ConnectED Briefing #24



Working with ethnically or racially minoritised people with dementia or mental health needs: Best practice when commissioning 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 is known about how best to commission services for people from ethnically or racially minoritised groups who have mental health needs or who are living with or care for someone with dementia?

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 focusing 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 nine reviews and four qualitative studies. The reviews included one rapid realist review exploring the experiences and needs of minoritised communities when seeking to access social care services¹ and eight reviews that synthesised respectively the experiences of people with mental health needs,²⁻⁵ unpaid carers,⁶⁻⁸ and those seeking access to dementia care.⁹ A scoping review looked at the subject of language and culture for caregiving in care homes.¹⁰

The qualitative studies covered a survey of care and support provision for older women from minority ethnic backgrounds, ¹¹ people's experiences of direct payments, ¹² managing eating and drinking for people with dementia at home, ¹³ and experiences of South Asian family carers for people with dementia. ¹⁴

What the evidence suggests

When commissioning services, it is important to acknowledge publicly the existence of systemic and other barriers faced by people from ethnically and racially minoritised groups needing to access support and the effects of these.^{1,2}

Research highlights the variety of experience within and between different groups and individuals from those groups. Person-centred approaches provide an effective way of working with difference, and of addressing the specific needs of people and their families.^{1,2,12} Such approaches require recognising and acknowledging individual differences within and between people from minoritised groups when commissioning and developing services.^{1,2}

Awareness and communication

Ensure that front doors to services are visually, textually and verbally inclusive.¹

Translate written resources so that they are inclusive of and accommodate the diverse languages of minoritised groups.⁸ Be aware that within and between communities, peoples' communication preferences may differ. For example, in one area, the Somali community preferred spoken communication over written information and suggested audio information or WhatsApp as alternative methods of reaching people.¹²

Communication with people using services will be improved through the use of professional interpreters or translators familiar with the individual's language and/or dialect; services should not rely on family members or friends for translation. Recruiting bilingual and dialect speakers could support people to access services and help provide a more personal service. 1,9

Working with voluntary sector, community, and grassroots organisations

Consider working with community or religious leaders,² forming partnerships with grassroots organisations and funding existing smaller valued community services,^{2,3,5} as well as supporting peer-delivered interventions⁵ or user-led organisations.¹ For people living with dementia, support offered to groups (or 'clubs') meeting in non-institutional settings may help build trust in care providers.

Because people may view voluntary sector organisations as more culturally aware than statutory services, services should link into these and existing community networks.^{1,8}

Cultural and ethnic matching

When care workers share a common culture and background with the person they are supporting, this can improve communication and trust.¹ For example, having a shared religion may mean that a person or their informal carer does not have to explain rituals for praying or washing to care workers.¹ In care homes, language matching may facilitate understanding and opportunities for social stimulation and increased happiness of residents.¹⁵

However, ethnic or cultural matching may not always be the right response.^{1,5} It may be more important to ensure that professionals have, and can communicate, a good understanding of the person's cultural background, rather than being 'matched'.¹

'Bridge' people

Formally-recognised bilingual advocates may help by acting as 'bridges' or 'navigators' to services. For example, one study showed how older Chinese people valued the role played by bilingual and bicultural 'bridge people' (either family and friends, or public sector or community workers) who arranged appointments or transport, or provided interpretation, advocacy, and companionship. 1

Long-term care services and care settings

In care homes, where a mismatch between the cultural values of a person living with dementia and the practices of the home can cause loneliness and distress, activities that provide cultural congruity (for example, hosting culture-specific festival days) can support social stimulation, calmness and understanding.¹⁰ Access to culturally appropriate food is important. Long-term services for people with dementia should provide food and nutritional advice in line with people's cultural values and beliefs.^{9,13}

Culturally-tailored services for carers

Services should avoid cultural assumptions that can create social exclusion, such as that families will prefer to provide care themselves. Seeking the views, experiences and outcomes

of ethnically minoritised carers and those they care for would help commissioners to better understand the impact of ethnic inequalities and issues such as migration, culture and religion. This could help commission and develop services that align with what families want and complement what families can offer themselves, as well as encouraging communication and trust. For example, services could be designed to include culturally tailored modifications that align with religious or cultural beliefs, such as when providing end-of-life care for a person with dementia.

Providing culturally tailored information and psychoeducation on conditions such as dementia, could help to address a lack of understanding that can cause some people to feel stigmatised.⁶

Quality and completeness of the evidence

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

Some studies examined the experiences of people identifying with a particular ethnic or racial group; others attempted to understand the experiences of ethnically or racially minoritised people as a whole. Practitioners are encouraged 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 should be considered alongside their ethnic or racial identity.

Further resources

Two linked ConnectED briefings accompany this one: #22 Working with ethnically and racially minoritised people with dementia and mental health needs: Barriers to accessing social care services and #23 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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- 10 Martin, C., Woods, B., and Williams, S. (2019) Language and culture in the caregiving of People with dementia in care homes what are the implications for well-being? A scoping review with a Welsh perspective. *Journal of Cross-Cultural Gerontology*, 34(1), 67-114.
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- 12. Dunnion, M. (2023) *Direct Payments and People from Black and Asian Minority Ethnic Communities: Summary Report.* Birmingham: IMPACT. Improving Adult Care Together.
- 13. Nair, P. et al. (2022) Experiences of carers and people with dementia from ethnic minority groups managing eating and drinking at home in the United Kingdom, *Nutrients*, 14(12), 2395.
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