ConnectED Briefing #22

# Working with ethnically or racially minoritised people with dementia or mental health needs: Barriers to accessing social care services

## The issue

People who are minoritised because of their ethnic or racial identity experience inequalities in the care they receive, and they are less likely to approach services for support.

## What we wanted to find out

What barriers are experienced by people from ethnically or racially minoritised groups and their carers in accessing adult social care services in the UK? Two linked briefings present implications for practitioners and those involved in commissioning or developing services.

## What we did

We searched Web of Science, SCOPUS, Google Scholar and the NIHR Evidence website for relevant reviews exploring barriers to access for people from ethnically or racially minoritised groups published since the implementation of the Care Act 2014, and for relevant recent single studies published after these reviews (2022 onwards) or not included in them. We excluded studies not conducted in the UK, those which focused primarily on health rather than social care services, and those not relating to people with mental health needs or those living with or caring for someone with dementia.

## What we found

We found one rapid realist review exploring the experiences and needs of minoritised communities when seeking to access social care[1] and eight reviews that synthesised respectively the experiences of people with mental health needs,[2-5] unpaid carers,[6-8] and access to dementia care.[9] Systematic reviews of both quantitative and qualitative research examined Pakistani women's use of mental health services,[10] and barriers to access and carers' satisfaction with social care services in the community.[11] Finally, a scoping review looked at evidence around language and culture for caregiving of people with dementia in care homes.[12]

We found five additional qualitative studies not included in any of the reviews. These covered a survey on care and support provision for older women,[13] people's experiences of direct payments,[14] managing eating and drinking for people with dementia at home,[15] experiences of South Asian family carers for people with dementia,[16] and South Asian older adults' access to dementia care.[17]

## What the evidence suggests

### Stigma

Research suggests that stigma of all kinds may be more keenly felt by people who are ethnically or racially minoritised, because they experience both the stigma relating to their care and support needs (for example, mental health or dementia), and to their race or ethnicity. This ‘double-stigma’ can present a significant barrier to them seeking and accessing care and support.[2,4-7,10,11]

In some communities a dementia diagnosis may be kept within the family, with family members concealing the condition because of feelings of denial, guilt, fear, embarrassment or shame.[7-9]

Some people feel shame about having a mental illness[2] or fear being given a psychiatric ‘label’.[4,5] They may be afraid of isolation from family members or others in their community.[2,3,5] They may worry that a diagnosis will damage their social standing or that of their family.[10] Within some South Asian communities there may be fears about a diagnosis of mental illness affecting marriage arrangements.[17] In some groups, accessing formal support for mental health problems is not viewed as the norm.[2,5,10] Cultural or religious beliefs may lead individuals to feel they are not ‘allowed’ to be ill, to disclose mental illness, or to seek help.[3]

Carers can also experience shame and stigma associated with the needs of the person they care for; they may fear isolation from their community [6,7,11] and therefore not seek help from services.[6,11] Some family carers of people with dementia feel guilt and shame if needing to access help for their parents, viewing this a sign that they have failed in their familial duties.[7] A cultural expectation that family members will provide support can lead to people only seeking help at crisis point.[1]

## People’s experiences and perceptions of professionals or services

People’s perceptions and their experiences of discrimination or systemic inequality can affect their willingness and confidence to engage with social care services.[2,3,5-9]

Practitioners should bear in mind that people may view services as white, Eurocentric or racist.[3,4] They may feel they are not a ‘safe’ space in which to discuss sensitive issues.[2,3] Historical over-representation of African Caribbean people in the mental health system has led to their informal carers not wishing to engage with services.[8] Some people also report experiences of a lack of respect for non-western religious or spiritual beliefs.[4,5]

People describe professionals as being unwilling, or lacking the time or necessary understanding to talk about how aspects of a racial or cultural identity might impact on care and support.[1,3,4] For example, South Asian interviewees in one study said that professionals asked only about the mental illness and not about how their cultural identity impacted upon it; some also felt that professionals did not appreciate the importance and value of the family.[5]

Mistrust of government assistance and fear of allowing ‘outsiders’ into the home has been linked to fear of racism, previous negative experiences and to a perception of a lack of culturally appropriate choice.[9] Research in this area illustrates the diversity of perspectives among people and groups of people who are ethnically or racially minoritised: for example, people in some Arabic communities viewed another person coming into the home to assist with personal care as unacceptable;[9] other research uncovered how, in one South Asian Indian community, people talked more positively about the service delivering care when they had built trusting relationships with individual care workers, while negative feelings were more closely linked to their perceptions of the service as a whole.[1]

### *Cultural ‘matching’*

Limited availability of care workers means that people may not be supported by professionals who match their language or religion.[1,14] For some carers a lack of services provided by someone of the same ethnicity was seen as a barrier to seeking support.[11] However, while some people will prefer to see a practitioner from their own culture,[1,10] others express concerns about confidentiality if culturally ‘matched’ with a practitioner from within their community.[1,5,10]

### *Choice and culturally appropriate provision*

Services were sometimes viewed as providing limited choices of support to fulfil cultural needs.[2,3,5,14]

Food is important in many cultures and people often prefer familiar food cooked in traditional ways.[1] Families may be reluctant for family members to be placed in care homes where suitable food is not available, and there is a perception of a lack of culturally appropriate food available for home delivery.[15]

Some carers fear feeling diminished by services that do not understand their cultural needs or those of the cared-for person.[7] They may be reluctant to approach services because they anticipate delays in accessing them, lack of availability of appropriate support, high cost, and language barriers.[16] They are concerned that services or care settings will not be culturally or religiously appropriate,[8,11] and that care packages might not respect cultural, religious and personal values.[16] For example, some carers choose not to access support, believing that services will not be sensitive to or able to meet their cultural needs,[7] and some report finding conversations on intimate topics such as continence difficult for cultural reasons.[11]

### Awareness and understanding of care needs and the social care system

People who are ethnically or racially minoritised describe not being aware of what services are available to support them with their mental health,[1,2,4,10] with dementia,[9,17] or with unpaid caring roles.[7,11] For migrants or refugees, systems and services may be very different from those experienced in their country of origin.[1] Confusion about health and social care systems and services, terminology and paperwork could lead people to give up attempting to access support.[8] They may have to rely on others within the community to act as navigators or to signpost them to services.[1]

People may differ in their understanding of, and beliefs about their need for support, and the form that support should take. For example, in some minoritised groups mental health difficulties are viewed as less serious than, or not as ‘real’ as, physical health problems.[2,3] Some people may look to non-western knowledge to help them understand mental health conditions and may distrust services based around the western medical model.[3] In some communities, dementia is seen as part of the normal process of getting older and people may lack knowledge of its symptoms.[6,9,17] Some carers of people living with dementia felt that if they provided better care the person would improve.[7]

In some groups (including Pakistani and South Asian communities) there is a strong reliance on family structures,[2,5,10] with family dynamics and responsibilities affecting whether both men and women are likely to seek outside support. Minoritised carers reported feeling that they (rather than outside services) were best placed to take on the caring role, citing motivations such as love, responsibility and religious duty.[7] Some did not see a need for outside help,[11] or (for example, children of South Asian parents), saw the caring role as a normal extension of existing familial responsibilities.[6,8] Research has noted that Pakistani women expected to ‘cope alone’ with mental health difficulties.[10]

### Communication and language

Poor availability of information in a preferred language is consistently identified as a barrier to accessing social care support.[1,8,9,13,16] Although translators or interpreters may be available for appointments, some people also need them at other times, to understand letters for example.[1] Lack of access to translators and the quality of translation can affect the provision of support.[1]

Having to call on friends to interpret over a length of time can affect social relationships.[1] People also report conflicts of interest or other difficulties when family members are relied upon for interpretation,[1,5] and concerns about confidentiality when interpreters are provided through community networks.[1]

Not being able to communicate in a preferred language can lead to misunderstandings around care, and to loneliness, distress and agitation for people living with dementia in care homes.[1,2]

## Quality and completeness of the evidence

We are moderately confident that we have reviewed the best current evidence relevant to our question. However, research in this area is still limited and has historically been focused on understanding people's access to health services, rather than social care.

Some studies examined the experiences of people identifying with particular ethnic or racial groups; others attempted to understand the experiences of ethnically or racially minoritised people as a whole. Practitioners may wish to seek out research that relates specifically to the identity of the individual they are working with.

People's access to social care is also affected by their socio-demographic characteristics, life experiences, gender, and their age, health or disability status. These intersectional aspects must be considered alongside their ethnic or racial identity.

## Further resources

Two linked ConnectED briefings accompany this one: #23 *Working with ethnically and racially minoritised people with dementia and mental health needs: Best practice for social care practitioners* and #24 *Working with ethnically and racially minoritised people: Best practice when commissioning services*.

On person-centred care: Research in Practice (2024) *Delivering person-centred care for the UK's culturally diverse communities: Frontline Briefing* https://www.researchinpractice.org.uk/adults/publications/2024/august/delivering-person-centred-care-for-the-uks-culturally-diverse-communities-frontline-briefing-2024/.

On 'intersectionality': Research in Practice (2024) *Equity: Change Project,* https://www.researchinpractice.org.uk/adults/content-pages/change-projects/equity-change-project/.

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