

The purpose of this paper is to give an overview of equality issues and dementia. The focus is evidence of effective interventions to raise awareness of dementia among different population groups with characteristics protected by the Equality Act 2010.

Key messages

In Scotland, it is estimated that approximately 9% of the population over the age of 65 years have a diagnosis of dementia. A small percentage (<0.2%) of people under 65 years are also affected.

National policy supports timely diagnosis of dementia in order to facilitate access to treatment, information and support for people with dementia and their families.

This review found a lack of evidence of effective interventions that raised awareness of dementia in different population groups with protected characteristics as defined by the Equality Act 2010.

An individualised care approach that recognises all aspects of people's identity, such as race, religion and sexual identity, is essential to encourage early help-seeking among different population groups.

More research is needed to examine the most effective ways to raise awareness of dementia amongst different population groups.

Dementia

The term dementia is used to describe a syndrome associated with ongoing decline of brain function. Common symptoms are memory loss, difficulty with thinking and understanding, and decreased language skills and judgement. The most common type is Alzheimer's disease but other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Mixed pathologies are common.¹

In Scotland, it is estimated that approximately 9% of the population over the age of 65 years have a diagnosis of dementia (n=86 666). A small percentage (<0.2%) of people under 65 years are also affected (n=3213).²

Even though there is no cure for dementia, treatment is available that can help people cope better with their symptoms and improve the quality of their own and their families' lives. National policy supports timely diagnosis of dementia in order to facilitate access to treatment, information and support for people and their families.³

Socio-economic inequalities

There are few large scale studies that have looked at social inequalities in dementia.⁴ Currently, there is limited evidence that suggests that dementia is socially patterned. In a meta-analysis of eleven community-based cohort studies, Russ et al⁴ observed an association between lower occupational social class and dementia death in men, but not in women, after adjustment for alcohol consumption, smoking, cardiovascular disease, diabetes, psychological distress and age of leaving full-time education. However, this association was not statistically significant.

Given that it is known that health inequalities persist into old age and that many of the risk factors for dementia (Box 1) are associated with socio-economic disparities in mortality and morbidity, it is possible that as the age structure of the population changes social patterning in dementia may

become apparent.¹ Alternatively, it may be that people suffering the worst health die before dementia is diagnosed.

Box 1: Risk factors for dementia¹

Age	Hypertension
Genetics	Diabetes
Head Injury	High cholesterol
Education and occupation	Atrial fibrillation
Obesity	Anxiety
Smoking	Depression
Alcohol misuse	Social isolation
Physical inactivity	

No information was found about effective interventions to raise awareness of dementia in different socio-economic groups.

Equality

Age

Age is a known risk factor for dementia. As people get older they are more likely to experience dementia. Estimated prevalence rates increase from 0.1% of people under the age of 64 years to 15.9% of people aged over 90 years (Table 1).⁵

Table 1: Estimated prevalence rates of dementia by age group⁵

Age	Estimated prevalence
20–64 years	0.1%
65–69 years	0.7%
70–74 years	1.4%
75–79 years	3.1%
80–84 years	6.4%
85–89 years	10.5%
90+ years	15.9%

In the next 20 years it is predicted that the numbers in the population who are over 65 years will increase significantly, with a disproportionate greater increase of people in the oldest age groups.⁵ As a result, it is likely that numbers of people with a diagnosis of dementia in Scotland will increase markedly.

No information was found about effective interventions to raise awareness of dementia in different age groups.

Gender

Prevalence estimates suggest that women are at increased risk of dementia (Table 2).⁵

Table 2: Estimated prevalence rates of dementia by age group and gender⁵

Age	Estimated prevalence	
	Male	Female
20–64 years	0.1%	0.1%
65–69 years	0.6%	0.8%
70–74 years	1.3%	1.5%
75–79 years	2.8%	3.4%
80–84 years	5.2%	7.2%
85–89 years	7.6%	11.9%
90+ years	10.2%	17.8%

This may reflect the longer life expectancy of women.⁶ However, the age at which the current cohort of older women left full-time education may contribute. The meta-analysis by Russ et al⁴ found an association between the age that women left full-time education and age of dementia death. This association remained after adjustment for alcohol consumption, smoking, cardiovascular disease, diabetes, psychological distress and occupational class. A similar association was not seen for men.

No information was found about effective interventions to raise awareness of dementia in different gender groups.

Gender reassignment

No information was found about people experiencing dementia who had undergone gender reassignment.

Pregnancy and maternity

No information was found about people with a diagnosis of dementia and who were also pregnant.

Disability

Dementia is a leading cause of disability in older people. Many have physical co-morbidities which can impact further on their abilities.⁷

Sensory impairment

People, with sensory impairment, who experience dementia face additional challenges, including an increased sense of disorientation and an increased risk of social isolation. Those with sight loss may suffer from disruptive visual hallucinations.⁶

Down's syndrome

Up to 75% of people with Down's syndrome over the age of 50 years of age will develop dementia.⁶ In general, dementia presents at an earlier age in this population group. Pre-existing cognitive impairment makes diagnosis difficult; symptoms affecting personality, emotion or behaviour may manifest before any change in language ability or memory.⁸

No information was found about effective interventions that raise awareness of dementia amongst groups with pre-existing disabilities. Literacy levels amongst the deaf community are often low, so written information about dementia is not necessarily understood. Information about dementia in British Sign Language (BSL) is scarce.⁶

Race and ethnicity

In Scotland, about 4% of the population identify themselves as from the Black and Minority Ethnic (BME) community.⁹ The majority are from Asian or African-Caribbean backgrounds (Table 3). The age structure differs from the general population; the proportion of people aged over 65 years at the Census in 2011 was significantly less than the Scottish total. However, this is likely to change as people who migrated to the UK in the 1950s and 1970s become over 65 years old.¹⁰

Table 3: Ethnicity by age group¹¹

	Total % (n)	< 65 years % (n)	> 65 years % (n)
Scotland	100% (5, 295, 403)	83.19% (4, 405, 069)	16.8% (890, 334)
White: Scottish or British	92.83% (4, 862, 787)	82.16% (3, 998, 059)	17.78% (864, 728)
White: Irish	1.02% (54, 090)	79.63% (43, 071)	20.37% (11, 019)
White: Gypsy/ Traveller	0.08% (4, 212)	93.28% (3929)	6.72% (283)
White: Polish	1.16% (61, 201)	98.59% (60, 340)	1.41% (861)
Asian	2.66% (140, 678)	95.88% (134, 884)	4.12% (5, 794)
African	0.56% (29 638)	98.76% (29 270)	1.24% (368)
Caribbean or Black	0.12% (6, 540)	95.50% (6, 246)	4.50% (294)
Mixed	0.37% (19, 815)	97.51% (19, 321)	2.50% (494)
Other	0.27% (14, 325)	96.90% (13, 881)	3.10% (444)

The estimated prevalence rates for dementia in the BME community are similar to the general population with the exception of early onset (presenting

before age 65 years) and vascular dementia which have been found to be more prevalent.⁷ However, people from the BME community who experience dementia are less likely to present to services and tend to make contact at a later stage of the disorder.¹²

Evidence from systematic reviews of qualitative research^{12, 13} suggests that barriers to help-seeking for dementia are a) knowledge-related, b) society-related and/or c) healthcare-related:¹⁴

Knowledge-related

In a systematic review, Muckadam et al¹² looked at the determinants of whether and at what point people from BME communities present to services. They found that beliefs about dementia and its aetiology acted as a barrier to help-seeking. Overall, dementia was not seen as an illness for which help could or should be sought. Many believed that cognitive decline was to be expected as a 'normal' part of the ageing process.^{10, 13} Linked to this belief was a perception that nothing could be done even if dementia was diagnosed.

Society-related

Perceptions of the stigma associated with a diagnosis of dementia were identified as a barrier to help-seeking. Equally, with cultural expectations that relatives, particularly women, should care for the older person with dementia, help-seeking may be frowned upon by other community members.¹²⁻¹⁴

Healthcare-related

The general practitioner is usually the first point of contact for people with dementia and their families.¹⁴ Even though members of the BME community access primary care in a similar way to the general population, there is a reluctance to engage with mental health services. Previous experiences of discrimination may be a factor.¹³

Language barriers may contribute to beliefs about the healthcare system; older people from BME communities may have limited fluency and/or literacy

in English. Indeed, they may not be literate in their first language. Many of the assessment instruments used to diagnose dementia rely on literacy and/or English and may be culturally biased.^{7, 15}

There is very little information about interventions that aim to encourage help-seeking or raising awareness of dementia among the BME community.^{7, 13} Good practice examples identified by Johl et al¹³ and Mukadam et al¹⁴ suggest that targeted information that addresses the concerns of the BME community about dementia delivered by a trusted source, such as a community or religious organisation, might have greatest impact. However, whilst similar strategies have been found to improve attitudes to help-seeking for mental health issues, the numbers seeking help did not appear to change.¹⁴ It is likely that different approaches may work better in different communities in different places.⁷ In the published literature, little or no mention was made of minority ethnic groups, such as the Irish or Gypsy/Traveller communities.¹⁶

Religion or belief

Religion is closely associated with race and ethnicity.⁶ No information was found about effective interventions that raise awareness of dementia amongst different religious groups.

Sexual orientation

Very little research has been carried out with members of the lesbian, gay, bisexual and transgender (LGBT) community with a diagnosis of dementia. Information from the limited evidence base about LGBT members' experiences of accessing health and social care services, in general, suggests that previous negative experiences may act as a barrier to early diagnosis of dementia. The current cohort of older people is likely to have experienced prolonged stigma and discrimination from professionals and services.¹⁷

No information was found about effective interventions that raise awareness of dementia in the LGBT community.

Marriage

No information was found about people experiencing dementia differentiated by their marital status.

Conclusion

Overall, there was a lack of evidence of effective interventions that raised awareness of dementia in different population groups. There was limited information available about different population group's beliefs about dementia and attitudes to help-seeking for mental health issues.

Understanding these may be one way to overcome potential barriers that prevent people presenting for early diagnosis. However, published research tended to be limited to small locally-based studies, with the majority based in North America.¹⁰

Recommendations

The following recommendations are based on good practice examples identified by the published literature:^{7, 13, 14}

- 1** An individualised care approach that recognises all aspects of people's identity, such as race, religion and sexual identity, which are important to them, is essential to encourage early help-seeking among different population groups.
- 2** Services for people with a diagnosis of dementia and their families should be culturally competent. A culturally competent service is defined as

'a service which recognises and meets the diverse needs of people of different cultural backgrounds ... It includes, but is not

limited to, making provision for religious and cultural beliefs such as worship, diet and hygiene requirements, catering for communication and language diversity'.^{18 (p2)}

Having staff members from diverse population groups may facilitate understandings of different communities.

- 3 As part of a culturally competent service, the health and social care workforce should receive adequate training in order that they feel confident and competent to deal with language and cultural differences.
- 4 Assessment of people experiencing dementia should be conducted in a culturally sensitive way using assessment instruments that do not rely on literacy and/or fluency in English or are culturally biased.
- 5 It is important to work with local communities of different population groups to develop culturally sensitive information about dementia and available services and to establish effective ways of distributing information.
- 6 More research is needed to examine the most effective ways to raise awareness of dementia amongst different population groups.

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Methodology note

This briefing has drawn together information from a diverse range of literature including academic papers, articles in peer-reviewed publications, reports and information from government along with material from voluntary and advice organisations. The standard of information, detail and evaluation contained across this breadth of material is, therefore, variable. In addition to relevant organisations and government departments, the following databases were searched for review-level information: Cochrane, DARE, Medline, ASSIA/Social Science Abstracts/Psych Articles, Embase and PsychInfo using the search terms 'dementia', 'alzheimer', 'alzheimer's' in combination with 'ethnic*', 'BME', 'minority group*', 'disab*', 'learning disorder*', 'hearing impair*', 'visual* impair*', 'lesbian*', 'gay', 'homosexual*', 'bisexual*', 'transgender*', 'queer', 'religion', 'faith', 'poverty', 'impoverished', 'disadvantaged', 'health inequalit*', 'health inequit*', 'socioeconomic', 'depriv*', 'men', 'women' OR 'young-onset' AND 'raise*', 'raising', 'increase*', 'promot*', 'rise', 'improve*', 'better', 'develop*', 'expand*', 'enhance*' NEAR 'awareness', 'perception', 'knowledge', 'understanding', 'appreciat*', 'recogni*', 'comprehen*'. Reference lists of retrieved articles were searched for additional relevant papers.

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