

Policy briefing on intercultural care and support for people with dementia and their informal carers/supporters

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The issue

People with dementia from minority ethnic groups are not using support and services to the same extent as the general population as a whole, and are notably absent in residential care homes.¹⁻² Those who do, often find services inappropriate or of poor quality. They encounter barriers at individual, societal and structural levels. Governments and other policy makers have a moral and legal obligation, based on the principles of non-discrimination,

human rights, beneficence, non-maleficence, and respect for human dignity and personhood, to ensure equity in the provision of dementia care and services. This obligation is based on governments having signed up to the provisions contained in a range of European and international documents such as the European Convention on Human Rights, the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities to name but a few.

Background

The number of people over the age of 60 in the European Union has risen considerably³ and this trend is likely to continue. Many people who migrated to Europe in the 1960s to 1980s are now reaching an age at which the likelihood of developing dementia is significantly higher.^{1,4} Some ethnic groups are at higher risk of developing dementia, with a

higher prevalence of dementia in certain ethnic groups compared to others having been reported.⁵ Some groups are less visible and their needs and interests risk being further overlooked, such as people from Traveller communities, people from the Deaf community and people from various predominantly White communities, such as Russia and Ireland.

Key facts

- Estimated increase from 7 to 15 million people over 60 in the EU (2010 to 2015).³
- Minority ethnic groups account for 9% of the population of Europe.⁶
- Predicted to rise dramatically within the next few decades.
- Sevenfold increase in the prevalence of dementia amongst people from minority ethnic groups in the next 40 years, compared to a two-fold increase amongst the general population.^{1,7}
- The impairments experienced by people with dementia may result in disability as defined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).^{9,10}
- Estimated 476,500 people over 64 with a migration background and dementia in 2017 in the EU and the EFTA countries.⁴
- In 2019, with over 13 million migrants, Germany had the largest foreign-born population of any country in Europe.¹²
- 23 out of 35 EU and EFTA countries have a national dementia strategy of which 13 do not refer to migration.⁸
- The total cost of dementia care in Europe was EUR 103.3 billion in 2008, of which one third was for informal care.¹³

Challenges related to the provision of intercultural care and support

- **Information about dementia and services**

Materials are culturally biased and not suited to the language, level of education, belief system and values of many people from minority ethnic groups.

- **Culturally biased dissemination of information**

People are not “difficult to reach” if appropriate channels of communication and methods are used. They may, however, be “easy to avoid”.

- **Stigma and shame**

This is more common in some communities and is often linked not only to the person with dementia but also to the direct and wider family. Sometimes, it is linked to religious beliefs; sometimes it is because of negative connotations surrounding terms for dementia or the link to mental disorders, which may result in prejudice and discrimination.

- **The belief that “they look after their own” and do not want support**

Such statements fuel stigma and prejudice, and make it difficult for people who do want support to seek and obtain it. Families that don't use residential care services often care for their relatives at home without sufficient support.

- **People with dementia from minority ethnic groups are absent from research**

Their needs, values and interests are therefore not being considered in healthcare research which will eventually influence service development.

- **Failure to reach carers**

In some ethnic groups there is often a male spokesperson for the family but the care is provided by one or more women. Gender issues need to be considered but without judging.

- **Insufficient focus on religion and spirituality**

Fulfilling care duties is often linked to fulfilling religious and cultural obligations. This can be a source of inspiration and pride but also make family carers reluctant to ask for support.

- **Multiple jeopardy**

Carers of people with dementia from minority ethnic groups may have combined challenges linked to the stigma of dementia and to actual or perceived racism, sexism, ageism, prejudice against migrants, health literacy and lower socio-economic status.

- **Prior experience or the expectation of discrimination and prejudice, and prior experience of poor quality care**

This may hamper help-seeking.

- **Lack of cultural competence of health and social care professionals**

Lack of cultural competence, language difficulties and lack of culturally appropriate and validated tools may result in late or wrong diagnosis of people with dementia from minority ethnic groups and to inappropriate treatment and care.

“ We didn't know about dementia or that there was any help to get... we thought we had to manage on our own.”

(Mohammed, 45-year-old son of a woman with Alzheimer's dementia)

Recommendations

At national level, governments should work together with people with dementia and carers from minority ethnic communities (and if not possible, with key people from the relevant communities) to:

- raise awareness about their needs and wishes,
- set priorities and criteria for culturally appropriate assessment, diagnosis, treatment and care,
- make necessary funds available for nation-wide as well as local services that are sustainable services (avoid focusing solely on pilot schemes and upscale successful local projects where appropriate),
- monitor the development and provision of services and support (access and quality) which correspond to the needs of all members of society,
- ensure that intercultural care and support is meaningfully addressed in all national dementia strategies,
- address barriers linked to language and literacy by:
 - making it a right to be assessed and diagnosed in one's own (or best) language,
 - ensuring that assessment and diagnostic tools are culturally sensitive and properly validated,
 - agreeing on standards for professional interpreters and intercultural mediators, including appropriate training curricula and accreditation,
 - establishing guidelines and restrictions for the involvement of lay-interpreters,
 - making it a right to have access to an interpreter if needed for assessment, diagnosis and care decisions,
 - taking measures to increase the number of bilingual or multilingual staff working at all levels in the health and social care profession (e.g. by creating posts, creating minimum requirements and making such careers more accessible and attractive).
- actively promote cultural diversity in research by:
 - involving people from minority ethnic groups in research funding programmes,
 - requiring their involvement in research ethics committees, and
 - encouraging people from minority ethnic groups to become involved in dementia research as participants, in the context of Public Involvement and as researchers.
- regulate the living and working conditions of live-in migrant carers (salary, time-off, complaints system, health and social care support, care responsibilities in home country),
- address structural and interpersonal discrimination (against people from minority ethnic groups) across the whole health and social care system by:
 - raising cultural awareness, sensitivity and competences across the whole health and social care system through voluntary and on-going professional education,
 - addressing inequity inherent in policies, practices and procedures.

At regional and local level, policy makers should, together with people with dementia and carers from minority ethnic communities (and if not possible, with key people from the relevant communities):

- develop culturally sensitive health and social care materials for awareness raising and information about health and social care and treatment options (i.e. which challenge negative stereotypes, are suited to different linguistic abilities and educational levels and portray people from a range of ethnic communities),
- use appropriate channels of communication to reach, inform and engage in exchanges with people from minority ethnic communities about available care and support (e.g. through community centres, places of worship, sheltered housing and day centres, community radio stations, bilingual support workers and dedicated roadshows),
- promote health literacy amongst minority ethnic groups,
- create incentives for health and social care professionals and be prepared to take disciplinary measures when necessary.

Conclusions – why act now?

The EU is starting a new mandate, including the forthcoming EU4Health programme, which is about promoting the well-being of all people of all ages and ensuring that everyone has access to affordable, high quality healthcare. The “all” and “everyone” mentioned in this goal must include people from minority ethnic groups and their informal carers.

Person-centred care (the gold standard for dementia care) and “reasonable accommodation” (the principle enshrined in the CRPD) cannot be provided or said to have been achieved without cultural awareness, sensitivity and competence.

Cost is not an excuse for inaction. Investing in intercultural care and support by creating a greater awareness

of dementia amongst minority ethnic groups and of the needs of minority ethnic groups amongst health and social care professionals, improving timely diagnosis and developing appropriate services and support, all contributes towards a healthier population (mental, physical and social health), the creation of jobs, the retention of informal carers in the workforce and avoiding the cost of managing crises and premature institutionalisation.

Making a commitment to and investing in intercultural care and support are key steps towards ensuring a just society, one in which people with dementia and their carers, regardless of their cultural backgrounds, can live well and flourish.

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