

# The challenges of achieving timely diagnosis and culturally appropriate care of people with dementia from minority ethnic groups in Europe

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## Abstract

In a just society, everyone should have equal access to healthcare in terms of prevention, assessment, diagnosis, treatment and care. Europe is a multicultural society made up of people who identify with a wide range of ethnic groups. Many older people from minority ethnic groups also have a direct migration background. Several studies have shown that there is a lack of equity in relation to dementia diagnoses and care because equal opportunities do not necessarily translate into equal outcomes. An expert ethics working group led by Alzheimer Europe has produced an extensive report on this issue, a policy brief and a guide for health and social care workers. In this brief summary, the authors/members of the expert working group present some of the key challenges and recommendations for healthcare clinicians striving to provide timely diagnosis and good quality care and treatment to people with dementia from all ethnic groups.

## KEYWORDS

challenges, intercultural, minority ethnic groups, recommendations, timely diagnosis

## Key points

- The number of people with dementia from minority ethnic groups is steadily increasing.
- Timely diagnosis is essential for access to equal and appropriate dementia care for everyone.
- A range of interacting factors and structural discrimination hinders such timely diagnosis.
- Clinicians need access to training and culturally sensitive/fair and appropriately validated screening, assessment and diagnostic tools for people from minority ethnic groups.

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The proportion of older people within minority ethnic groups living in Europe is increasing and many will develop dementia in the next few decades. In 2017, there were an estimated 476,500 people over the age of 64 with a migration background and dementia in the European Union (EU) and the European Free Trade Association (EFTA) countries,<sup>1</sup> with considerable regional differences regarding number and country of origin.<sup>2</sup> The term “minority ethnic group” includes people who do not necessarily have direct experience of migration but nevertheless identify with a minority ethnic group. Timely consultation and diagnosis of dementia amongst minority ethnic groups is essential to ensuring that everyone has equal access to culturally appropriate treatment and care.<sup>3</sup> Although Europe is becoming increasingly multi-cultural, intercultural care and support does not, in most parts of Europe, correspond sufficiently to the needs and wishes of this growing and diversifying population.<sup>4–7</sup> Moreover, 23 out of 35 EU and EFTA countries have a national dementia strategy, of which 13 do not specifically refer to people from minority ethnic groups.<sup>8</sup> Measures are needed to raise awareness about dementia, promote help seeking and living well with dementia, and improve timely and accurate diagnosis and access to appropriate care.

In recognition of the above, Alzheimer Europe set up a multi-disciplinary working group in 2018. This group gradually evolved over three years to include researchers, clinicians, representatives from associations providing intercultural support and Alzheimer associations, from different cultural and linguistic backgrounds and with expertise in the diagnosis, treatment and support of people from minority ethnic backgrounds. Members of the working group were from Denmark, Finland, Germany, Israel, Luxembourg, the Netherlands, Sweden and the United Kingdom. Recognising that this remains a relatively under-researched area and that people from minority ethnic groups are notably absent from much of mainstream dementia research, the group set out to explore the limited research available and to share expertise and experience in order to reach consensus between researchers, clinical experts and other key stakeholders on how to improve intercultural care and support of people with dementia. This was achieved by means of a scoping of the literature, two rounds of face-to-face meetings (in May and October 2018), one virtual meeting (in March 2020) and email exchanges during which the literature, scope, methodology, successive drafts and recommendations were debated. Feedback on the topic and scope of the work was also provided by members of the European Working Group of People with Dementia, as well as by Alzheimer Europe's member associations, in separate meetings in 2018 and 2019. This led to the development of an extensive report on the challenges faced by relevant stakeholders, recommendations, practical guidance for health and social care workers and a policy statement.<sup>9</sup> Clinicians are particularly important in bringing about change but often have to operate within systems that are not conducive to the provision of intercultural treatment, care and support. In this article, we highlight some of the key challenges faced by healthcare clinicians and call for some necessary changes within health and social care, and broader society.

Help-seeking and possible future diagnosis are complex issues involving a range of factors, which cannot be reduced solely to characteristics or qualities of individuals and groups. There are, for example, broad political, historical, economic and social factors which contribute towards potential differences between minority and majority ethnic groups.<sup>3,10</sup> It is important to recognise difficulties with language, literacy and education experienced by many people from minority ethnic groups but to avoid stereotyping. It is also important to recognise the possible experience of prejudice and discrimination (at the interpersonal level and structurally, within healthcare systems) as well as the intersection of different factors (e.g. linked to gender, socio-economic status, employment and housing).

A key challenge is to ensure that people from all cultural groups have sufficient health literacy to recognise basic signs of potential health problems and know where and from whom to seek information and help.<sup>11,12</sup> Several factors affect initial help seeking such as language difficulties, lack of trust, experience or fear of discrimination, dementia not being perceived as a medical condition and stigma.<sup>3,4,7,11,13–15</sup> Some minority ethnic groups already experience stigma, which includes actual or anticipated discrimination. In some communities, the additional stigma of dementia is rooted in religious beliefs and attitudes towards mental disorders, with issues surrounding honour, duty and shame affecting the whole family.<sup>3,11</sup> Different understandings about the cause of dementia may result in some people limiting their help seeking to a spiritual leader rather than a clinician.<sup>9</sup>

Language and communication are key challenges for clinicians wishing to establish a relationship of mutual trust and respect because patients from minority ethnic groups speak a wide range of languages and dialects and many are not fluent in the national language of the country in which they live. Some revert to the language used in their childhood because verbal and non-verbal language becomes increasingly impaired as dementia progresses and the maintenance of proficiency in additional languages increasingly demanding.<sup>16</sup> Others may simply use language differently. Cultural traditions may affect what is expressed or withheld, including willingness to speak about parts of the body or discuss certain issues with male or female clinicians and with regard to gestures and body language. In some cultures, there are strict gender roles and an emphasis on the family unit rather than the individual. Cultural awareness and sensitivity, and the ability to communicate together, are needed to support patients through shared and supported decision-making, ensure that they do not get lost in the system, obtain informed consent, allay possible fears and concerns, ensure equal opportunities and outcomes, and ensure compliance with treatment.

Language is also a significant barrier to diagnosis.<sup>7,17,18</sup> Some studies suggest that people from minority ethnic groups are not being referred to specialists and/or receiving formal diagnoses of dementia.<sup>19–23</sup> One study in Denmark, for example, revealed that only 11% of the expected number of older people from minority ethnic groups with dementia received a formal diagnosis of dementia.<sup>23</sup> A UK-based study comparing the incidence of dementia

diagnosis over time (2007–2015) of people from White, Black and Asian ethnic groups revealed that people from Asian ethnic groups had the lowest proportion of diagnoses, followed by people from Black ethnic groups, and with people from the White ethnic group having the highest proportion of diagnoses.<sup>24</sup> The ethnic groups involved in this study were based on self-reported ethnicity which was then sorted into categories in accordance with Office for National Statistics classification. The authors point out that the lower incidence for Asian people of dementia diagnosis may be due to under-diagnosis but could also be linked to a lower incidence and that further research is needed. An obstacle to such research in Europe is the lack of reliable and comparable data on ethnicity. Although such information is collected in some contexts, as pointed out by the UK Office for National Statistics, “There is no consensus on what constitutes an ethnic group and membership is something that is self-defined and subjectively meaningful to the person concerned.”<sup>25</sup> Ethnic groups are not permanent, inflexible entities but rather open to change and to people moving in and out of them.<sup>26</sup>

Whilst people from minority ethnic groups experience the same symptoms of dementia as people from majority ethnic groups, they sometimes experience them earlier<sup>27</sup> and may describe them differently and have difficulty doing so because of limited levels of education and literacy.<sup>28,29</sup> In addition, GPs may encounter difficulties understanding people from minority ethnic groups (due to differences in language, accent and the manner of expression) and correctly interpreting answers to questions about patients' cognitive and physical functioning. Consequently, clinicians sometimes have difficulty obtaining consent for various investigations (e.g. blood tests and lumbar punctures) that may be needed for the diagnostic procedure.<sup>8</sup>

The lack of access to culturally sensitive screening and diagnostic tools is a major challenge facing GPs and specialists. Tests are often used in languages that patients are not fluent in. Translated versions of the MMSE exist in numerous languages but there is a shortage of translated versions that have been validated on relevant minority ethnic groups in Europe.<sup>9</sup> A cross-country comparison carried out by Nielsen et al.<sup>28</sup> of cognitive assessment instruments in Europe revealed that in most countries, tests were used with people from minority ethnic groups which had not been validated in those groups. It is not sufficient to provide translation or interpretation for tests that have not been validated on people from the relevant communities and that may be culturally biased or inappropriate.<sup>30,31</sup>

Moreover, standard tests for screening and diagnosing dementia have repeatedly been found to be biased with regard to education.<sup>32</sup> Scores may be affected by the number of years' formal schooling that people have had.<sup>33</sup> Many older people from minority ethnic groups (with a migratory background) may have lower levels of education and poor literacy. Some cannot read or write in their first language.<sup>30</sup> Importantly, lack of formal education does not mean that people are less intelligent than others but often that they lack the kinds of skills that are typically acquired through education (e.g. handling writing materials, using computers, managing time and answering questions that may seem irrelevant in everyday life).<sup>34</sup> They are often

unfamiliar with the formal procedures associated with testing.<sup>9</sup> Some tests require drawing or copying skills, fine motor finger movements, visuospatial skills and visually guided motor behaviour (e.g. moving a cursor on a computer screen). Just one to two years' schooling can make a significant difference in performance on some neuropsychological tests.<sup>35</sup>

There is also a risk that the questions and tasks in some tests are culturally biased. They reflect aspects of an environment or culture with priorities, traditions and values that can be alien to people from some ethnic groups, and may require experience or knowledge (e.g. about politics, nature, wildlife, traditions, economic factors, social expectations and religious celebrations) that they do not have. For this reason, it is important that clinicians use tools which minimise the impact of language, education and cultural knowledge (for example the Rowland Universal Dementia Assessment Scale,<sup>36</sup> the Cross-Cultural Dementia screening tool<sup>37</sup> and the European Cross-Cultural Neuropsychological Test Battery,<sup>38</sup> and others currently being developed that have been validated on people from a specific or a wide range of ethnic groups).<sup>9,39</sup>

People should have the right, as is the case in some countries, to be assessed in their best/preferred language<sup>40,41</sup> and this right should be backed up by an appropriate system to ensure that this happens. However, there are clearly not enough trained professional interpreters or health/social care staff across all locations, who can communicate in the person's best/preferred language with credibility and knowledge. There are logistical and financial implications linked to the provision of professional and properly trained interpreters.<sup>7</sup> Clinicians frequently have to rely on relatives as interpreters during consultations and when administering tests<sup>28</sup> but this is not a satisfactory long-term solution.

Using relatives and close friends as interpreters fails to support them in their role as carers and may affect family roles and relationships, especially when the relative most able to fulfil that function is not necessarily the one who would normally be privy to such private information. It also overrides patients' rights to privacy.<sup>9</sup> Moreover, relatives may sometimes be selective about the information and details that they convey either to patients or healthcare professionals.<sup>42</sup> They may also prompt or in some way help their relative to find the right answer. Interpretation is a skill that requires professional training. Being proficient in a particular language is not sufficient and it is essential that interpreters (and clinicians using their services) are knowledgeable about dementia and understand the purpose and the boundaries of interpretation in the medical context (as do medical interpreters of which there are far too few).<sup>9,40</sup>

Promoting equity in the timely assessment, care and treatment of people with dementia from minority ethnic groups is complex and remains a challenge.<sup>5,11,27,43,44</sup> This is partly due to the impact of assumptions, misconceptions, prejudice and unconscious bias, culturally biased tools and the inadequacies of the healthcare system to respond to the needs and indeed the rights of people from different ethnic groups within Europe. Most European studies of relevance to this topic have been carried out in the United Kingdom,

Scandinavian countries, the Netherlands, Belgium, and more recently in Germany and Italy. As more attention is gradually paid to this important topic, a more structured, systematic approach involving rating the quality of evidence and identifying different trends will be needed.

Meanwhile, certain changes need to occur at national and European level and this requires the backing of relevant policy makers. Alzheimer Europe has called on governments to address barriers linked to language and literacy, to make it a right to be assessed and diagnosed in one's best/preferred language and to ensure that assessment and diagnostic tools are culturally sensitive and properly validated. This must be accompanied by standards for professional interpreters and intercultural mediators, including appropriate training curricula and accreditation, as well as guidelines and restrictions for the involvement of lay-interpreters, and measures to increase the number of bilingual or multilingual staff working at all levels in the health and social care profession. Finally, on the basis of the comprehensive overview of the literature and shared experience of the experts in the working group, Alzheimer Europe's expert working group calls on healthcare clinicians to:

- Raise awareness about dementia and improve health literacy amongst minority ethnic groups by developing and using culturally sensitive and appropriate materials. Such materials should respect all perspectives, challenge negative stereotypes, be suited to different linguistic abilities and educational levels and portray people from a range of ethnic communities, and use appropriate methods and channels of communication.
- Build up and maintain collaborative relationships with members of the relevant communities and/or relevant gatekeepers not only to develop but also to implement appropriate tools and materials in these communities.
- Undergo training in cultural awareness, sensitivity and competence so as to improve communication and build a relationship with people from minority ethnic groups, thereby helping ensure timely, accurate and differential diagnoses and treatment of dementia amongst members of minority ethnic groups.
- Use culturally sensitive/fair and appropriately validated screening, assessment and diagnostic tools for people from minority ethnic groups, administered with the help of qualified/trained interpreters (preferably with medical accreditation) when needed. Mere translations are not sufficient.
- Make every effort to enable every person to be assessed and diagnosed in their best/preferred language at no extra charge, and for people to be informed of this possibility.
- Not ask relatives and friends to act as interpreters, except for emergencies or exceptionally, but to consult them during the assessment process if required and subject to the agreement of the person being assessed.
- Be attentive to and address interpersonal and structural discrimination against people from minority ethnic groups within health-care systems.

- Recognise that inequity is not always directly linked to culture but is often inextricably bound to other variables such as income, education and housing.

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#### CONFLICT OF INTEREST

None.

#### DATA AVAILABILITY STATEMENT

Our article is a commentary and we have not used datasets so none of the options seem appropriate or necessary.

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