

Barriers Faced by the People with Dementia in the Black and Minority Ethnic Groups in Accessing Health Care and Social Services

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Abstract

This paper explores the barriers in accessing services for dementia by people from ethnic minority populations. The paper is divided into two main sections: the first part will examine how social, cultural, and religious attitudes within ethnic minority groups in relation to mental health and healthcare in general affect service utilisation and the second section will discuss how extrinsic factors such as service structure affects access to services. Finally, we offer recommendations related to improving access to healthcare services.

Keywords: Dementia; Health care; Social services; BME

Background

Members of the public from black and minority ethnic (BME) groups are marginalized in healthcare services as they are more likely to receive poorer quality of care, have worse health outcomes, and have long term illnesses in comparison to the majority population [1-3]. This is supported by censuses from the UK identifying that health disparities affected ethnic minority groups more so than the general population and the elderly ethnic minority group were most adversely affected [4,5]. Due to the changes in age demographics in the UK this has raised concerns about the suitability of healthcare services, especially dementia services, for older adults from BME groups [6,7].

Currently, there are around 820,000 people with dementia in the UK of which 15,000 are from black and minority ethnic (BME) groups [8]. It is predicted that there will be over a million people with dementia by the year 20218: the rate of increase will be particularly high in the BME group as they have a greater risk of developing vascular dementia and early onset dementia [9,10]. However, despite these figures there is low uptake of ethnic minorities in old age psychiatry services [7] and often the services are accessed at a late stage of the disease [10]. The importance of addressing these health disparities cannot be understated as the predicted increase in both the elderly population as a whole and therefore also from BME groups will mean that there will be an increase in patient needs [6,7].

Current epidemiological studies show that older adults from the BME population in the UK are mainly from Black Caribbean and Asian Indian ethnic groups [7,10]. Within these ethnicities there are varying cultural and religious practices, but little is known about these different groups and their varying attitudes and experiences of using services for people with dementia.

The Relationship between Social, Cultural, and Religious Views and Dementia Services

Traditionally it has been accepted that due to the concept of 'familism' – the view that the extended family care for older relatives – ethnic minority caregivers were more likely to take on the responsibility of care-giving without external support [11]. Studies of African-American, Latino and White families found differences in caregiving and family dynamics that would account for this view. An example is a study by Haley et al. who found that white caregivers were more likely to be spouses than other groups, report depression, and view caregiving as stressful compared with African-American caregivers [12]. Latino carers are more likely to be daughters, whereas amongst the White population spouses provide care [13]. There is an underlying implication that as care is provided by family members other than spouses in minority groups, there is a greater desire from younger members to help their relatives. This was identified by a UK study by Lawrence et al. who found that participants from South East Asia and Black Caribbean who had traditional views were more likely to view caregiving a positive light [14]. This study found that service usage was influenced by whether the participants had a traditional versus a non-traditional view of caregiving rather than ethnicity. This was highlighted by the fact that participants from the latter group were more likely to give up their role as caregivers and demand more from services, whereas the former group were likely to be happy with services but overall depended on them less than the former group [14].

Taken together, these studies show that there are diverse responses to caregiving are based on the individual traits of caregivers even within the large cultural context and hence a homogenous perspective of caregiving cannot be attributed to ethnic minority groups. Arguably, the invisibility of ethnic minorities and the misperception of ethnic minorities 'looking after their own' has contributed to services not tailoring to the needs of ethnic minority service users and may have influenced these carers to carry out caregiving in the community in addition to cultural expectations. It may be that most of the care is carried out in the community, as minority groups also face difficulties

when giving care, especially caregivers who do not hold traditional views but have the cultural expectation of providing care.

It is apparent that there are myths surrounding dementia in both minority and majority groups that may hinder service utilisation. This was seen in a focus group of Pacific Islander Americans and Asian participants who viewed dementia as a normal part of ageing which could not be treated or managed and hence people with dementia and their carers did not look for services to help with their needs [15]. This attitude is also evident in the indigenous populations in the UK where some people refer to dementia euphemistically as having 'memory problems' and therefore did not view dementia as a syndrome affecting behaviour and cognition in a progressive and pathological manner [16]. A study of Chinese and Vietnamese elders revealed that some dementia patients viewed their symptoms as a consequence of migration and cultural shock, which illustrates that whilst dementia is not seen as a normal part of aging there are misconceptions associated with it that may prevent people from seeking medical help [17]. Furthermore, due to the stigma associated with mental health services in most communities, people may choose not to access services even after diagnosis of dementia. This was revealed by a report by the House of Commons, which found that the attitude about dementia in UK is extremely negative and akin to the view of cancer in the 1950's viewed as untreatable and unmanageable [16]. The report urges for an open and honest discussion of dementia on a national level [16]. The studies discussed above also demonstrate that there needs to be more awareness about the symptoms and management options available to people with dementia on a local level which addresses issues or misunderstandings held by ethnic minority groups.

Religious beliefs, which form the basis of cultural views, may impact the perception of disease and illnesses, and hence influence whether people access services. As BME groups are heterogeneous there are many religious practices within this population and a systematic review found that most ethnic minority populations in the UK followed non-Christian faiths, namely Islam, Buddhism and Sikhism, although those following the Christian faith were also influenced by their religion in how they approached services [18]. The review found that religion influenced most of the decision making related to accessing services, in particular religious women were less likely to use in home services compared to non-religious women, this was in part due to the sense that carers had a religious obligation to their care recipient [18]. Intriguingly the review concluded that religious organisation did not provide support for those struggling to cope due to the stigma attached to mental health, although religiosity was helpful for carers in aiding acceptance of their difficult experiences [18]. Other factors which impacted service access include the notion that dementia was part of a karmic consequence, punishment or a test from God [18]. It is important to highlight that whilst these are barriers which could explain why BME patients accessed services later, participants also experienced prejudice from service providers due to their religious beliefs and activities such as praying; therefore, the personal barriers to service utilisation were exacerbated by organisational barriers [18]. Finally, religion plays a role in the low service use of ethnic minority carers and care recipient; however it is also beneficial for individuals in coping with their struggles. Due to the strong influence of religion there may be a role for religious leaders to be part of the discourse of dementia healthcare.

The Impact of Extrinsic Factors in Utilisation and Access of Services

Studies have identified that members of minority groups over the age of 65 years can struggle with social issues associated with employability, finance, and difficult family dynamics which may have larger consequences in relation to using mainstream services [19,20]. A study that assessed the perceptions of care-giving and dementia amongst Vietnamese migrants identified that social problems such as overcrowded living conditions, unemployment, and language difficulties were at the forefront of patient's concerns, and hence they viewed seeking mental health services as a secondary issue [20]. A focus group of Tamil and Chinese elders showed that participants had a high awareness and concern for social stressors such as isolation and family conflict in comparison to knowledge about services [19]. Other social stressors such as living in dangerous urban neighbourhoods, access to transportation and living in high rise estates which prevent the elderly from leaving their home have also been identified as reasons for not accessing services [21].

These examples demonstrate that factors related to the social environment need to be addressed to improve service access and utilisation. However, as the social stressors are varied and encompass both interpersonal stressors (such as family conflicts) and community issues (such as dangerous neighbourhoods) it is not useful to formulate a one size fits all solution. Nonetheless, certain barriers such as dangerous neighbourhoods or transport issues which prevent people from accessing services highlights that there needs to be strong primary care role or involvement of local community services in providing information about dementia services. In addition, transportation provisions may need to be addressed for people with dementia who need more specialised services that may not be available locally. If carers or people with dementia are not accessing services as it requires leaving the home it may be useful to find ways to help people with dementia and carers in their own homes. This can be resolved by bringing certain services to the homes of the person with dementia or those who care for them. In a dementia advisor service pilot carried out by the NHS North of Tyne, Alzheimer's Society, and North Tyneside Council found that people with dementia preferred to speak to advisors at their home or the home of the carer as it was an informal and stress free environment [22]. The report identified that this was important in allowing people to feel comfortable when discussing confidential issues [22].

Certain features of mainstream services may deter people from ethnic minority backgrounds from using services outside their local community. One feature that was voiced in a focus group of Tamil and Chinese dementia patients was the low representation of staff from their ethnic background in mainstream services that made participants of the study use local community services even if these services did not cater to their health needs [19]. This is problematic as local community services are not equipped with the knowledge and expertise related to healthcare. However, understanding the perception of mainstream services as alienating spaces in a group of patients from two different cultures is useful as it highlights that mainstream healthcare services may be perceived as being disconnected from local communities and therefore not catering to the cultural and linguistic needs of the service users. Indeed this was identified by a report by the University of West England and Dementia Voices which found that participants felt that services did not appreciate the cultural, religious needs of minority groups [23]. Other studies have identified that the experiences of racism in healthcare

services was a factor in deterring patients from accessing mainstream services [18]. These studies suggest that there is a lack of understanding about different cultures from service providers and this is a barrier in aiding service use in BME. Although representation of staff from minority ethnic groups is one way of communicating the all-inclusiveness of mainstream services, it would be beneficial for staff to be trained on the cultural and religious differences of service users.

Language barriers that include the inability to speak the main language, read, or write the main language impacts service utilisation. The study conducted by the University of West England and Dementia voices highlighted how participants had adverse experiences in an emergency situation due to lack of interpretation facilities [23]. Other studies reinforce this concern as they revealed that language barriers resulted in high burden for carers especially in Chinese and Latino populations [24]. In addition, the inability to speak the dominant language has wider implications as a study by McCracken, et al. found that there was a higher prevalence of dementia among the non-English-speaking members of ethnic group compared to the English-speaking members of the same group, indicating that the diagnosis of dementia is hindered by the language barriers [24]. This may be a reflection of the socioeconomic position of minority groups who are able to speak the majority language or it could be due to the inability of mainstream services to meet the needs of those who are unable to speak the majority language. It appears that the language barrier is a factor which is not resolved in mainstream services, despite its impact on diagnosis, service access, and service delivery. This results in higher burden of care for caregivers and may impact the quality of life of people with dementia.

Summary and Recommendations

In our opinion, in order for access to be improved for people with dementia from BME groups there needs to be a comprehensive, systematic and on-going collection of data related to dementia service uptake and utilisation. More research needs to identify the issues faced by elderly people in BME communities, with dementia. The available treatment and services information related to dementia need to be circulated by an approach that is culturally and linguistically appropriate for the target group. Information could be circulated on a national and local level involving community and religious leaders. Creating a strong cohesion between primary care, local community projects and mainstream services is useful in breaking barriers to access, as services will be perceived as credible and less alienating.

Language barriers and cultural prejudices need to be overcome by the establishment of interpretation services and the availability of staff that understands the culture needs of the service users.

The heterogeneous nature of ethnic minority groups in the UK and the continual change of the demographics in the UK population ensure that improvements to service access will be an evolving field.

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