

BETTER HEALTH BRIEFING 46

Dementia and Minority Ethnic Carers

Dr Sahdia Parveen
Professor Jan R Oyebode

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Key Messages

- 1 *Do they look after their own?* Although many minority ethnic carers feel culturally obliged to provide care, this does not mean that all minority ethnic carers feel willing to provide care or feel prepared for the various aspects of providing support for the person living with dementia. Assumptions should not be made that minority ethnic communities do not require health care services due to their cultural values.
- 2 *The nature of family care in minority ethnic communities* differs in comparison to White British families. In South Asian cultures, for example, the main care responsibilities tend to fall on the daughter or the daughter-in-law and therefore the carer population in South Asian communities is younger than the British carer population. Care is more often shared between several of adult-children, and therefore dementia has a more widespread impact on the family beyond the 'main carer'.
- 3 *Health service support for carers* from minority ethnic communities is limited by a wide range of barriers to accessing services. There appears to be a preference for utilising third sector voluntary organisations, and partnership working may be a good strategy for service development.
- 4 *Carer coping strategies* are often focused around religion and spirituality. Many minority ethnic carers report satisfaction and pride from fulfilling their care duties and meeting their religious obligations.
- 5 *The negative impact of caregiving* is significant for minority ethnic carers as they are more likely to experience multiple jeopardy (the stigma of dementia, being perceived as a migrant, racism, and a lower socio-economic status).

Introduction

There are currently 850, 000 people living with dementia in the UK of whom approximately 25,000 are estimated to be from a minority ethnic background (APPG,

2013). The number of people from minority ethnic communities living with dementia is set to increase to 50,000 by 2051 and 172,000 2051. This is a seven-fold increase in 40 years compared to the two-fold increase in the majority population (Wohland et al, 2010). The main reason for this expected increase is the ageing of some key immigrant populations but better awareness amongst minority ethnic communities and current policy to increase timely diagnosis may also play a part. Furthermore, evidence suggests vascular dementia is more common in minority ethnic groups (particularly South Asian, African and Caribbean) due to higher prevalence of risk factors such as diabetes, hypertension, and cardiovascular disease. Young onset dementia (under 65 years) comprises a larger proportion of those diagnosed in minority ethnic communities (6%) compared to the White British population (2%) (Knapp et al, 2007).

Currently minority ethnic people living with dementia are under-represented within dementia services (Giebel, 2015; Mukadam et al, 2011) and it is thought that care is mainly provided at home by family members (Carers UK, 2011). The number of family members providing care for relatives with dementia is unclear. However a report by Carers UK (2011) suggests that 10% of all carers (for any condition) are from a minority ethnic background with South Asian Indian being the largest group (2.2%) of minority ethnic carers, followed by Black Caribbean (0.9%). The report also found that minority ethnic carers are more likely to provide 24-hour support for relatives with poor health (Carers UK, 2011).

One difficulty in establishing the number of carers within minority ethnic populations is the term carer. The term has been found to be difficult to define and translate for minority ethnic communities (Katbamna et al, 2004), and many family members perceive the support they provide as a natural dimension of family relationships that does not bring any special status of being 'a carer'. Within this briefing, the term carer is used to mean family members providing support for a relative with dementia, whether that be emotional, practical or nursing support.

It is also noted that the majority of research literature from the UK has focused on South Asian populations (i.e. people of Bangladeshi, Pakistani, Indian, Nepali and Sri Lankan heritage). There is very little research on the experience of other minority ethnic groups, such as African-Caribbean, Eastern European and Irish communities. This may be due to the South Asian population being the largest minority ethnic

group in the UK (Census, 2011) with approximately 12, 000 people living with dementia being from a South Asian Background (APPG, 2013). In contrast, the American literature has focused on the experience of primarily African-American carers followed by Hispanic and East Asian (e.g. Korean) carers (Knight & Sayegh, 2010). Although the cultural values and health systems between the two countries vary vastly, some knowledge about perceptions of dementia, cultural values and coping styles amongst minority ethnic families may be transferable from the US context to the UK. Another issue of interest noted within the literature is that minority ethnic communities and White communities are often treated as homogenous groups. However in reality both of these populations are very heterogeneous. Parveen et al. (2011) report that often differences between ethnic groups at the micro level (for example, between Bangladeshi and Pakistani carers) are larger than the differences at the macro level (differences between south Asian and White British carers).

Do they look after their own?

A common stereotype is that minority ethnic families are culturally obliged to provide care for elders and are able to do so due to support from large extended family networks. There is some evidence that this has led to carers not being offered services that they require (Parveen et al., 2017). In the UK, there is evidence to suggest that South Asian carers feel more culturally obliged to provide care than White British carers (Parveen, 2013, 2014). Lawrence et al. (2008) report that South Asian and Black Caribbean carers of people with dementia both held a more traditional caregiver ideology than White British carers, viewing caring as natural, expected and virtuous. However there is very little evidence from other minority ethnic communities in the UK. In America, Knight and colleagues (2010) report that African-American carers also feel more culturally obliged to provide care than their White American counter parts. Although minority ethnic communities may feel obliged to support relatives, the assumption that this is enabled by large extended family networks may not be true. The structure of South Asian families has been changing as a result of a number of influences such as the 1962 Immigration Act making it harder for families to unite across borders, economic changes in Britain increasing pressure on working age adults to relocate away from parents in order to find work, and absorption over time of some aspects of the more dominant culture of the UK. This has led to British South Asian families fragmenting and the extended

family is no longer the norm (Katbamna et al, 2004). It is also worth noting that feelings of cultural obligation to provide care do not necessarily equate to willingness to care. Within the UK there is some evidence to suggest that despite feeling more culturally obliged to provide care, South Asian carers do not significantly differ from White British carers with regards to willingness. The link between cultural obligation and willingness to care amongst minority ethnic communities requires further exploration.

The nature of family care

Evidence suggests that there is a greater distribution of caring among family members amongst minority ethnic families. In addition, although specific statistical differences in family demographics are difficult to ascertain, the limited literature on South Asian carers in comparison to White British carers suggests that South Asian carers are significantly younger, more likely to be adult children as opposed to spousal carers, and have other dependents (Parveen et al, 2013). Clinical and community practice suggests that the identified carer, in terms of the named next-of-kin who accompanies their relative to appointments or who speaks to health care staff on behalf of their relative is often male (either son or spouse) and may have a family role as the main decision-maker. This person may not have insight into the specific care needs of the person with dementia as they do little of the day-to-day personal care. Much of the responsibility for these aspects of care falls upon daughters and daughter-in-laws, who are often 'hidden carers' providing long hours of care without recognition from services or support for themselves (Parveen, 2011). Due to the lack of a single identified carer in many minority ethnic families, it becomes difficult to calculate numbers of carers and who should be receiving support. As minority ethnic carers are more commonly daughters or daughters-in-law rather than spouses they are also more likely to be the 'sandwich generation' whereby they are providing care for both older parents and children whilst also being in employment.

Support for carers

There is considerable evidence to suggest that minority ethnic communities are under represented in dementia services (Giebel et al, 2014)). A number of barriers may prevent access to services such as: dementia not being perceived as an illness,

shame and stigma being associated with dementia, negative experiences of services in the past, inadequate provision of culturally appropriate services, language barriers and lack of awareness of available services (Parveen et al, 2017; Giebel et al, 2014; Mukadam et al, 2010 & Daker-White et al, 2002). Some in minority ethnic communities have expressed a preference for community based services provided by third sector organizations (Parveen et al, 2017) perhaps due to such organizations being more readily trusted and being better equipped to meet cultural needs, for example, many third sector organisations employ engagement workers to work with minority ethnic communities. There is a need for health care services to work in partnership with third sector organisations to enable better service provision for minority ethnic communities (Blakey et al, 2016). Significant effort has gone into raising awareness of services amongst minority ethnic families (Bhattacharya & Benbow, 2013), however some minority ethnic families report health care professionals not offering them available support (Parveen et al, 2017). This may be due to health care professionals making assumptions about families 'looking after their own' and not requiring services or feeling they may cause offense by mentioning services.

As well as raising awareness of services there is a need for the development of specific support packages for minority ethnic communities. One example of a support package culturally adapted to meet the needs of South Asian families is the Alzheimer's Society IPSAF (Information Programme for South Asian Families). The programme has been found to enable South Asian carers to gain a deeper understanding of dementia, adopt more effective coping styles and enable the person with dementia to live better (Parveen et al, 2018). START (STrategies for RelaTIves) which is a carer's psycho-education skills and training programme which has been found to be effective with White British carers, and is now being adapted for south Asian carers (Livingston et al, 2013). Further work is needed to adapt services and interventions that have been found to be effective within the mainstream population for minority ethnic carers.

Carer coping strategies

The current literature suggests that minority ethnic families utilise religion and spirituality as a form of coping more than is the case in the UK White British population (Parveen et al, 2017 & Johl et al, 2014). This may be due to the

combination of lack of appropriate services and religiosity being stronger in such communities. Regan et al (2013) reported that religion can hinder access to traditional health care pathways as families may favour using community support and religion to assist in coping rather than turning to health services. Parveen et al (2014) found that religion was a mediating factor which explained the connection found between cultural obligation and positive gains found from caring in South Asian and White British carers. Research by Knight and colleagues (2010) suggests that African-American carers also focus more on spirituality and the positive aspects of caregiving, including the satisfaction of fulfilling religious obligations than White American carers. The African-American carers were found to retain stronger relationship bonds with the person living with dementia and as a result experienced higher levels of grief once the care role ended. There has been little focus on developing services and support packages that meet the religious and spiritual needs of minority ethnic carers. However there is a growing body of evidence outside the field of dementia that suggests religious faith can give positive benefits (Parveen et al, 2012) and that religious or spiritually based therapy can significantly reduce stress, anxiety and depression in individuals who perceive religion to be an important aspect of their life (Gonclaves et al, 2015).

The negative impact of caregiving

Carers UK (2011) state that although minority ethnic carers may face the same challenges as White British carers, they experience the additional barriers of institutional racism, language issues and cultural and/or community barriers. Minority ethnic carers of relatives with dementia experience a multiple jeopardy due to the additional stigma associated with a dementia diagnosis within their community, alongside the stigma of the minority ethnic status within society, and also being perceived as a migrant and often holding a lower socio economic status (Bamford et al, 2014). Within contemporary White British society, old age is devalued and when it is coupled with dementia this makes a double jeopardy. However many minority ethnic cultures hold onto the traditional values of 'respecting your elders'.

Due to the multiple jeopardy experienced by minority ethnic families, many carers experience poorer outcomes than their White British counterparts. Carers UK (2011) report that minority ethnic communities are at an increased risk of poverty, ill health, unemployment and social exclusion. In their surveys, caregiving was associated with

restricted opportunities for education, employment and promotion in employment. Carers UK interviewed 28 community-based organisations and reported that 78% perceived minority ethnic carers to be at a greater risk of being marginalised and to face increasing poverty and discrimination from health and welfare systems. There is a lack of academic literature comparing minority ethnic carer outcomes with those from a White British background. There is a small amount of evidence to suggest that south Asian carers experience more burden, anxiety and depression than their White British counterparts (Parveen et al, 2013).

Implications for policy and practice

To ensure services that meet the needs of minority ethnic families caring for a relative with dementia it is important that policy-makers and commissioners are aware of the influences of ethnicity and conscious of variations between and within ethnicities. Overarching phrases, such as 'minority ethnic' or 'Black and Asian Minority Ethnic' (BAME), assume common experiences. Yet those from ethnic minorities are not all united by experiences of immigration (as many have lived in Britain for generations) or by being 'non-White' (as those from, for example, Ireland and Eastern Europe are not visibly different from the White British). Even communities with a common national heritage (e.g. Pakistan) may include differences in language, religion and culture. This rich variety demonstrates that services based only on dominant White British cultural values will not provide appropriate support for all (even the spectrum of White British sub-cultures). It is important for policy-makers to recognise the importance of catering for diversity and for commissioners to understand the ethnic composition of their local populations and to develop service offers accordingly. Since there are indications that minority ethnic families may prefer to access community-based services via local third sector organisations, partnership working is likely to be a helpful way of developing local dementia care strategies to meet diverse needs.

There are many implications for health and social care professionals. The research evidence refutes the notion that those who look after their own do not need support from services. Indeed, if a family has a greater obligation to care, one consequence is that the carers continue to support the person with dementia at home, even in the face of very high care needs. In these circumstances the family may require more support than those whose relative moves into care. Since some minority ethnic

carers may be uncertain about whether they will be understood or offered appropriate support, service providers need to give time to build a trusting relationship with family carers, in order to be able to support them across the 'journey' of dementia. Given that family structures and roles often differ for minority ethnic groups, it is important for health and care practitioners to establish who in the family is involved in care. Rather than focusing on one primary carer, it may be appropriate to offer family meetings and to make it clear that multiple members of a family are welcome to attend appointments or carers' groups. Where carers differ in terms of relationship to the person with dementia then it is important to ensure the content of carer information is directed at their particular needs, for example, addressing issues for daughters in the sandwich generation rather than those more pertinent for older spouses/partners. Finally, given the likely value of religious coping, health and social care professionals may find it beneficial to consult with religious leaders about what they need to know to support families in their communities who are affected by dementia.

Conclusion

The information presented above demonstrates that ethnicity exerts a strong influence on the experience of supporting a relative with dementia, affecting access to services, patterns of family care, service use, ways of coping and well-being. Policy-makers, commissioners and service providers need to recognise the importance of providing culturally suitable services that address the social burden experienced during dementia care; a burden which is worsened for minority ethnic families by the lack of support that arises from service inequalities but which can be addressed in partnership with families and the communities that are served.

Resources and Reading

- *Meri Yaadain*: Set up to raise awareness of dementia and support minority ethnic communities in West Yorkshire. <http://www.meriyadain.co.uk/index.html>
- *Touchstone Support*: Similar To Meri Yaadain, remit is to raise awareness, provide one to one support and address barriers for south Asian communities in Leeds. <https://www.touchstonesupport.org.uk/services/bme-dementia-service/>
- *Dementia Alliance for Culture and Ethnicity (DACE)*: An alliance of groups currently providing information and support to people from Black, Asian and minority ethnic communities in the UK. <https://www.demace.com>

- *Policy Research Institute on Aging and Ethnicity (PRIAE)*: Combines policy, research, information, community engagement and service development. <https://www.priae.org>
- *Finding Patience*: A film produced by Health Education England portraying issues faced by minority ethnic communities coping with dementia. <https://www.youtube.com/watch?v=Q7zjL8nPqFg>
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Sahdia Parveen is a Senior Research Fellow at the University of Bradford with a background in Health Psychology research. Her research interests include a focus on the influence of ethnicity and culture on the experience of living with dementia.

Jan Oyeboode is Professor of Dementia Care at the University of Bradford and a registered clinical psychologist. Her current research interests focus on family relationships in dementia, and how the impact of dementia, and ways of coping with it, are influenced by diversity, including culture, type of dementia and age of onset.

Reader: David Truswell

We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

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Foundation**



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Unit 17 Deane House Studios
27 Greenwood Place
London NW5 1LB

T 020 74261880

E info@racefound.org.uk

<http://raceequalityfoundation.org.uk/>