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Abstract

Despite the rapidly aging population and a predicted sevenfold increase in the prevalence of dementia in minority ethnic communities, people from these communities remain under-represented in specialist dementia services. Leventhal's Model of Self-Regulation suggests perceptions of illness facilitate help-seeking behaviours such as the use of services. This scoping exercise makes use of the model to explore perceptions of dementia in British Indian, African and Caribbean, and East and Central European communities in the UK. Between August 2013 and April 2014, culturally specific dementia awareness roadshows were attended by people living with dementia, carers and members of the public. During the roadshows 62 British Indian, 50 African and Caribbean and 63 East and Central European attendees participated in discussion groups and a dementia knowledge quiz. Thematic and framework analysis were conducted on the discussion group data. Three main themes are presented: Perceptions of dementia, awareness of dementia in the wider family and community, and awareness and use of services. The findings suggest that although groups attributed a biological basis for memory loss, a number of misconceptions prevailed regarding the cause of dementia. Groups also made use of religion, as opposed to medical health care services, as a form of personal and treatment control. Seeking help from health care services was hindered by lack of awareness of services, and culturally specific barriers such as language. The findings have a number of implications for policy and practice including the development of public health interventions and the need to focus further on reducing barriers to accessing services.

Key words:

Illness perceptions; Alzheimer's disease; BME; support; ethnic; carer

What is known about this topic?

- Minority ethnic communities are currently under-represented in specialist dementia services and often access services at a later stage in comparison to the majority population
- There is lack of awareness of dementia, and those from minority ethnic communities may attribute symptoms to old age
- South Asian groups report a number of culture-specific barriers (e.g. language) to service use.

What this paper adds

- Participants demonstrated an understanding of the organic basis of dementia but also associated development of dementia with stress and held a number of misconceptions about its consequences
- Indian participants reported a lack of support and understanding from extended family members
- A significant barrier to service use was the lack of awareness of the existence of specialist dementia services.

Background

It is estimated there are currently 850,000 people diagnosed with dementia in the U.K of whom approximately 25,000 are from a minority ethnic background (Alzheimer's Society 2014). The minority ethnic population is currently demographically younger than the majority white British population in the UK. However this is set to change and will lead to increased prevalence of dementia amongst minority ethnic communities. It is predicted that the number of people living with dementia from minority ethnic communities will increase to 50,000 by 2026 and 172,000 by 2051. This is a predicted seven-fold increase compared to the two-fold increase in the white British population (Wohland *et al.* 2010). Vascular dementia is thought to be the most common form of dementia amongst minority ethnic communities in the UK (particularly South Asian and Black Caribbean), affecting 22% of those living with dementia. This is due to the higher prevalence of risk factors such as diabetes, hypertension and cardiovascular disease (Moriarty, Sharif & Robinson 2011). Young onset dementia (affecting those under the age of 65 years) has also been found to be more common amongst minority ethnic groups accounting for 6% of the population living with dementia compared to 2% of the white British population with dementia (Knapp *et al.* 2007).

Due to the ageing population there has been a policy drive to improve timely diagnosis and improve services for people living with dementia (National Dementia Strategy 2009). The All Party Parliamentary Group on Dementia (2013) emphasises the need to develop appropriate services and improve access to high quality services for people with dementia from minority ethnic groups. The report further highlights the need for service providers to avoid the stereotypes and assumptions that minority ethnic families 'care for their own' so do not require outside help. However despite policy, evidence continues to suggest that people from minority ethnic communities are diagnosed at a later stage and

continue to be under-represented in services (Cooper *et al.* 2012, Mukadam, Cooper & Livingstone 2011, Moriarty, Sharif & Robinson 2011).

It has been suggested that the under-representation of minority ethnic groups in dementia services may be due to cultural stigma attached to dementia, lack of knowledge of dementia and little awareness of services. A study by Mackenzie (2006) with South Asian and East European groups in the UK suggests that there is greater cultural stigma attached to a diagnosis of dementia and therefore additional consequences of being diagnosed with dementia for those from minority ethnic backgrounds. Parveen, Oyebode and Downs (2014) suggest that people living with dementia from minority ethnic groups face a multiple jeopardy which involves the combination of stigma associated with a dementia diagnosis, the stigma of a minority ethnic status, being perceived as a migrant and also for many, having a lower social economic status.

A recent systematic review of eight UK studies by Johl, Patterson and Pearson (2014) exploring perceptions of dementia in minority ethnic communities, found that symptoms of dementia such as memory problems were often attributed to a normal process of ageing. A further three systematic reviews summarise research on barriers for minority ethnic groups in accessing health services (Greenwood *et al.*, 2014), mental health services (Giebel *et al.*, 2014) and specialist dementia services (Mukadam *et al.*, 2011). Culturally specific barriers to service access were found to include lack of knowledge of dementia, language, attitude (desire for ethnically matched staff in services) and concern about the cultural and religious appropriateness of services.

The reviews identify a number of limitations within the field. The majority of studies included were atheoretical in nature. Much research has been qualitative, with studies in the UK mainly focusing on South Asian populations with no comparison groups. It has been

suggested that further research is needed on the Caribbean population, with statistics suggesting that 30% of this population will be aged over 65 years by 2015, and the growing East European population (Truswell 2013). The majority of the studies were based on the views of family carers as opposed to people with dementia or the wider community. Furthermore, there has also been a greater focus on minority ethnic service use as opposed to perceptions of dementia. Focus on specific (mis-)conceptions amongst minority ethnic communities would allow tailored dementia awareness initiatives that could impact on the community as a whole (as opposed to those already affected by dementia). The purpose of the scoping exercise described here was to explore perceptions of dementia and awareness/use of services amongst people from British Indian, African and Caribbean, and East and Central European communities.

Much research in the field of health psychology suggests that misattribution of symptoms and absence of help-seeking behaviours (for example use of health services) results from the conflict between medical and lay models of illness (Hamilton-West *et al.* 2010). Leventhal's Self Regulation Model of Illness (Leventhal, Diefenbach & Leventhal 1992, Leventhal Meyer & Nerenz 1980) may be a useful theoretical model for understanding perceptions of dementia and help-seeking behaviour in minority ethnic communities. The model suggests individuals acquire illness cognitions through exposure to the media, personal experience and their family and friends. Illness cognitions are defined as the individual's own common sense beliefs about illness and provide a framework for understanding and coping with illness. The model proposes that when an individual is faced with a health threat, this information is processed resulting in a coping response. If the coping response is unsuccessful, then it is amended or the initial representation of the health threat is revised. If an individual, for example, becomes aware of memory problems, they may initially explain these as being due to old age and continue living as normal (Nolan & Keady, 1996). In

minority ethnic communities this may be further reinforced by the wider community in which changes in memory are seen as being due to old age rather than dementia (Johl et al, 2014). However as memory problems become more persistent and pervasive, the individual and family members may doubt their initial explanation of old age and decide to seek help/advice.

The Self Regulation Model encompasses five domains including: identity (the signs and symptoms of a health condition), cause (biological, psychological or environmental), timeline (perceptions related to duration of illness), consequences (long and short term effects of the illness on the individual's life) and cure/control. The Revised Illness Perceptions Questionnaire, developed by Weinman *et al.* (1996), is based on this model and includes two additional domains of emotional representations (how the individual is affected emotionally by the illness) and illness coherence (understanding of the illness) and further distinguishes between personal (the individual's control over the illness) and treatment control (effectiveness of treatment to control the illness; Moss-Morris *et al.*, 2002). There is considerable evidence to suggest that illness cognitions influence outcomes such as seeking treatment and support (Hagger and Orbell 2003).

A small number of studies have applied the model as a framework to understand perceptions of dementia (Clare, Goater & Woods 2006; Hamilton-West *et al.* 2010; Roberts

& Connell 2000). Clare *et al.* (2006) and Harman and Clare (2006) used the model to explore illness cognitions amongst individuals with early stage dementia. The model was found to be useful in exploring specific cognitions, with perceptions of a long illness timeline reflecting understanding of the nature of the condition. Roberts & Connell (2000) used the model to explore illness cognitions in first degree relatives of people with dementia. Participants were reported to be knowledgeable about dementia but held specific misconceptions with regard to causes, for example, the belief that all cases are hereditary. Participants also expressed

unrealistic expectations with regard to treatment efficacy. Hamilton-West *et al.* (2010) utilised Leventhal's model to explore lay perceptions of dementia and help-seeking behaviour. Participants were found to associate cognitive deficits with dementia but also commonly attributed dementia to stress and depression. Those who held inaccurate cognitions were less likely to seek help. These studies highlight the efficacy of Leventhal's model in identifying specific illness cognitions and help-seeking behaviours related to dementia.

The model has potential to be useful in identifying specific (mis-)conceptions about dementia and to facilitate our understanding of help-seeking behaviours in BME populations. Furthermore by identifying specific illness cognitions as opposed to highlighting a general lack of knowledge, we are better able to design health interventions and undertake more informed awareness-raising. Therefore this scoping exercise makes use of Leventhal's self-regulation model as a framework to explore perceptions of dementia and use of services amongst British Indian, African and Caribbean, and East and Central European communities.

Method

Setting and Participants

The All Party Parliamentary Group on dementia released a report in 2013 which contained seven recommendations with regard to minority ethnic communities. Two key recommendations were to raise awareness of dementia in minority ethnic communities and challenge the stigma, and to improve access to high quality dementia services. Based on these key recommendations, funding was sought from a council small grant scheme and a series of dementia awareness-raising roadshows were delivered between August 2013 and April 2014. The roadshows were delivered in a metropolitan city in the North of England in which 36% of the population has a minority ethnic background. The roadshows were adapted and

delivered to specific ethnic groups including: Indian, African and Caribbean, and East and Central European. The roadshows were advertised locally, including in venues frequented by people from the target populations, and were open to people living with dementia, carers, family members, and general members of the community. Further details of the delivery and content are reported by Parveen, Peltier, Powell and Oyeboade (2015). Although the roadshows had the primary aim of raising awareness of dementia, they also provided insight into dementia-related cognitions and use of services and it is information on these aspects that are presented here.

Procedure

Ethical approval was obtained from the University of Bradford's ethics committee to make use of the information gathered during the roadshow discussions, and those attending were also asked permission for dissemination. During the roadshows, attendees were divided into groups of 6 to 8 for informal discussion of the following: what is dementia, how much understanding is there of dementia in your community, what is the awareness of dementia in your community, what services do you feel should be available for people living with dementia in your community and what stops people from your community accessing dementia/social care services. The discussions were facilitated by two members of the organising team (community engagement workers), with at least one facilitator having relevant language skills. The main points of the discussion were noted down by the facilitators in English. As well as discussion groups, attendees participated in a multiple choice quiz containing 8 questions about the nature of dementia and available services which served as a quantitative indicator of levels of knowledge. The quiz was devised by the community event organisers as an enjoyable icebreaker to start the event and also provide a measure of current community understanding. Each quiz question was asked by facilitators in English and community languages and the number of true and false responses (indicated by

attenders holding up coloured cards) noted. The quiz format overcame problems associated with a traditional questionnaire as participants were not required to read or write.

Data analysis

The data obtained from the discussion groups was combined to form one data set for each ethnic group. Framework analysis (Ritchie & Spencer, 2002) was used to analyse data related to perceptions of dementia using a priori themes drawn from Leventhal's model. Data about service use was analysed using inductive thematic analysis (Braun & Clarke 2006). Coding was carried out by the first author and an experienced qualitative researcher external to the team. The external researcher was unfamiliar with the theoretical model and acted as second rater to check the coding. Her coding was consistent with that of the first author. Internal team discussions also facilitated the data analysis process. Throughout the analytic process, constant comparisons were made between ethnic groups to identify similarities and differences in perceptions. Frequencies and percentages were calculated for data obtained from the quiz.

Findings

The roadshows were well attended by people with dementia, carers and members of the community. The British Indian roadshow was attended by 62 people who were divided into 6 discussion groups. Five discussion groups were held in the African and Caribbean roadshow with a total of 50 participants. The East and Central European roadshow was attended by 63 people and eight discussion groups took place. The findings from the discussion groups are presented below, under three main themes. Firstly we present the framework analysis of perceptions of dementia (organised under domains from Leventhal's self-regulation model). Then we present the inductive thematic analysis of community awareness of dementia and

service use. Direct statements from participants are given in quotation marks. The data obtained from the quiz are presented at the end.

Perceptions of dementia

Illness identity and coherence

The groups were asked ‘*what is dementia?*’ in order to generate signs and symptoms of dementia. The following were the most common responses in each cultural group:

“Brain confusion. Illness of the brain” (Indian group)

“Dying of brain cells”(African and Caribbean group)

“Sickness of the brain. Bits of your brain stop working” (East and Central European group)

All groups associated dementia with having memory problems, and when a word did not exist for dementia in the community language, dementia was referred to as “*memory problems*”. The groups commonly noted “*memory loss*” and being “*forgetful*” as symptoms of dementia. African and Caribbean groups and East and Central European groups further attributed confusion of names and places and regressing back to childhood (“*takes you back to childhood*”) as symptoms of dementia. However both these groups stated they had a lack of knowledge with regard to the signs and symptoms of dementia. The Indian group in contrast associated aggressive behaviour and physical symptoms, such as loss of appetite and mobility problems, with dementia. In addition people with dementia were perceived to be “*unhygienic*” by the Indian group.

Cause

All three groups attributed a biological cause for dementia and mentioned loss of brain cells and dementia as being an illness of the brain. The African and Caribbean group highlighted a possible genetic link with a number of people asking: “*Can’t it be inherited?*” Further

potential causes were thought to be bereavement: “*Can dementia be triggered by bereavement?*” and also a result of medicine: “*Certain medicine can create side effects which lead to dementia i.e. blood pressure medication*”. The East and Central European group believed dementia was caused by old age. The Indian group thought family stress and worry caused by family issues may be a contributory factor in dementia (“*Have stress from family which contributes to dementia*”).

Timeline

Although this was not discussed at length, all groups were in agreement that dementia is a progressive condition that gradually worsens (“*Does not get better*”). The participants did not discuss or mention young onset dementia.

Consequences

The three groups talked about various consequences of dementia for the person with dementia and the wider family. The Indian group focused on the consequences dementia had on the family particularly when the diagnosis became known in the wider community, as opposed to consequences for the person living with dementia. The diagnosis was thought to create stigma for the family and as long as the diagnosis was kept in the family, the consequences would not be as significant: “*In a family it’s ok, if in the company of others more impact*”.

For the African and Caribbean group, the consequences focused upon the person with dementia “*getting lost*”. The East and Central European group discussed the loss of independence for the person living with dementia as a consequence of the condition and also the isolation caused by dementia: “*People with dementia do not have friends*”.

Personal and treatment control/cure

Both the African and Caribbean and the Indian groups focused on religion and spirituality as methods for personal control noting, *“religion is helpful”*. The Indian group perceived pride and independence in being able to manage (*“I can manage”*) and also highlighted the need for spiritual treatment in managing dementia. The East and Central European group focused on keeping the person living with dementia’s mind active and suggested the use of *“brain activities”* such as cross words and word searches: *“Need to stimulate people’s memories such as reminiscence work”*.

Emotional representations

All groups discussed the *“embarrassment”* associated with forgetfulness by the person living with dementia. In addition, the Indian group also discussed the shame and guilt associated with dementia, perceiving the condition to be *“damaging to self respect”*, though it was not clear whether these emotional representations extended also to family members. The East and Central European group attributed a number of emotional representations to the person living with dementia such as the person feeling angry, depressed, confused, lonely, frightened and perhaps ashamed: *“Some people are ashamed to admit they have memory loss”*.

Family and community attitudes and awareness of dementia

All groups thought that families withdrew from the wider community network when someone was diagnosed with dementia and this was due to wanting to hide the diagnosis from others: *“Not easy to admit you have dementia or a relative with dementia”* (East and Central European group). The Indian group felt that the extended family failed to acknowledge the condition and often families did not consider the needs of the person living with dementia: *“Family and carers don’t take the view of people cared for”*.

All groups also discussed the lack of awareness and knowledge of dementia in their communities. It was thought that people were not interested in dementia until it personally

affected them and many did not discuss the condition due to the stigma in the wider community: “Dementia is a taboo subject; people are ashamed to speak about it” (African and Caribbean group). The East and Central European group thought many in the community were frightened of dementia. The Indian group perceived dementia to be “tolerated” in the community but acknowledged the lack of understanding and how dementia was generally thought to be related to old age: “They think it’s do with old age”.

Awareness and use of services

Use of support

All groups primarily relied on support from family, social workers and their GPs. The African and Caribbean, and the East and Central European groups also cited a number of third sector organisations such as Alzheimer’s Society, Age UK and local day centres as sources of support. The African and Caribbean group also made use of religious support from their church.

Negative Experiences of services

All groups perceived a lack of awareness and cultural sensitivity from services particularly from GPs. Many perceived that their GPs lacked dementia knowledge and were too busy to provide the care and support people required. Some had experienced negative interactions with their GPs: “GP not interested and won’t refer to assessment clinic” (East and Central European group); “No awareness, not even in GP surgery” (African and Caribbean group). The East and Central European group further discussed negative experiences with care homes not meeting their needs, and also expressed the view that more equality in access to services was required: “[Need] More respite places in nursing homes – not well looked after”.

What should be available:

All groups said that they wanted more support and understanding from their GPs: “*GPs need more training as first contact point, not to feel one is being fobbed off*” (East and Central European group). They also felt that more support groups should be set up for carers, and services should be based on the cultural needs of the community and should provide language support. However, services should seek to maintain high standards of confidentiality when employing translators. In addition groups wanted more information with regard to the causes of dementia and potential preventative measures and also the legal aspects around dementia such as power of attorney. The groups also stated that more health care professionals who understood their culture were needed.

“*Having workers who are Black who understand Black people*” (African and Caribbean group)

Barriers to accessing support

All groups cited cultural stigma as a main barrier to service access, e.g. the Indian group perceived use of services as “shameful” and the East and Central European group thought using services was “embarrassing”. The groups also saw language as a major barrier, e.g.: “*Language is important as people go back to first language*” (East and Central European group). In addition, the African and Caribbean, and the East and Central European groups also cited lack of knowledge and awareness of services. All groups perceived GPs to be gatekeepers to services and thought GPs should be more proactive in referring them to services. The Indian group reported the extended family and religion as presenting additional barriers to service use (“People’s perceptions what people will think?! Izzat (respect for) religion stops you accessing services”) and the East and Central European group focused on the practical barriers such as finance and transport.

Knowledge and use of services

The results of the multiple choice quiz on knowledge of dementia and services are presented in Table 1. This shows a degree of similarity across ethnic groups for some aspects and some striking difference for others. A third or fewer in each group felt they would be able to identify the signs and symptoms of dementia, with fewer in the African and Caribbean groups feeling they had knowledge than in the other two groups. The vast majority (over 70%) of every group felt there was insufficient information available in their community; most did not know how to access social services for support and were not aware of specific services. The belief that people with dementia usually become aggressive was held by a considerable proportion in every group, and the majority in all groups felt that people with dementia have the same needs as young children, with both these beliefs being more widely held in the Indian group. The Indian group were also more than twice as likely as the other two groups to believe that everyone who is old has a poor memory.

Insert Table 1 about here

Discussion

This paper focuses on perceptions of dementia in minority ethnic groups in the UK (Indian, African and Caribbean, and East and Central European) utilising Leventhal's (1992, 1980) Self-Regulation Model of Illness as a theoretical framework. Interestingly all groups perceived a lack of knowledge with regard to dementia but predominantly saw dementia as comprising cognitive dysfunction (memory loss and confusion) and having a biological basis (loss of brain cells), in line with the conventional biomedical model. Alongside these beliefs, approximately half of the Indian group continued to believe that memory loss was inevitable in old age, and ageing was also cited by the East and Central groups as a cause. In addition, some believed that bereavement or stress might cause dementia. The inclusion of organic causes as a primary explanation in all three groups, contrasts with previous research (see

review by Johl *et al.* 2014) which reports carers as perceiving dementia as a normal part of ageing. It was notable that despite some understanding of the neuropathology of dementia and recognition of symptoms, many continued to feel unable to recognise signs and symptoms, and some continued to perceive dementia to be a normal part of ageing. The findings are similar to studies with white British samples, with cognitive deficits being cited as symptoms of dementia but cause being attributed to stress (Hamilton-West *et al.*, 2010), participants regarding their difficulties to be a part of normal ageing (Clare *et al.*, 2006) and perceiving dementia to be a progressive condition (Harman & Clare, 2006)

The use of religious and spiritual practices was a common theme among the Indian, African and Caribbean groups as a form of personal and treatment control. The Indian group in addition identified religion as a barrier to health care service use. It is worth noting that in the current discussion groups, minority ethnic groups did not state a preference for religious and spiritual treatment, over and above support from services.

Interestingly although it has previously been assumed that South Asian families have a large extended network of family members who 'look after their own', (All Party Parliamentary Group on dementia, 2013) many of the Indian group reported that the strong stigma attached to dementia meant that it was often concealed from the wider family, and that wider family networks were not supportive. In some cases they perceived the stress caused by family members to have caused the dementia. The presence of stigma attached to dementia and significant perceived consequences for families has also been found by Parveen *et al.*, (2014), in a wider sample of South Asian people; and Mackenzie (2006) also reports significant consequences for South Asian families where a member has been diagnosed with dementia, such as being ostracised from the community. Furthermore Mukadam *et al.* (2011) report the experiences of shame and stigma in the community as a barrier to accessing services.

We noted that the Indian group were particularly focused on the consequences of dementia for the family unit such as the stigma and isolation for family, as opposed to the person living with dementia. In contrast the African and Caribbean and East and Central European groups reported the consequences for the person living with dementia. The differences in findings between ethnic groups in this regard may be due to higher levels of perceived stigma and also higher levels of familism (a cultural value pertaining to solidarity and loyalty amongst family members) in the Indian group, thus focusing more on the family unit as opposed to individuals. Parveen, Morrison and Robinson (2013) in a quantitative study compared South Asian and White British carers and found South Asian carers had significantly higher levels of familism. There has been no equivalent research exploring cultural values in the East European or African and Caribbean populations in the UK but it may be that these groups subscribe more to the cultural value of individualism. We found that both East European and African and Caribbean groups placed greater emphasis on the consequences for the person affected, in terms of losing their independence.

All groups perceived lack of awareness with regard to dementia in the wider family and community. The use of support was reported to be limited by all groups, due to lack of awareness of existing specialist dementia services, with reliance on family and on third sector organisations for East and Central European and African and Caribbean groups. Negative experiences with GPs were reported by all three ethnic groups. Such negative experiences of health care services by minority ethnic groups are well documented and it is suggested that these may be a major contributory factor in their late presentation to specialist dementia services (Mukadam *et al.* 2011). Reported barriers to accessing services, such as language and cultural issues, were found to be similar to those reported by Greenwood *et al.* (2014). However, the lack of service use and reliance on family should not be taken as indicating that

minority ethnic groups do not require services, as the groups in this report stated a desire for more culturally appropriate services based in the community.

Implications for policy and practice

Based on this exercise, and findings of the three studies with white British samples, Leventhal's Model of Self-Regulation appears to be a useful framework for identifying specific (mis-)conceptions about dementia which could inform the development of tailored dementia awareness work. The findings reported in this paper suggest that despite a potential shift in perceptions there remain a number of misconceptions with regard to dementia amongst minority ethnic groups in the UK, such as that people living with dementia are unhygienic, aggressive and have the same needs as children. This suggests further dementia awareness raising work is required with a particular focus on a person-centred understanding of dementia. In addition, participants held misconceptions with regards to causes of dementia, with stress and old age highlighted as potential causes. Many expressed an interest in receiving more information about causes and how to reduce risk. This suggests the development of culturally sensitive health promotion interventions would be beneficial. However it is clear that raising awareness of the nature of dementia within minority ethnic communities alone will not be sufficient to facilitate help-seeking behaviours. A significant barrier to seeking help is that many are not currently aware of existing specialist dementia services. A recommendation for service providers would be to participate in community engagement work to promote their services at 'the ground level'. Minority ethnic groups also perceive a number of culturally-specific barriers to service use, and help-seeking behaviour will not increase until such barriers are overcome. Recommendations for reducing cultural barriers include: training and employment of more minority ethnic staff in services, and use of interpreters who at least a basic level of dementia training. It is also vital for all

staff to have cultural competence as well as being clinically skilled and knowledgeable regarding dementia.

Strengths and Limitations

Although the findings of this exercise have a number of implications for policy and practice, a number of limitations are acknowledged. The current work capitalised on naturally occurring data from discussion groups at community events rather than purposefully recruiting participants for a research study, although we would argue that this allowed us to capture a wider range of views than might be accessed if recruiting to a conventional research project. The analysis was conducted on written notes made by group facilitators rather than being based on recordings and transcripts. We are therefore not able to contextualise the findings as no information was collected with regard to age, gender or socio economic status of participants. Also we did not include a White British sample, and therefore have had to draw conclusions about aspects that may be culturally specific by relying on comparison of our findings with those of other studies on illness perceptions of dementia. In addition, two of the three groups in the roadshows included ethnic diversity and a number of nationalities and languages and there may have been many significant differences between sub-groups. Furthermore the groups and quiz occurred in a social setting, so the influence of social desirability cannot be discounted.

Despite the limitations, the data provides information from larger samples of people from minority ethnic groups in the UK than has been usual in past research, from a wider range of minority ethnic groups and possibly wider ranging community samples. By including people living with dementia, carers and general members of the community, we were able to gain a more rounded view of perceptions in minority ethnic communities.

Conclusion

Our findings suggest that perceptions of dementia may be changing amongst minority ethnic communities with regard to illness identity and cause. However, perceived consequences and control strategies were heavily culturally influenced leading to there being a number of persisting barriers to the use of mainstream dementia services. Work to raise dementia awareness in minority ethnic groups needs to continue to reduce misconceptions and associated stigma, but also further emphasis is needed on developing culturally appropriate services in order to remove barriers to the use of specialist dementia services.

Conflict of interest: None

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Table 1. Data obtained from the quiz with regard to knowledge about dementia and services.

Percentage responses are presented for each group.

Quiz question/response	British Indian (n=62)	African/Caribbean (n=50)	East and Central European (n=63)
<i>How much do you know about dementia?</i>			
A lot	25.5%	5.9%	11.8%
Some knowledge	55%	76.5%	62%
Nothing	19.5%	29.4%	26.2%
<i>Could you recognise the signs and symptoms of dementia?</i>			
Yes	34%	23.5%	23.8%
No	11.7%	2%	25.5%
Unsure	54.3%	74.5%	50.7%
<i>Everyone who is old has a poor memory?</i>			
True	59.5%	25.5%	23.5%
False	40.5%	74.5%	76.5%
<i>People with dementia have the same needs as young children?</i>			
True	93.6%	61.8%	72.5%
False	6.4%	38.2%	27.5%
<i>People with dementia usually become aggressive?</i>			
True	61.7%	55.9%	49%
False	38.3%	44.1%	51%
<i>Do you feel there is enough information available in your community about dementia?</i>			
Yes	6.4%	5.9%	29%
No	93.6%	94.1%	71%
<i>Are you aware of how to access social services for support?</i>			
Yes	23.4%	29.4%	43%
No	76.6%	70.6%	57%
<i>Are you aware of specific services for people with dementia?</i>			
Yes	8.9%	35.3%	29.4%
No	91.1%	64.7%	57%