to the African Caribbean carers.

Another distinct perception of mental health services held by carers was captured by Mukadam, Cooper, Basit and Livingston (2011). Using semi-structured interviews with 18 African Caribbean and South Asian carers, the study found that a lack of trust in the healthcare system affected their experience of caring for someone with dementia. This lack of trust was also aligned with a perception that mental health services could only offer a diagnosis of dementia rather than treatment, intervention

or general support. For many carers, a diagnosis would not change their circumstances and therefore, was not perceived as useful (Mukadam, Cooper, Basit, & Livingston, 2011).

### **The impact of migration on the caring role**

It is noteworthy that some carers from BME communities appear to have distinct perceptions of what existing mental health services can provide. For some carers, mental health services were experienced as untrustworthy, having variable knowledge of dementia and only able to provide a diagnosis and nothing further. An additional finding which developed throughout the present literature review was the impact of migration on the caring experiences of BME carers. Jutlla (2010) conducted 2-3 narrative interviews with 12 carers from a Sikh community in Wolverhampton about their experiences of caring for a family member with dementia. Utilising a grounded theory approach to analyse the narrative interviews, Jutlla (2010) found that the migration route of Sikh carers influenced their role. The study coined the process of migration as a “repositioning of existence” which occurs when someone migrates to another country and culture. The study suggests that when caring for a family member with dementia, BME carers experience a further episode of “repositioning of existence” which may manifest itself in adopting new responsibilities and also a role repositioning from a husband or wife to that of a carer (Jutlla, 2010).

The study also found that carers who had migrated to the UK often held narratives of how support would be “back home”. Referred to as “idealised narratives of situations and perceptions pre and post migration”, carers would idealise their societies of origin in relation to the presence of an extensive family network and community

support. Although the carers acknowledged the improved health and social support services available in the UK, they still expressed a desire for their caring role to be located in their country of origin (Jutlla, 2010).

A study by Jutlla and Moreland (2009) also identified the influence of migration on Sikh carers. Interviewing five Sikh carers of a family member with dementia from Wolverhampton, it was revealed that within the Sikh community, there was a range of different experiences of migration to the UK. The study revealed how different migration routes, age at which a person migrated, and the reason for the migration influenced their caring experience (Jutlla & Moreland, 2009).

Presenting the findings of only two out of five participants interviewed, the study by Jutlla and Moreland (2009) captured differences in migration experiences. One carer had only recently immigrated to the UK due to marrying a UK born Sikh male. For this carer, her experience was one of isolation and lack of support from the community around her and a huge contrast to the support available if providing care in India. This experience contrasted with that of a male carer who came to England in the 1960s and lived with other young men whilst seeking employment. During this time the carer learnt how to cook, clean, be self-sufficient, and it was these skills learnt when first immigrating to England which were then used when he began caring for his wife with dementia (Jutlla & Moreland, 2009).

This concept of migration influencing a carer's role is supported further by Botsford et al. (2011) who conducted 43 interviews with 13 carers from Greek Cypriot and African Caribbean communities in London. Using the term "shielding process", the author identified a concept of resilience held by the carers from a BME community. This was

believed to be due to the carer having to overcome important challenges and obstacles whilst settling into a new country of residence. Thus the carers had already developed ways of coping and possessed a number of resources to draw upon which came into play in their present situation of caring for a family member with dementia (Botsford et al., 2011).

These two studies (Jutlla, 2010; Jutlla & Moreland, 2009) have highlighted some very noteworthy findings with regard to the impact of migration on a carer's role. However, a limitation of the study by Jutlla and Moreland (2009) is the small sample size of Sikh carers which limits generalisability of results. Furthermore, by concentrating on only one BME community, the findings can only be related to members of the Sikh community who have in fact migrated. It is predicted that a number of carers from the Sikh community will not have migrated and may therefore have a very different experience of caring for a family member with dementia. In addition, for carers born in the UK, they may have little knowledge of the systems of support available in their ancestral country of origin.

### **Impact of stigma on a carer's role**

The impact of stigma is a phenomenon that has been widely reported with regard to BME communities accessing mental health services (Taha & Cherti, 2005). The experience of stigma when caring for a family member with dementia was present in the findings of a study by Mackenzie (2006) who carried out semi-structured interviews with 18 carers from Eastern European and South Asian communities in a northern English city. Through thematic analysis of interviews, the author found that stigma was present in both cultures.

East European carers, caring for a family member with dementia experienced stigma from within their own community. This led to a number of carers to not seek help from fellow members of their community and instead described “hiding” the person with dementia whilst beginning to sever ties with family and friends. This process of isolation was seen as an inevitable outcome in trying to limit stigma. Furthermore, this fear of stigma was also present in relation to other mental health problems (Mackenzie, 2006).

Remaining with this study, the construct of stigma was also encountered by carers from a South Asian background. South Asian carers viewed dementia as a mental health issue caused by spiritual influences. Such explanations imposed a level of stigma on the family and dementia sufferer, which led carers to act in a similar way to the Eastern European carers by concealing the person with dementia from the rest of the community.

A similar concept of stigma featured in the findings of Mukadam et al. (2011) who assessed why ethnic elder carers present later to dementia related health services. By interviewing 18 carers, it was found that stigma was a barrier to accessing support from mental health services only for BME carers. The fear of stigma was not present in White carers interviewed for the study (Mukadam et al., 2011).

Overall, the findings of Mackenzie (2006) highlight a fear of stigma that is found in other aspects of mental health experiences among BME communities (Knifton, Gervais, Newbigging, Quinn, Wilson, & Hutchinson, 2010). However, a limitation of Mackenzie’s (2006) study is in relation to the sample. A lack of understanding of cultural differences between different sub groups of the South Asian population was

found in this study. Taking into account culture specific beliefs, the study reports findings in relation to Pakistani carers viewing dementia as “evil spirits” and being a “curse” on their family. This phenomenon is very common in Pakistani cultures but not as prevalent in Sikh and Hindu cultures (Khalifa & Hardie, 2005). Therefore, this explanation for what they perceived to be the cause of dementia should have been limited to the experience of Pakistani carers rather than suggesting it has relevance for Sikh and Hindu carers as done in this study. This indicates the importance of knowledge and awareness of the various BME communities when research is conducted in the UK.

### **Female responsibility**

A final issue found throughout the articles reviewed was the responsibility of care provision falling predominantly on female carers from BME communities. For example, Jutlla and Moreland (2009) found that when providing care for someone with dementia in a Sikh household, there was an expectation for the daughter-in-law to provide the care. These researchers found that this example added to the already high incidence rate of daughter-in-laws remaining as “hidden” carers in Sikh families.

The presence of female care responsibility featured in a second study by Jutlla (2010), conducted with Sikh carers in Wolverhampton. Whilst assessing the impact of a carer’s migration to the UK on their caring experience it was also found that females in particular held an existing care identity. This would suggest that females in particular, may already have been providing a caring role for the person with dementia. Furthermore, this was in contrast to male carers who exhibited a change of

their current identity into a caring role which they had not previously identified with (Jutlla, 2010).

A similar finding was present in a study by Adamson and Donovan (2005) who interviewed 21 African Caribbean and 15 South Asian carers of a family member with dementia. This grounded theory study found that female carers felt a stronger moral obligation to care than the male carers (Adamson & Donovan, 2005). In line with these findings, Botsford et al. (2011) identified an expectation that daughters would provide care for the person with dementia. This tendency was found to be more prominent in a Greek Cypriot community than in an African Caribbean community.

It is suggested that this is not an uncommon concept, with an increasing number of females caring for parents and parent in-laws in general (Hirst, 2001). These findings from Adamson and Donovan (2005) appear to relate to those of Botsford et al. (2011) and Jutlla (2010) in females holding an existing, moral obligation to care that may not be seen as much in male carers. However, what is unclear from the findings of these three studies, is whether this female care responsibility can be explained by gender differences, or is due to being part of a BME community.

## **Discussion**

The aim of the present review was to critically evaluate empirical evidence on the experiences, attitudes and needs of members of BME communities caring for a family member with dementia in the UK. The present review highlighted a number of complex and culture bound factors which characterised their experience of caring for

a family member. These related factors were consistent findings across the majority of studies reviewed.

It was noted that the level of understanding of dementia impacted on the carers' experience. A number of carers viewed a decline in cognitive functioning as being a normal process of ageing. These findings are also consistent with a previous literature review by Milne and Chryssanthopoulou (2005) which identified that carers viewed symptoms of dementia as a normal process of ageing. This would imply that carers from BME communities continue to view the person they are supporting as presenting with symptoms of old age and not as someone with a medical condition that they should seek support for.

The majority of articles reviewed here found that, for a number of BME carers, their role was seen as a natural progression in their life, and a way of repaying the care they had received previously from the family member with dementia. In relation to whether or not carers from BME communities are likely to access mental health services for support, this finding suggests that carers may not identify a need for support from mental health services. However, further larger scale research is needed to adequately test this hypothesis.

The current review has also highlighted the value held by family members of being able to care for a relative with dementia. Lawrence et al. (2008) describes this value as an, "obligation to provide the care themselves", with a number of family members feeling that placing their relative with dementia in a care home would cause them to encounter stigma amongst their community or a feeling of failure. The findings of Botsford et al. (2011) also support the premise that caring for a family member with

dementia should be completed by the family members themselves in BME communities. Furthermore, these findings also support a previous literature review which found that family members from BME communities in the UK, providing care for someone with dementia considered their role to be part of normal kinship responsibilities (Milne & Chryssanthopoulou, 2005).

In a similar vein, Mackenzie (2006), when interviewing carers of family members with dementia from an Eastern European community found that carers viewed, “keeping it in the family” as a very important value to adhere to. The participants placed particular value on familial responsibility to look after the person with dementia and that outside help was viewed as intrusive. This would suggest that mental health services could improve by offering a type of support for carers which enable the person with dementia to be supported at home. This may help to minimise the risk of carers feeling stigmatised by other community members, and would allow them to complete their familial obligation to care for an elder.

The present review has highlighted a construct present in several qualitative studies which describes how migration of carers from BME communities has an impact on their caring experience. Evidence from these studies indicates that carers who migrated to the UK held a strong sense of resilience. This attribute seemed to assist first generation carers to manage the role and responsibilities of being a carer for someone with dementia without accessing mental health services for support. This would imply that services would benefit from being aware of the migration route of carers from BME communities and consider how this would impact on their desire to access mental health services for support.

Furthermore, the findings of Mackenzie (2006) were explicit in relation to the impact of stigma on a carer's experience. The fear of being stigmatised led carers to isolate not only themselves, but also the dementia sufferer. This could potentially lead to members of the community who are suffering and in need of specialist support from mental health services being isolated. This was not dissimilar to the finding by Milne and Chryssanthopoulou (2005) who found that carers felt stigmatised due to a family member having dementia. This would suggest that services need to consider providing education and psycho-education for BME communities on the nature of dementia as a lack of understanding appears to continue to cause carers to feel stigmatised from other members of their community.

The present literature review has highlighted a general tendency for female family members to be the principal providers of care for family members with dementia. This particularly related to the main carer being a wife, daughter or daughter-in-law being expected to take responsibility for caring for a relative. For many BME communities, it was a cultural norm for female family members to adopt this role more typically than their male counterparts. In some instances, the studies revealed that this cultural norm was an extension of an already existing obligation held by the female family members.

The findings from the present literature review are also in line with a previous review by Milne and Chryssanthopoulou (2005) which identified a cultural role among females from Black and South Asian communities to provide the majority of care for someone with dementia. This would suggest that the majority of carers of someone with dementia from BME communities in the UK are likely to continue to be female.

Therefore, further qualitative research could usefully determine the extent to which mental health services are providing adequate support for female carers and whether this has implications for tailoring mental health services to support their needs.

### **Limitations**

The present review has identified a number of limitations of the existing evidence base. The first is the lack of male participants across most of the studies. The majority of existing published research provides an insight into the experience of how females cope with being a carer, which most likely represents the majority of carers for someone with dementia in BME communities. However, whilst bearing this in mind, we still lack an understanding of the male experience of caring in BME communities. Several of the studies reviewed here have acknowledged this limitation and recommend that further studies should assess the experience of male carers from BME communities. This is also a recommendation of the present literature review.

A specific limitation of the UK literature in this area is the pattern of the majority of participants being recruited from only one major city or different boroughs of London. Although this provides an insight into the experience of carers in these specific areas, it limits generalising findings to the wider UK. Considered together with the fact that the majority of research into this topic has, until now, relied on qualitative methodologies with small sample sizes, it is recommended that researchers should now start to build on the current evidence base with larger quantitative studies encompassing multiple sites in the UK, and including BME carers in more contexts.

A further limitation which has arisen from the present review is the number of ethnic sub communities which were grouped under the umbrella term of “South Asian”. A number of studies presented their findings using the term “South Asian” to express the experiences of Pakistani, Sikh and Hindu carers (Adamson & Donovan, 2005; Mackenzie, 2006; Mukadam et al., 2011). Mackenzie (2006) for example, highlighted that Pakistani carers viewed their carer role as a means to gain ‘blessings from god’, whilst Sikh and Hindu carers described their role as ‘repaying’ the person with dementia for previous acts of kindness. These are two very different narratives underpinning why participants take on a caring role, and the author has grouped these practices as a “South Asian” experience.

This observation is reiterated by Jutlla and Moreland (2009) who emphasise how BME communities are not homogenous, and there are differences of experience when caring for someone with dementia between these communities. It appears that when studies have adopted this “South Asian” labelling approach they have not adequately captured the full range of experiences, attitudes and needs of individuals from BME sub communities.

Interestingly, this limitation identified in the current literature review was also identified in a previous review by Milne and Chryssanthopoulou (2005) who criticised research in this area for using terms which were not clearly defined, resulting in a reduced validity of UK research. From the findings of this present literature review, there appears to be a continued lack of rigour in using appropriate terms to describe BME communities with regard to their experiences, attitudes and needs when caring for someone with dementia.

Overall this limitation has huge bearings on our understanding of the experience of carers from a BME community. By grouping a number of ethnic communities together, the ability to compare and contrast caring experiences, and assess whether different BME communities have different needs for mental health services is lost. At present, it is only possible to compare and contrast the experiences, attitudes and needs between White, African Caribbean and “South Asian” carers.

### **Implications for practice**

Although the research has highlighted how carers from BME communities experience caring in different ways from a White British community, it is evident that within BME communities, there are differences in the experiences, attitudes and needs when caring for a family member with dementia. This has been evident when comparing the experiences, attitudes and needs of Greek Cypriot with African Caribbean carers and also when comparing Eastern European carers to those from a South Asian background (Botsford et al., 2011; Mackenzie, 2006).

In addition to this, Lawrence et al. (2008) also found that African Caribbean carers who were born in the UK (second or third generation) held less traditional views of caring for an elder than first-generation African Caribbean carers (Lawrence et al., 2008). These findings have significant implications for mental health services. It means that services need to be aware of these cultural and generational differences and tailor their services to accommodate the individualistic nature of BME communities in the UK.

With regard to changing immigration patterns in the UK, it would be predicted that mental health services will come into contact with carers from a wider range of BME communities in the future who will have their own individual perceptions and experiences of caring for a family member with dementia. Therefore, it would be essential for mental health services to be able to provide a meaningful, flexible and accessible service to these carers.

The findings from this present review have also found how many carers from BME communities viewed their role as an extension of an existing responsibility to provide support for their family member with dementia. This would imply that carers from BME communities may be at risk of carer burden or stress when providing for this family member without assistance from formal care services. Therefore it is important that mental health services are supporting carers from BME communities with their own mental health and ensuring that carers are not suffering from any specific mental health difficulties due to the impact of their carer role.

A lack of knowledge appears to be a common thread among the research collected which would imply that mental health services need to be aware of existing beliefs held by carers with regard to dementia. This was particularly pertinent in findings by Mackenzie (2006) where carers from a Pakistani background believed symptoms of dementia to be an “evil spirit” which had consumed their family member. These beliefs would greatly impact on the experience of being a carer and on their intent to access mental health services. Therefore, it would be advisable for mental health services to aim to increase this knowledge of what dementia is for family members and also be aware of cultural beliefs held by BME carers.

However, it is also important to acknowledge how attempts to tailor mental health services to meet cultural needs can be misunderstood by members of a BME community. Rao (2006) raised the issue that service providers may lack confidence in producing specialist services in the worry of appearing racist or singling out a community. To limit this, perhaps mental health services would benefit from employing staff from a range of ethnic backgrounds with a number of language skills. This implication for practice was also found in a recent systematic review of innovative practice of mental health services for BME communities (Bhattacharyya & Benbow, 2012) which found that services were already beginning to employ more staff from communities of interest with similar cultural background and language characteristics.

If the employment of staff from a range of ethnic backgrounds could not be achieved, mental health services could also increase the knowledge of existing staff members in their service on the range of BME communities which exist in the UK through staff training. This would provide staff working in mental health services with the cultural awareness of certain BME communities and would assist them in understanding the cultural significance of being a carer for a family member with dementia within different cultures.

To further support this, a literature review by Jutlla (2013) found that existing mental health services could drastically improve their engagement with BME communities by providing an individualised care approach. The review proposed that this could be achieved by existing services increasing their understanding and the importance of life histories and migration; culture and community norms when caring for a family

member with dementia; raising awareness and tackling stigma; and making services culturally competent.

Finally, dementia related services may benefit from using initiatives adopted by other mental health services to increase the access and engagement of BME communities. Kaur, Jutlla, Moreland, and Read (2010) for example, found that the use of a “link nurse” which was a community psychiatric nurse, who spoke Punjabi and English, and understood the relevant cultural issues, helped people from BME communities to gain a better understanding of mental health, thus increasing their level of engagement in mental health services.

### **Implications for future research**

It is clear from this literature review that there are a number of complexities when carrying out research in relation to dementia and ethnicity. These include the complexity of carrying out research with BME groups who are reluctant to access mental health services for support and are still influenced by stigmatisation. Furthermore, this literature view has highlighted the feeling of shame carried by carers of someone living with dementia. These aspects would all impact on how readily carers from BME groups respond to taking part in research on their experiences of caring for someone living with dementia.

However, whilst taking into account the complexities of research in this area, the literature review has highlighted a number of implications for future research. One implication is that future research in this area should address a gap in the literature in terms of capturing the experiences, attitudes and needs of male carers from BME

communities. This would not only strengthen our knowledge of carers from BME communities in general, but would also add to the literature of how males experience being a carer for someone with dementia. Some of the studies in this present review have clearly identified how gender roles held in BME communities impact upon the experience of being a carer (Adamson & Donovan, 2005; Botsford et al., 2011; Jutlla, 2010).

Further research would also benefit from examining the experience of caring in a range of geographical locations across the UK. Although the research included in this article has provided an in-depth insight into one particular ethnic minority group in one specific location: widening the range of locations in which participants are recruited from would allow research to assess if there are any similarities or differences in carer experiences, attitudes and needs depending on geographical location. This is also supported by the findings of Jutlla (2013) and the All Party Parliamentary Group (2013) which recommend that further research should be carried out on the experiences of carer's of someone with dementia from BME communities to provide us with a better understanding of their support needs.

Whilst conducting this present literature review, it was evident that very little research has been conducted on the largest BME community in the UK; namely the Irish community. Research has found that there are a number of "hidden" dementia sufferers from Irish communities in the UK who are not accessing mental health services for support. This appeared to be caused by a reluctance to engage in services which are seen to ignore their distinct cultural needs and experiences (Tilki, Mulligan, Pratt, Halley, & Taylor, 2010).

This apparent reluctance to engage in existing mental health services may explain why so little research has taken place with this BME community. Therefore, future research should again aim to understand the experiences, attitudes and needs of this large and long established community to allow a broader understanding of the experience of caring for a family member with dementia among the variety of BME communities in the UK. This is also supported by evidence from the 2001 census which found that members of the Irish community have the highest proportion of elders among BME communities in England (Royal College of Psychiatrists, 2009).

## **Conclusion**

This paper reviewed the recent literature on the experiences, attitudes and needs of caring for someone with dementia in BME communities in the UK. The review found memory loss being viewed as a normal process of ageing among BME communities with the role of a carer being perceived as an extension of an existing responsibility. The review found that carers from BME communities were most likely to be female and that they held a poor understanding of what support services were able and what these services could provide.

The review also highlighted how a carer's migration to the UK affected their experience of caring for a family member with dementia. Furthermore, the review found that carers from BME communities continued to encounter stigma in relation to a family member living with dementia. This not only impacted on their carer experiences, but also impacted on their willingness to access formal mental health services for support.

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