![Alzheimer Europe logo]

The development of intercultural care and support for people with dementia from minority ethnic groups

![Robert Bosch Stiftung logo]

The development of intercultural care and support for people with dementia from minority ethnic groups

Contents

1. Preface

This report and the accompanying recommendations are the result of work carried out in 2018 in the context of Alzheimer Europe's European Dementia Ethics Network with funding from the European Commission and the Robert Bosch Stiftung. The goal of this work was to explore issues related to the need for and provision of intercultural care and support for people with dementia from minority ethnic groups in Europe. The report is targeted mainly at service developers and providers, health and social care professionals, policy makers and researchers. This is a topic of utmost importance in today's society in the light of the ageing population and the increase in the number of older people from minority ethnic groups with dementia. A sevenfold increase in the number of older people with dementia from minority ethnic groups, for example, has been predicted in the UK. This, combined with reports of a lack of culturally appropriate services as well as low rates of diagnosis, and misdiagnosis of people from minority ethnic groups, are just some of the many factors which highlight the need for action. The topic of intercultural dementia care also fits in with Alzheimer Europe's goal to promote a rights-based approach to dementia care. People from minority ethnic groups have a right to receive good quality and appropriate dementia care and support, starting with timely and accurate diagnosis. This does not always happen and when it does, all too often it is provided within a framework which reflects the cultural traditions, norms and awareness of the majority ethnic group.

The work was carried out by experts in a working group set up by Alzheimer Europe, with input from Alzheimer Europe's member associations and the members of the European Working Group of People with Dementia. The report was circulated for wider consultation from additional experts in the field. A short biography of the members of the working group can be found in Appendix 1 (p. 81), as well as the names of all the experts, by experience or training, who provided feedback. Alzheimer Europe is immensely grateful to the members of the working group who produced this report, to all those who reviewed it and to the European Commission and Robert Bosch Stiftung for their financial support.

A broad review of the literature was carried out in a systematic manner, covering articles in peer-reviewed scientific journals as well as grey literature. Literature solely based on non-European minority ethnic groups was excluded, with the exception of a few published reviews covering a mixture of European and non-European studies. Members of the expert working group and contributors provided additional references to relevant peer-reviewed and grey literature, dissertations and chapters of books which they considered relevant.

One of the challenges was to report what has been learnt from research and experience working with specific minority ethnic groups (e.g. the Pakistani community in Norway, the Moroccan community in Belgium etc.) and to adapt this to a broader understanding of cultural and linguistic diversity across Europe (as well as within the specific groups studied). In this respect, it is important to bear in mind that some minority ethnic groups have been more widely researched than others. According to Nielsen et al. (2018), the largest minority ethnic groups in Western Europe are made up of people identifying with Middle Eastern (especially Turkish), North African (especially Moroccan), Eastern European and South Asian communities but less research is available on the experience of people from the first three groups.

People in socially vulnerable situations (e.g. living in poverty and in poor housing conditions, having difficulties reading and writing etc.) have a greater chance of health disparities but they are often not included in research. This typically includes people from minority ethnic groups who are considered as being 'hard to reach' and as not meeting the inclusion criteria for studies (e.g. because they have an insufficient number of years' education, cannot read or write the main language of the country fluently or have other chronic health conditions). Invitations to take part in research are frequently written in a style that may be difficult to grasp for people with low levels of education and difficulties understanding the official language of the country. It is estimated that 60% of first-generation immigrants in the Netherlands lack proficiency in the Dutch language and consequently, may often be under-represented in healthcare research (Uysal-Bozkir, Parlevliet and de Rooij 2013). Research findings are nevertheless generalised and used to support the development of health and social care provisions for whole populations even though people from minority ethnic groups were not involved and the findings do not correspond to their needs and interests.

An additional goal of this project was to develop a database for the target groups mentioned earlier but also containing information of potential interest to people with dementia themselves and their supporters (e.g. family, friends and informal carers) from minority ethnic groups. As concluded by Bhattacharyya and Benbow (2013) in their systematic review of innovative practice with service provision and policy implications, the identification

and sharing of good practice helps avoid the duplication of efforts and contributes towards replicating established and tested service models elsewhere. This database is an ongoing repository of information, which can be consulted on Alzheimer Europe's website: https://www. alzheimer-europe.org/Ethics/Ethical-issues-in-practice

As this report covers a range of issues of relevance to the promotion of intercultural care and support and is targeted at a fairly broad audience, some sections might be of more interest to some readers than others. A summary of key points, recommendations/points for reflection can be found at the end of the different sections.

2. Introduction

Why intercultural care and support needs to be developed

The number of people over the age of 60 in the European Union is estimated to have risen from 7 million in 2010 to 15 million in 2015 (Diaz, Kumar and Engedal 2015) with minority ethnic groups accounting for 9% of the population of Europe (Mazaheri et al. 2014). 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 (APPGD 2013, Cheston and Bradbury 2016).

The number of people with dementia from minority ethnic groups in Europe is predicted to rise dramatically in the next few decades (APPGD 2013, Prince et al. 2015, Nielsen et al. 2011 and 2015, Parlevliet 2017). In the Netherlands, for example, a population-based prevalence study carried out by Parlevliet et al. (2016) recorded three to four times more people with mild cognitive impairment and dementia from non-western populations (i.e. Turkish, Moroccan Arabic, Moroccan Berber, Surinamese-Creoles and Surinamese-Hindustani) compared to native Dutch people. Such figures were reported as being similar to those found in four other recent studies comparing groups described as immigrants[1] with native populations in the Western world (Sagbakken and Kumar 2017). Similarly, a seven-fold increase in the prevalence[2] of dementia amongst people from minority ethnic groups is predicted in the UK in the next 40 years (APPGD 2013), compared to a two-fold increase amongst the general population (Nielsen et al. 2018).

The word 'minority' is therefore perhaps misleading, suggesting that only small numbers of people are affected, which is not the case. Even if it were, it would not justify the current lack of appropriate intercultural care and support although it might partly explain the lack of perceived urgency to develop it. People from minority groups face challenges similar to those faced by older people from majority ethnic groups but many in addition experience challenges linked to holding a lower socio-economic status, discrimination and stigma linked to minority ethnic status and of being (or perceived as) a migrant and languages difficulties (Parveen, Oyebode and Downs 2014, Sagbakken and Kumar 2017). Moreover, according to Truswell (2016), the well-documented projected increase in the incidence[3] of dementia in developing countries, accompanied by calls for increased funding and improvements in health policy, largely bypasses minority ethnic communities. This means

that there is a risk of more and more people from minority ethnic groups developing dementia in the coming years and not having access to appropriate care and support which other members of society benefit from. There is an urgent need to address this issue.

The increasing numbers of the older people from minority ethnic groups as a proportion of the population must also be considered in the light of evidence that some groups are at higher risk of developing dementia, with a higher prevalence of dementia in certain ethnic groups compared to others having been reported (Adelman et al. 2011, Plejert, Antelius, Yazdanpanah and Nielsen 2015). Livingston et al. (2017) report increased rates of dementia at a younger age amongst people of African origin living in the UK and USA who have high rates of hypertension. Similarly, in the UK, higher levels of dementia amongst Asian and Black Caribbean communities have been noted, which are attributed in part to high blood pressure, diabetes, stroke and heart disease, as well as to socio-economic factors (Adelman et al. 2011). Whilst some risk factors for dementia are not modifiable (e.g. linked to age and genetics), many are, and many symptoms can be managed with good dementia care (Livingston et al. 2017). It is therefore important that all members of society, including people from minority ethnic groups, have access to such care. This is currently not the case.

People with dementia from some minority ethnic groups are notably absent in residential care homes (Cooper et al. 2010, Stevnsborg et al. 2016). They and their families also tend to use fewer services compared to majority ethnic groups (APPGD 2013, Giebel et al. 2015, Greenwood et al. 2015, Jutlla 2015, Mukadam et al. 2011 and 2015, Parveen and Oyebode 2018). Possible explanations for this have been suggested such as ethnocentricism, lack of culturally appropriate services, cultural beliefs surrounding dementia and care, stigma and shame and negative evaluations of mainstream services, to name but a few. Also, older people from minority ethnic groups are in a potentially vulnerable situation based on what Rait et al. (1996 in Beattie et al. 2005) call a 'triple whammy' of age, ethnicity and socioeconomic deprivation. Consequently, some may feel that they have more pressing health and social concerns resulting in seeking help for possible dementia being low

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[1]   The use of various terms is discussed in the following sub-section and in Appendix 2 (p. 83).
[2]   Prevalence means the total number of cases in a population (includes old and new cases and is often expressed as a percentage of the population).
[3]   Incidence means the number of new cases in a given period (e.g. within a year).

on their list of priorities, especially if they are not familiar with the condition. It should therefore not automatically be assumed that all challenges experienced by people from minority ethnic groups can be explained by cultural factors (Seeleman 2014).

Dementia can be disabling, preventing people from participating in society on an equal basis with others. As emphasised in Alzheimer Europe's work on disability and dementia (2017), according to the social and rights-based models of disability, the barriers to equal participation in society do not reside solely in the individual but are also the result of the way that society is organised (including attitudes, practices, physical structures and procedures etc.). Society therefore has a responsibility towards people with disabilities (which by definition can include people with dementia) to provide timely and appropriate support. Recognising dementia as a potential disability means recognising that people with dementia have a right to receive such care and support, to express their needs and wishes, and to have a say in decisions relating to that care and support. This is also closely related to the ethical principles of respect for autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2001) but also of respect for dignity, privacy and personhood. With regard to civil and political rights, Article 27 of the 1966 International Covenant on Civil and Political Rights is also relevant:

> "In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities should not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language."

The term 'reasonable accommodation' is sometimes used to refer to the measures that should be taken to maximise the potential of people with disabilities to participate in society on an equal basis with others. However, when determining what is 'reasonable', there is a risk of this being based on the needs and wishes of the majority ethnic group. Those of minority ethnic groups risk being overlooked,

ignored or neglected – hence the need for intercultural care and support. In some cases, this may be an oversight resulting from a lack of awareness and understanding of cultural differences, needs and preferences; in others, there may be an element of discrimination, either interpersonal or structural (i.e. perpetuated through existing structures and practices). Such oversight or discrimination is unacceptable in today's multicultural Europe and must be challenged on the grounds of equity/justice, respect for all human beings and for the dignity of the individual, tolerance and recognition of cultural diversity as a source of richness.

The overall aim of this project is to improve the situation of people with dementia, their supporters and professional carers from minority ethnic backgrounds through the identification and promotion of intercultural care and support. Intercultural care and support in the context of this project is about looking at ways to respect and respond to the cultural diversity of people with dementia, their relatives and friends and of those caring for people with dementia.

The members of the expert working group acknowledge that work on this document was initiated within a cultural frame of reference reflecting broad values embraced predominantly by majority ethnic groups within the European community, such as human rights, equity and respect for autonomy. However, within the expert working group, there are people from both majority and minority ethnic groups, including some who have migrated to or within Europe in the last few decades. There are also members of the group who are familiar with some of the main world religions i.e. Sikhism, Islam, Christianity and Judaism. In addition, for most members of the group their work brings them into direct contact with people with dementia and carers or supporters from minority ethnic groups on a regular basis. We have tried to be aware of the influence of the context and of our own, albeit varied cultural backgrounds, in order to explore the literature systematically but with an open inquisitive mind, attentive to other possible values, perspectives and priorities.

About ethnic groups: concepts and terminology

This report contains a lot of different terms which some people might not be familiar with. In the following sub-sections, we provide a brief definition and explanation for our use of certain key terms, explore some of the

assumptions about majority ethnic groups, especially in relation to the concept of a unified, homogenous nation, and finally, look at the fluctuating and dynamic nature of ethnic groups.

Some of the key concepts mentioned in this section

- Interculturalism: the acceptance and promotion of cultural diversity, reflected in the way that people interact, understand and relate to each other, and through policies and practice which help ensure equal opportunities, respect and fair treatment of people from all ethnic groups.
- Ethnicity: a shared culture, often incorporating a common language, geographic locale or place of origin, religion, sense of history, traditions, values, beliefs and food habits.
- Cultural awareness: knowledge about different cultures (e.g. different religions, traditions, common beliefs and preferences, history and shared values).
- Cultural sensitivity: acknowledging cultural differences and similarities between people without assigning them a value (e.g. good or bad, right or wrong).
- Cultural competence: knowledge combined with appropriate attitudes and skills (e.g. openness, respect, awareness of one's own background, readiness to question one's own assumptions, ability to communicate with people from different cultures and readiness to use external help when needed).
- Minority ethnic group: a group of people who share a common cultural identity which differs in some way to that of the majority ethnic group in a particular country.
- Majority ethnic group: the group of people sharing the most common ethnicity in a particular country, often believed to be a homogenous group and often considered as being one unified nation consisting of a single ethnic group. Sometimes referred to as 'native' or 'White' even though these terms are problematic.
- Migrant and immigrant: unclear concepts with varying definitions. Sometimes defined by foreign birth, foreign citizenship or movement into a new country to stay temporarily or to settle for the long-term. Often associated with ethnic or religious minorities and with asylum seekers and refugees.
- Race: a contested concept reflecting the categorisation of groups of people into sub-groups on the basis of alleged biological differences (including visible physical traits or characteristics as well as behaviours), which it is claimed have been passed down from generation to generation through people's genes.

Overview and reasons for the choice of key terms used in this report

There are several key terms, which are central to the topic of this report, namely 'intercultural care and support', 'cultural awareness', 'cultural sensitivity', 'cultural competency', 'minority ethnic group', 'ethnicity', 'migrant' and 'immigrant'. The following quote, from Age Action, provides a broad description of the main principles of interculturalism, which can be applied to different domains such as education and healthcare:

"Interculturalism is essentially about how we interact, understand and respect each other. It is about ensuring that the cultural diversity of a population is acknowledged and catered for; so that minority ethnic groups are included by design and planning not as an add-on or afterthought. An intercultural approach recognises and encourages people's freedom to keep their identities alive, supporting all cultures to flourish together and share their heritage. It sees difference as something positive that can enrich society and recognises racism as an issue that needs to be tackled in order to create a more inclusive society" (Age Action 2015, p. x).

Intercultural care and support for people with dementia should not start after diagnosis when needs arise but prior to diagnosis, ensuring that people from minority ethnic groups are aware of dementia and obtain timely and accurate diagnoses which make care and support, as well as treatment, possible if and when needed. For this reason, our definition of 'intercultural care and support' is quite broad, covering the period preceding diagnosis up to the end of life. Intercultural

care and support should respond to and respect the cultural identities of people from minority ethnic groups and it is therefore essential to have some understanding of what is generally important to people from different ethnic groups and of the things that many members of those groups have in common. At the same time, it is important not to lose sight of individuals amongst generalisations and stereotypes or to go overboard by seeking to impose cultural traditions which are not meaningful to a particular individual (e.g. assuming that people are strict or practising Muslims or Hindus because of their name, appearance or the language they speak, and for that reason denying them certain food, which they might actually like and regularly eat). Ethnicity is often an important aspect of a person's identity but only one aspect. Moreover, people from all ethnic groups have a great deal in common and these similarities also need to be recognised and promoted.

Intercultural care and support requires cultural awareness, cultural sensitivity, cultural competence, willingness and motivation, as well as support from policy makers and funders. Ardila (2005, p. 185) has identified three different aspects of culture, namely:

1. The internal, subjective or psychological representation of culture, including thinking, feeling, knowledge, values, attitudes, and beliefs.
2. The behavioural dimension, including the ways to relate with others, ways of behaving in different contexts and circumstances, festivities and meeting, patterns of associations, etc.
3. Cultural elements: the physical elements characteristic of that human group such as symbolic elements, clothes, ornaments, houses, instruments, weapons, etc.

These aspects focus on things that people from a particular ethnic group might have in common but do not rule out individual differences between the members of a particular group. Cultural awareness means having some knowledge about different cultures (e.g. about different religions, traditions, common beliefs and preferences, history and shared values). Seeleman emphasises the need to be aware of one's own cultural background and perspectives, adding that "culture is not something that only belongs to others" (2014, p. 98). Cultural sensitivity means being aware of different cultures but not linking that awareness to value judgements. Cultural competence means being able to put that knowledge into practice. It therefore requires not only knowledge but appropriate attitudes and skills such as openness and respect, awareness of one's own background, readiness to question one's own assumptions, stereotypes, biases and prejudices, flexibility and creativity, the ability to make

information understandable and readiness to use external help (e.g. interpreters) if and when needed (Seeleman 2014). Cultural awareness and competence can be acquired through training, through experience and through observation and communication with people from minority ethnic groups (i.e. when in doubt, asking explorative questions, listening and being aware of the context) (Seeleman 2014).

The term 'minority ethnic group' is used to refer to a group of people who share a common cultural identity which differs in some way from the majority ethnic culture in a particular country (the latter representing the standard cultural norm in terms of food, language, cultural activities, pastimes, religion, traditions and festivals etc.). Members of some ethnic groups are in a minority by virtue of numbers and in relation to ethnicity (Botsford and Harrison Dening 2015). The cultural and linguistic diversity of minority ethnic groups, combined with other societal contributing factors, means that greater effort is needed to ensure that their needs and preferences are equally addressed. The term 'minority ethnic group' is sometimes used in preference to 'ethnic minority group' to emphasise that everyone belongs to an ethnic group, as opposed to suggesting minority status based on being a member of an ethnic group per se. We are not assuming that everyone identifies with an ethnic group but accept that most people probably do.

References to 'ethnicity' (or 'ethnic') are generally associated with the identification with a group of people or a community on the basis of a perceived shared culture. Smedley and Smedley (2005) describe this as follows:

> *"Ethnicity refers to clusters of people who have common culture traits that they distinguish from those of other people. People who share a common language, geographic locale or place of origin, religion, sense of history, traditions, values, beliefs, food habits, and so forth, are perceived, and view themselves as constituting an ethnic group" (2005, p. 17).*

As language gradually changes over time, terminology surrounding ethnicity and the people from different ethnic groups also changes, with some terms coming to be considered as offensive or disrespectful (Botsford 2015). This can also lead to uncertainty about which term to use. To complicate matters, some terms are considered appropriate and respectful in one geographical area or language but not in others (e.g. such as Black, coloured and gypsy). Terms can also be considered more or less acceptable depending on who uses them, how and in what context. The term 'gypsy', for example, is used by some people from traveller communities and by some associations representing their rights[4] but many people consider the term offensive[5]. In the

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[4] For an overview of various related terms used in the UK, please see: http://leedsgate.co.uk/sites/default/files/media/Ethnicity-Briefing.pdf
[5] In this report, the term 'traveller' or 'member of traveller communities' will be used.

context of her research, Jaakson (2018) asked members of the Finnish Roma community what they would like to be called (e.g. Roma, travellers or gypsies). They replied that the term used was of little importance; what mattered was the way a person addressed them (e.g. the tone of voice, facial expression etc.).

Some terms gradually fall out of use because they reflect concepts which have come to be considered as scientifically invalid. 'Race' is one such example. It is a highly contested concept which neither Alzheimer Europe nor the members of the expert working group adhere to. It nevertheless continues to be used in various policies and in everyday life. The terms 'race' and 'ethnicity' are frequently found in documents side by side with no explanation about their respective meanings, and sometimes used as if they were interchangeable. The term 'race' reflects a categorisation of groups of people on the basis of alleged biological differences (often including visible physical traits or characteristics), which it is claimed have been passed down from generation to generation (i.e. genetic differences). The concept of race is often associated with the belief that some races are inferior and even 'less human' than others, with devastating consequences for certain groups of people (e.g. discrimination, colonisation, slavery and genocide). Opponents of this concept point out that so-called racial groups are not genetically discrete, measurable or scientifically meaningful and that there is more genetic diversity within 'races' than between them (Smedley and Smedley 2005, Mersha and Abebe 2015). The term 'race' has been largely replaced by concepts such as 'genetic background' or 'hereditary factors'.

A few additional terms are used in this report which have been taken from the numerous studies that we cite, the most frequent being 'migrant' and 'immigrant' (as well as BME and BAME which are discussed in the next sub-section). Migrant and immigrant are fairly unclear concepts for which there is no commonly agreed definition. They are sometimes based on criteria reflecting foreign birth, foreign citizenship or movement into a new country to stay temporarily or to settle for the long-term. Sometimes fixed periods of residency in the receiving country are stipulated. The term 'native' (e.g. native-Norwegian or native-Italian), which is used by some researchers to refer to the majority ethnic group, might also reflect an emphasis on whether or not a person was born in a particular country although it is then unclear where 2nd or 3rd generation minority ethnic groups fit in. On the other hand, this might avoid the use of the term 'White' and an emphasis on skin colour (bearing in mind that some minority populations in Europe, such as Irish and East-European communities, also tend

to be predominantly 'White'). The terms 'migrant' and 'immigrant' are often associated with ethnic or religious minorities and with asylum seekers and refugees. Sometimes, as with the terms 'White' and 'native', it is not clear to which groups they apply. Because of possible ambiguity and the risk of misrepresenting researchers' findings, we have decided to stick to the terms used by the researchers when reporting their findings and elsewhere to refer to minority and majority ethnic groups[6]. In Appendix 2 (p. 83), we provide a few more details about issues surrounding the use of the terms race, ethnicity and minority ethnic groups.

The conceptualisation of majority and minority ethnic groups

Some of the issues described in this report might, at first glance, seem to be based on clearly defined, stable concepts reflecting 'binary oppositions'[7]. Two distinct groups are identified, namely people from minority ethnic groups and people from majority ethnic groups. The problem with binary opposition, is that it can create boundaries between groups of people such as between men and women, between people from different social classes and, of interest to our work, between people from different ethnic groups. According to Rock (not dated), binary oppositions can lead to prejudice and discrimination, often fuelled by fear and perceptions of the opposite group as being 'the other'.

For centuries, the traditional notion of nations as one unit, one people, one culture and one language has permeated many countries in Europe. A nation, in this sense, is considered as:

> "A group of people who see themselves as a cohesive and coherent unit based on shared cultural or historical criteria. Nations are socially constructed units, not given by nature. Their existence, definition and members can change dramatically based on circumstances. Nations in some ways can be thought of as 'imagined communities' that are bound together by notions of unity that can pivot around religion, ethnic identity, language, cultural practice and so forth. The concept and practice of a national work to establish who belongs and who does not (insider vs. outsider)" (Rock, not dated).

The term 'Nation-State' is sometimes used to describe the concept of a country in which the cultural boundaries match the geopolitical boundaries. This is often characterised by a uniform national culture with state policy influencing to some extent education, language use and

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[6] Except in Section 6 (p. 63) where we specifically look at the experience of professional carers from minority ethnic groups who have recently migrated to Europe.

[7] Binary oppositions are generally perceived as being things that cannot co-exist. A light switch, for example, can be off or on, but not both at the same time.

a common interpretation of history, and the state being perceived as representing a homogenous group. Whilst rare in practice, such perceptions may have implications for minority ethnic groups, contributing towards a 'them' and 'us' situation[8].

A closer look at what may seem to be clearly defined groups reveals that they are not entirely homogenous in that there are many similarities as well as differences between apparently opposing groups. Moreover, most countries are actually 'polyethnic' (made up of numerous ethnic groups), with very few states meeting the criteria for 'one nation, one state' (approximately 10% worldwide) (Rock not dated). The notion no longer holds true in the current period characterised by free movement of citizens within Europe and of great migration from other continents. Consequently, whilst it may be helpful to identify certain groups of people in order to explore their needs, rights, beliefs and preferences etc., care must be taken to avoid making assumptions, stereotyping and overlooking the many similarities between groups, as well as the fluctuating boundaries between groups and concepts, and their dynamic nature.

Fluctuating boundaries between and within minority ethnic groups

According to Barth (1998), ethnic groups are also not permanent, inflexible entities but rather open to change, with the possibility of people moving in and out of them. People define themselves as belonging to a particular ethnic group and are also identified by others as belonging to that group (as opposed to another group). They also develop together the criteria for group membership, emphasising similarities between members of the group which are significant and ignoring those which are not (also with regard to intra-group differences).

An important aspect of ethnicity is that it is not something that is biologically determined, fixed or linked to nationality or a place of birth, even though members of

a group might share a common ancestral geographical origin and a tradition of common descent (i.e. including people who migrated to a country and their descendants). Not everyone from a minority ethnic group is a migrant[9] but descendants of migrants (e.g. second or third generation descendants from Portuguese migrants living in Luxembourg or from Somalia living in the Netherlands) sometimes encounter similar difficulties linked to cultural and linguistic issues and experience social exclusion or discrimination. However, minority ethnic groups and cultures are dynamic, constantly changing and adapting to new environments. Cultural practices and language use may gradually change as people adapt in relation to a new society. The term 'acculturation' is used to refer to the occurrence of change "when individuals from different cultural backgrounds come into prolonged, continuous, first-hand contact with each other" (Redfield et al. 1936, p. 136)[10]. So on the one hand, children of migrants may experience some of the same difficulties as their parents or grandparents, on the other hand as a result of the process of acculturation, their experience of and attitudes towards dementia, health and service use, might be quite different. Consequently, assumptions cannot be made based on a person identifying with a minority ethnic group.

The names given to minority ethnic groups often reflect the geographical origin of the members of that group who initially migrated to a particular country. This may lead to assumptions being made about similarities between groups bearing the same name in different parts of Europe (e.g. people from Syrian communities living in Norway and in Austria) and overlooking significant differences such as different languages, religious beliefs, shared histories and traditions.

Members of ethnic groups are increasingly making their voices heard and influencing how they are defined and labelled. The term BME (Black and Minority Ethnic), for example, which has been used in the UK for many years was adopted as a means to group together different ethnic groups under the universal term 'Black' to fight against discrimination. According to Sandhu (2018), some people

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8 In its glossary of terms related to international migration, UNESCO (2017) suggests that in Western Europe nationalism is currently more a matter of hostility against immigrants than against other nations, adding that this may well be motivated more by the implications that an ethnically diverse population has for the welfare state than by notions of cultural superiority.

9 This was one of the main reasons for not focusing on migrants when addressing the topic of intercultural care and support.

10 See also the sub-section on migrant carers in Section 6 on Issues and challenges encountered by professional and informal carers (p. 63)

were not happy about being grouped together under such a general term and to the prominence given to Afro-Caribbean people. The term BAME (Black, Asian and Minority Ethnic) therefore emerged as an alternative. Nevertheless, even though over 7.6 million people in the UK identified their ethnicity as BAME in the 2011 UK census, some people do not want to be categorised in this way, often wishing to incorporate the term 'British' into the description of their ethnic identity (e.g. Black British, or Caribbean British) (Sandhu 2018). Pressure groups have also campaigned for recognition as a minority ethnic group and not to be considered as part of the majority ethnic group on consensus forms (e.g. people from the Irish community and from traveller communities in England and Wales). It is not clear, however, whether people from minority ethnic groups outside the UK have been successful in influencing the terms used to refer to their members.

People have multiple, intersecting and overlapping identities. The sense of belonging and the different aspects of cultural identity a person wishes to emphasise may fluctuate over time and according to the situation. Different minority ethnic groups may have things in common such as certain shared values and preferences and, in many cases, a vulnerable status and lack of political power (Moodley 2005, APPGD 2013). Amongst those who migrated in the context of guest worker programmes, many had little or no education and experienced racism and prejudice. Many people from minority ethnic groups also have a low socio-economic status (Moodley 2005, APPGD 2013, Parveen, Oyebode and Downs 2014, Liversage & Jakobsen 2016, Sagbakken and Kumar 2017, Berdai Chaouni and De Donder 2018). However,

there are numerous differences between and within different ethnic communities (e.g. with regard to religion, gender, class and language). Rauf (2011) uses the term 'communities within communities' to explain these within-group differences. Vertovec (2007) highlights the "super diversity" of minority ethnic populations, drawing attention to the rising diversity within groups in relation to country of origin, socio-economic status and religious and cultural traditions. Such differences can, according to Uppal, Bonas and Philpott (2013), impact on defining individual norms, values and experiences. In this way, a person may feel closely connected to the Sikh community in relation to certain aspects of his/her life (the focus thus being on religion) but relate to the British Asian community in relation to certain other aspect of life (with a focus on other shared values and traditions). Religious groups are sometimes considered as minority ethnic groups *per se* even if the religion is interpreted and practised differently from one community to the next by people who do not all share the same cultural tradition or language and do not have the same common ancestry. Religion is sometimes a uniting factor which cuts across other aspects of people's cultural identity.

Inter and intragroup differences are important to bear in mind when developing services which are not only culturally sensitive but also respond to the needs and wishes of individuals. It should not always be assumed that people from minority ethnic groups are different from those in the majority ethnic group. The right balance is needed between respect for cultural diversity and respect for the individual as a person in his or her own right, regardless of any ethnic group that he or she might identify with.

Key points from the Introduction

A few words about terminology...

- The main emphasis in this report is on people from minority ethnic groups, irrespective of migrant or immigrant status.
- Neither minority nor majority ethnic groups are totally homogenous. There are many differences within specific minority ethnic groups, as well as similarities between minority and majority ethnic groups.
- Terms other than 'person/people from a minority ethnic group' are frequently used in this report to reflect the terminology used by researchers and writers whose work or findings are reported.
- The authors of this report consider 'race' an inappropriate term with no scientific validity.

The key points.....

- Ethnicity is generally associated with the identification with a group of people or a community on the basis of a perceived shared culture (e.g. in relation to values, beliefs, history, food preferences and/or religion).
- The number of people with dementia in Europe from minority ethnic groups is increasing.
- People with dementia from minority ethnic groups are potentially vulnerable due to a combination of several factors such as age and ethnicity and in many cases a history of discrimination, a lower level of education and a lower socio-economic status.
- People with dementia from minority ethnic groups are notably absent from residential care and use fewer services compared to people from majority ethnic groups.
- Several reasons might explain the low uptake of services by people from minority ethnic groups (e.g. culturally inappropriate services, beliefs about dementia, lack of awareness of services etc.). These are discussed in Section 5 (p. 41).
- As dementia is recognised as a disability, people with dementia are entitled to care and support to enable them to participate in society on an equal basis with others.
- Measures to make this possible often reflect the needs and wishes of the majority ethnic group. Those of people from minority ethnic groups are often ignored or overlooked.
- Intercultural care and support requires cultural awareness and cultural competence.

Recommendations/points for reflection

- In the context of dementia care and support, the cultural diversity of populations should be recognised and promoted in order to enable people from minority ethnic groups to keep their identities alive and for different cultures to flourish.
- The development and provision of intercultural dementia care and support should be a priority in Europe.
- Reasons for low levels of service use must be explored and appropriate action taken to ensure that people with dementia and carers from minority ethnic groups receive the same level and quality of care and support as that provided to people from the majority ethnic groups across Europe.
- The needs and wishes of people from minority ethnic groups, including those from less obvious (e.g. 'White') minority ethnic groups, should be incorporated into the design and planning of care and support and not treated as an add-on or afterthought.
- The development of intercultural dementia care and support should be properly funded, on a long-term basis, not just as pilot projects.
- Professional carers and service providers/commissioners should consider the need to address social as well as cultural factors in relation to issues experienced by people from minority ethnic groups.
- Public health initiatives should be developed as a means to empower people from minority ethnic groups living in deprived neighbourhoods and with a low socio-economic status to benefit from existing care and support on the same basis as other people.
- Policies should be developed to support collaboration between different health and social care professionals and to support them in acquiring the expertise needed to meet the needs of people from minority ethnic groups.
- The term 'race' (and derivatives such as 'racial') should, wherever possible, be avoided. It should not be considered as meaning the same thing as 'ethnic' or 'ethnicity' (please see Appendix 2 on p. 83 for a discussion about the definition and use of these terms).
- Consensus should be sought at European level about the definition of 'migrant' and 'immigrant'.
- People from specific ethnic groups should be given an active role in determining which terms are used to categorise and describe members identifying with those groups (e.g. in official documents, for the purpose of a census etc.).
- The potentially vulnerable position of many people from minority ethnic groups threatens their right to be treated equally and this must be challenged in order to respect the moral principle of equity.
- Ignorance, prejudice and interpersonal as well as structural discrimination need to be addressed.

The structure of this report

Following on from this Introduction (Section 2), the report is structured around four key topics:

- Section 3. Understanding dementia and help seeking,
- Section 4. Diagnosis, assessment and treatment,
- Section 5. Support and care and
- Section 6. Challenges encountered by professional and informal carers.

There are several themes which cut across these remaining sections, namely language difficulties, issues related to interpretation, the role of the family in relation to care and support, cultural perceptions of dementia and care, stigma, pride and shame, the importance of religion and the importance of trust. We have made some cross references in the text to indicate where similar issues are addressed elsewhere in the report and to avoid repetition.

3. Issues surrounding understanding dementia and help seeking

The main objective of this project is to contribute towards the development of intercultural care and support across Europe. Access to appropriate and timely support and care is dependent not only on its availability but also on people knowing about dementia, especially understanding that it is a medical condition, and seeking help. Lack of awareness and understanding about dementia is often a stumbling block for many people from minority ethnic groups. In this section of the report, we will explore the following issues:

- **Raising awareness amongst the general population e.g.**
  - communicating about dementia,
  - looking at how people perceive and make sense of dementia,
  - reflecting on how best to reach people from minority ethnic groups.

- **Promoting initial help seeking e.g.**
  - considering how different perceptions of dementia affect help seeking,
  - looking at other issues which may interfere with help seeking such as language barriers, lack of knowledge, financial barriers, distrust and preference for family care.

Information about the above issues is mainly based on findings from qualitative research studies. The terms used in this report to refer to different minority ethnic groups may at times seem somewhat inconsistent but, as mentioned in the introduction, the same terms are used in different ways by different researchers. Sticking to the terms used by the researchers themselves (and by authors of relevant reports) helps avoid making errors based on false assumptions.

Raising awareness about dementia amongst minority ethnic communities

Communicating about dementia

To raise awareness about dementia, it is important that people hear and read about it, and understand what is being communicated. This is important for everyone but lack of fluency in the main language spoken in the country and poor literacy[11] may be significant barriers preventing many people from minority ethnic groups from accessing information about dementia (La Fontaine et al. 2007, Mukadam et al. 2011, Rattigan and Sweeney 2018). In some languages, there is no word for dementia. This is the case in many Asian languages including, for example, the Punjabi language (Lawrence et al. 2011, Mohammed 2017, Uppal and Bonas 2014, Sagbakken, Spilker and Ingebretsen 2018). Adamson (2001) found that most of the African/Caribbean UK carers[12] they interviewed were aware of a medical or lay term for dementia but there was considerable variation in what they considered dementia to be and in their understanding of symptoms and possible causes of dementia

(see next section for more about how people from minority ethnic groups understand what dementia is). Some health and social care professionals prefer to use the term 'dementia' in combination with an explanation about what the term means even if the word does not exist in a particular language, also in the context of disclosure of the diagnosis, so as to raise awareness and contribute towards normalising dementia.

It is possible that the terms used by participants may also depend on their level of education or socio-economic status. There may also be differences depending on who is asked (i.e. the characteristics of participants in studies recording language use). The language in which the interview or discussion takes place, as well as the ethnic group to which the facilitator[13] belongs, might also affect the kind of language used. Whilst considering the different terms for dementia in minority ethnic groups, it should be

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[11] See also the subsection on the uptake of services and support by minority ethnic groups (p. 44) in Section 5 on Support and care).

[12] Here and elsewhere in this report, the term carer is used to refer to people who provide informal, unpaid care or support to a person with dementia (as opposed to professional carers who are paid and hopefully trained). Carers are usually relatives or close friends.

[13] The person conducting the interview or leading the discussion.

noted that in some countries, such as France and Finland, the term 'dementia' is now largely avoided by lay people and professionals. In France, for example, the term 'maladie d'Alzheimer et les maladies apparentées' (Alzheimer's disease and related disorders) is often used and in Finland, 'muistisairaus' (memory disease) or 'muistisairaudet' (memory diseases).

Alzheimer Europe and the vast majority of its member associations use the term 'dementia' as well as specific terms reflecting different diseases and conditions which may result in dementia. It is generally agreed that dementia is a syndrome (a group of symptoms that typically occur together and for which there is no definitive diagnosis) that is caused by one or more diseases (Alzheimer's disease being the most common). It can also be caused by fronto-temporal degeneration, brain injury, infections and alcohol abuse but this is less common (Livingston et al. 2017).

In addition to finding the appropriate terminology and producing information in a language that members of minority ethnic groups understand, materials must be suited to the educational level of the target audience. As many older people from minority ethnic groups may have had little or no formal education (Berdai Chaouni and De Donder 2018), it is important to keep materials brief and to use simple sentence structures and vocabulary. In some minority ethnic groups, there is a greater likelihood of older people being illiterate in their own language, especially older women (Bhattacharyya and Benbow 2013, Nielsen and Jørgensen 2013). For this reason, attempts to raise awareness about dementia should not be limited to printed materials but should also include DVDs and face-to-face communication. Szczepura (2005) emphasises the importance of using bilingual/bicultural staff, interpreters and link workers/advocates etc. to ensure equal access to healthcare for people from minority ethnic groups, including materials developed and tested for specific cultural, ethnic and linguistic groups and public awareness materials and campaigns in languages other than English and disseminated via ethnic media channels such as relevant television, radio, internet, newspapers and periodicals. Mukadam et al. (2015) emphasise the importance of presenting a personal story visually that people can relate to rather than purely clinical information.

How people perceive and make sense of dementia

The way that dementia is perceived and portrayed may affect the way that people with dementia are treated and how dementia is addressed within society. It may have an impact on care, social inclusion and respect for human rights. There may also be ethical implications, whereby certain ways of perceiving dementia might contribute towards promoting or condoning actions and attitudes that are harmful or beneficial to people living with dementia (Gerritsen, Oyebode and Gove 2018). Perceptions of dementia are not necessarily uniformly shared and there may be differences between and within different cultures. Members of some ethnic groups (or rather a considerable proportion of them) may have a common perception of dementia which differs to that held by the majority ethnic group. However, some members of majority ethnic groups may have similar perceptions of dementia. The aim of this section is not to suggest that the perceptions that people from minority ethnic groups have of dementia are right or wrong. Rather, the aim is to explore different perceptions and then in the next sub-section to reflect on the possible impact that such perceptions may have on seeking a diagnosis, care or support, especially when combined with other challenges that people from minority ethnic groups may face.

In this report, we focus on dementia (i.e. on the syndrome which can be caused by numerous neurodegenerative diseases and medical conditions) but many lay people from all ethnicities are unclear about the difference between dementia and the various underlying causes, the most common one being Alzheimer's disease. In a series of focus groups conducted in Scotland, lay people were found to use the terms dementia and Alzheimer's disease interchangeably (Devlin et al. 2007). However, in the Facing Dementia Survey, 19% of the 600 lay people interviewed associated dementia with being crazy or insane compared to just 4% for AD, suggesting that dementia and AD have different connotations in relation to mental illness[14] (Rimmer et al. 2005). This means that certain beliefs about dementia, which may interfere with help seeking and be more or less associated with stigma, might differ depending on the terminology used. This issue needs further exploration, especially in the light of recent developments resulting from changes in the way that medical researchers and some clinicians are now using the term 'Alzheimer's disease'.[15]

The perception of dementia as a medical condition is not described below because this is unlikely to represent an obstacle to seeking and receiving diagnosis, support and care in Europe. However, references to dementia being a 'medical condition' can be understood in the context of this report as reflecting the bio-psycho-social model of dementia, give or take some degree of emphasis on one or more particular aspects of this model. The bio-psycho-social

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[14] See sub-section on dementia as a mental illness (p. 18).

[15] The studies mentioned in this paragraph were conducted at a time when the term Alzheimer's disease (AD) was more or less synonymous with dementia. This has changed since the development of new conceptualisations of AD but these new conceptualisations are not yet widely understood by the general public. The issue here is therefore about the connotations and possible confusion surrounding the two terms.

model of dementia, developed by Tom Kitwood, has been increasingly accepted by healthcare professionals in Europe since the 1990s. Kitwood claimed that the progression of dementia was not determined solely by changes in a person's brain but rather by a complex interaction between five factors, namely the clinical manifestation of dementia, personality (in the sense of resources for action), biography, health, neurological impairment and social psychology.

Often, different terms are used for dementia within a particular cultural group, some from everyday language, some from the medical domain and these reveal different ways of understanding dementia. In the study about people with dementia of Moroccan descent living in Flanders, a range of everyday terms were used such as being "forgetful, crazy, possessed, spoiled 'fsoesh'" or as having "a confused head" (Berdai Chaouni and De Donder 2018, p. 8). Terms such as "Alzheimer", "Zheimer" and "Dementia" reflected awareness of dementia as a medical condition but older people did not always want to hear such terms and some of the carers did not know if there was a word for dementia in Arabic. Not enough is known about perceptions of dementia as a medical condition amongst minority ethnic groups. It is not always clear, for example, whether people who perceive dementia as a medical condition focus on bio-medical aspects (e.g. attributing all symptoms to changes in the brain, seeing medication as the sole solution and overlooking the importance of psycho-social support) or have a more holistic understanding similar to the bio-psycho-social approach described above. This is important in relation to help seeking and expectations with regard to care and support.

Understanding how people from different ethnic groups make sense of dementia is important when trying to raise awareness about dementia and ensure that people from different ethnic groups can benefit from timely diagnosis and access services, support, care and medication when needed and on an equal basis with other members of society. Successful awareness raising may sometimes involve providing information which respectfully challenges certain beliefs, whilst at the same time building on a group's current understanding and respecting its traditions. An important step when trying to raise awareness about dementia in minority ethnic groups is to understand how people in those communities make sense of dementia. It is therefore essential to involve people from different ethnic groups in the development of such materials.

The following sub-sections, which explore different perceptions of dementia, have been organised into different categories for the sake of comparison. People do not necessarily fall into one of these neat categories. Different thoughts might cross people's minds. They might fluctuate between different possible explanations or have a combination of beliefs, with some ambivalence and even conflicting views.

Dementia as part of normal ageing

There has been recognition of a strong association between cognitive decline and ageing for well over a thousand years. Berchtold and Cotman (1998) and Karenberg and Förstl (2006) point out that Pythagoras, Hippocrates, Plato and Aristotle seem to have considered cognitive decline as an inevitable part of ageing, and Aristotle and Galen may have considered old age and the last stage of life as a diseased state rather than natural (Berchtold and Cotman 1998). Cicero (ca. 150–200 AD), on the other hand, seems to have believed that "dotage" ("that foolishness which is associated with age") was not inevitable but typically associated with "old men of trivial character, not to all old men" (Karenberg and Förstl 2006, p. 7).

Evidence of the perception of dementia as part of normal ageing can still be found amongst members of many minority and majority ethnic groups in Europe, although perhaps more so amongst minority ethnic groups. The following list provides examples of some of the ethnic communities covered by recent studies:

- Turkish and Pakistani communities in Denmark, compared to native Danish and Polish communities (Nielsen and Waldemar 2016),
- Pakistani immigrants living in Norway (Næss and Moen 2015),
- Female carers of immigrants with dementia in the Netherlands (van Wezel et al. 2016),
- People with dementia of Moroccan origin in Flanders, Belgium (Berdai Chaouni and De Donder 2018),
- Black, Asian and minority ethnic communities in the UK (La Fontaine et al. 2007, Purandare et al. 2007, Truswell 2018),
- Greek Cypriot and African Caribbean carers in the UK (Botsford, Clarke and Gibb 2011),
- African Caribbean and South Asian carers in the UK (Jolley et al. 2009),
- People from East and Central European communities living in the UK, but not within the British Indian community (Parveen, Peltier and Oyebode 2017),
- People from the traveller community in the UK (LeedsGATE 2015).

A recent study by Næss and Moen (2015) into the perspectives and experiences of Pakistani immigrants within the Norwegian welfare state provides considerable insight into the normalisation of dementia and the implications for care and support. The authors describe a process whereby members of the Pakistani community have an awareness of various types of mental disorders (see following

sub-section) but consider certain symptoms of dementia as just signs of ageing and others not. The following quotes provide an example of this distinction.

> "If a person throws stones on other decent people, or uses an iron bar to hit someone, then we think he is sick. But if he just talks nonsense or has lost his memory, we think it is probably because he is old. Then it's OK and we have to take good care of them and act like usual"

> "It's only normal that old people become weird and difficult…" (Næss and Moen 2015, p. 1722).

At some point (e.g. if symptoms become more difficult for the family to manage and to attribute to normal ageing of the body and mind), the family may consider seeking outside help but according to Næss and Moen (2015) the threshold for doing so is quite high because of the tradition of filial piety (discussed in more detail later in this section).

Dementia as a mental illness

Some people from minority ethnic groups consider dementia as a mental disorder (Mackenzie 2006, APPGD 2013, Mukadam et al. 2015, Mohammed 2017). This is also the case amongst many people within majority ethnic groups (Mackenzie 2006, Rimmer et al. 2005) but the impact on help seeking may be different. Despite recent changes in terminology resulting in dementia being referred to as a major neurocognitive disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Livingston et al. 2017), and although the term 'dementia' in not actually used in DSM-5 as a formal classification, the association between dementia and mental illness is maintained. In some countries, services and support for people with dementia are provided within the framework of mental health.

However, what is important is not whether dementia is, technically speaking, a mental disorder but that the term 'mental disorder' tends to have negative connotations and that people with mental disorders are highly stigmatised[16]. Mental disorders are often associated with negative emotions and discriminatory behaviour (Angermeyer and Matchinger 2004 and Thornicroft 2006). Alternative words such as mad, crazy, insane and nutty are frequently used. The same terms are sometimes used to specifically refer to people with dementia e.g. crazy or forgetful within some Middle-Eastern communities in Sweden (Antelius and Plejert 2016), mental, mad, crazy or 'getting off your brain' within some Black Caribbean communities in the UK (Lawrence et al 2011) and 'bonkers' also in the UK (APPGD 2013).

The Chinese word for dementia has connotations of mental illness and stupidity (Loo 2014 in Truswell et al. 2015). Perceiving dementia as a mental illness (or even just as a medical condition) does not, as mentioned earlier, rule out beliefs about other possible causes.

Dementia as an "act of God" or caused by spirits

The belief that illness is caused by supernatural factors has been recorded in a number of studies involving people from a range of ethnic/cultural backgrounds, not just in minority ethnic groups (Landrine and Klonoff 1994). Studies which have focused on dementia suggest that in some cultural and ethnic groups, beliefs about fate, evil spirits, the evil eye, lack of faith in or punishment from God are common (Elliot et al. 1996, Patel et al. 1998, Adamson 2001, Turner et al. 2005, Downs et al. 2006, MacKenzie 2006, APPGD 2013 and Mukadam et al. 2015). In the UK-based study by Parveen et al. (2017) involving people with dementia, carers and members of the community from British Indian, African and Caribbean, and Eastern and Central European minority groups, spiritual causes of dementia were not mentioned. However, the first two groups emphasised the importance of religion and spirituality as ways to cope.

Spiritual beliefs about the cause of dementia have also been linked to black magic, demonic possession and menacing supernatural creatures (e.g. in the Black Caribbean and Pakistani communities in the UK – APPGD 2013). Mohammed (2017) explains that in Muslim societies, people often attribute mental illness and neurological disorders to 'Jinn' (or djinn), which can be found in Islamic folklore tales and in the Qur'an. Jinn are supernatural, menacing creatures which are believed to be able to harm people. He suggests that in some minority ethnic groups (e.g. with a link to the Indian sub-continent), people may have witnessed or heard about exorcisms and, not having a word for dementia or being familiar with this condition, may attribute the symptoms to demonic possession. However, whereas some researchers associate beliefs about evil spirits and curses with South Asian communities, Johl et al. (2016) point out that this is less common in Sikh and Hindu communities. This highlights the problem of grouping together very different cultural groups under one general title.

Dementia is not always understood as being either linked to spiritual forces or alternatively as being a medical condition. In some communities, dementia is recognised as a medical condition but nevertheless attributed to spiritual forces. In a qualitative study involving face-to-face interviews with South Asian carers of people with dementia living in the UK, it was found that they classed dementia as a mental illness but were sensitive to traditional

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[16]   See section on stigma (p. 45) in Section 5 of this report.

religious and spiritual explanations concerning the cause of mental illness (Mackenzie 2006). This included the consequences of an on-going tension between good and evil and the possibility of being possessed by evil spirits. This is echoed by Regan (2016) who cites a fairly old study (by Brownfoot 1998) which reports a tendency amongst people from the Black Caribbean and Irish communities in one area of the UK to perceive dementia as a mental illness with supernatural causes.

Dementia has also been described as a punishment for not praying enough, not having sufficient faith to ward off evil spirits, as a punishment for something the person with dementia or his/family did in the past (Adamson 2001, Mackenzie 2006) and in terms of reincarnation and karmic retribution (APPGD 2013, Regan 2016). In a study by Nielsen and Waldemar (2016), some participants from the Pakistani and Turkish ethnic groups living in Denmark described their belief that a reduced lifespan of people with dementia was an act of Allah rather than a consequence of the underlying disease.

Dementia as a hereditary disorder

Many people, irrespective of their ethnic background, are concerned that they will develop dementia because they have a close relative with dementia, but the vast majority of cases of dementia are not inherited. For some dementias, there are inherited and non-inherited forms. Only a tiny percentage of cases of Alzheimer's dementia (AD) are inherited compared to 30 to 50 per cent for frontotemporal dementia (Alzheimer's Society 2018). In some minority ethnic groups, the fear that dementia can be inherited is perhaps greater because of fears that dementia could have a negative impact on the family unit in terms of stigma and marriage prospects of younger relatives in the case of arranged marriages[17] (Mohammed 2017). Such heightened concerns, when combined with a lack of understanding about dementia, may lead to assumptions that all forms of dementia are inherited.

Other perceived causes and precipitating factors

Within the context of perceiving dementia as a medical condition, some minority ethnic carers have described their beliefs about factors which may have led to the onset of the condition. Examples include major life events such as retirement or bereavement, other physical conditions, medication for other conditions, moving house and social isolation (Adamson 2001, Mukadam et al. 2015). It should be noted, however, that these beliefs, as well as those linked to normal ageing, are not radically different to those reported by members of majority ethnic groups (Adamson 2001).

The belief that dementia is contagious has been found to be more common in some minority ethnic groups (Asian and Latinos in the United States and Asians in the UK) compared to their Caucasian counterparts (Ayalon and Aréan 2004, Purandare et al. 2007) but in one study 91.3% of South Asian American immigrants stated that AD dementia was not contagious (Lee, Lee and Diwan 2010).

A large-scale survey carried out by the UK Royal College of Psychiatrists found that only 4% of participants felt that people with AD (AD dementia) were responsible for their condition (Crisp 2005)[18]. However, in some minority ethnic groups, a person may be considered as being responsible for dementia because of social, physical and emotional factors or failure of the family to provide proper care and support (La Fontaine 2007) and in the US because of laziness and weakness of character (Low and Anstey 2009) and bad feng shui (Mahoney et al. 2005). In some minority ethnic groups, people who moved to Europe believe that dementia does not exist in their country of origin because everyone one lives together, the implication perhaps being that dementia is caused by loneliness and isolation (Antelius and Kiwi 2015).

Learning from other countries

In addition to literature about how people from minority ethnic groups make sense of dementia, there is a body of research into lay people's perceptions of, emotional reactions to and knowledge about dementia in different countries in Europe. Examples include studies carried out in Turkey (Sahin et al. 2006), Greece (Tsolaki et al. 2009), France, Germany, Poland and Spain (Blendon et al. 2012), and Israel (Cohen, Werner and Azaiza 2009, Werner and Davidson 2004 and Werner, Goldstein and Buchbinder 2010). Such information could be helpful when developing culture-specific materials and Alzheimer Associations could share the materials they have with associations or groups trying to develop culturally appropriate materials for minority ethnic groups. The German and the Turkish Alzheimer Associations, for example, created a twinning project which ran from 2013 and 2017 and the Turkish Alzheimer Association participated in an event for the Turkish community in Augsburg organised by the German Alzheimer Association in 2018.

Gaining access to minority ethnic groups

Successful awareness raising is also dependent on reaching people from the target communities, including the general public, people who may develop dementia or already have dementia, informal carers and key stakeholders in the community. The usual channels of communication (e.g.

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[18] See also Section 5 on Support and Care, sub-section on stigma (p. 45).

distribution of materials at stands, in chemist's, community centres, GP surgeries, and in places and by people or organisations which correspond to the interests and practices of the main ethnic group), may have limited success. Researchers and service providers are increasingly looking for appropriate ways to raise awareness within minority ethnic groups. As Rauf (2011) states, it is important to be proactive so as to avoid "hard to reach" becoming "easy to avoid". The following are examples of various approaches used in the UK and the Netherlands:

- holding roadshows in areas with a high population of people with a minority ethnic background, facilitated by people from the community and having the relevant language skills; specifically targeted at Indian, African and Caribbean, and East and Central European ethnic groups, including people with dementia, carers, relatives and members of the community (Parveen, Peltier and Oyebode 2017),
- reaching out to people in community centres, places of worship, sheltered housing and day centres and through community radio stations such as Radio Ramadhan and Radio Haji in the Bradford area (Rauf 2011),
- reaching out to family carers by ethnic bilingual professionals in community volunteer centres and starting co-creation processes with them (Smits et al 2018),

- establishing trust before broaching the topic of dementia, achieved by making initial contacts and consulting relevant members of minority ethnic communities (e.g. by a researcher spending time talking to older Sikh men at Gurdwaras and in barber shops, waiting for them to ask her about her research and then talking about dementia) (Baghirathan 2018),
- providing a dedicated Community Psychiatric Nurse to provide information about dementia to Punjabi-speaking Asian elders (Kaur et al. 2010).

Some researchers and services providers emphasise the importance of gaining the support and trust of influential people within the minority ethnic group such as spiritual leaders and people with respected roles in the community (Truswell 2018). This was echoed by Jaakson (2018) who found it essential to obtain the support of elders in order to gain access to and raise awareness about dementia within the traveller community in Finland.

The provision of accessible information about dementia serves to raise awareness, help people to understand issues they or people they know may be experiencing and find out where and from whom to obtain further advice about possible diagnosis, available support, care and treatment. The provision of information does not, however, always lead to people from minority ethnic groups seeking further advice, a diagnosis and support.

Key points from the section "Raising awareness about dementia amongst minority ethnic communities"

- It is important when trying to raise awareness about dementia to understand how people from different ethnic groups make sense of dementia (i.e. whether it is perceived as part of normal ageing, a mental disorder, a hereditary condition, a test or punishment from God etc.).
- In some languages there is no word for dementia. Sometimes, there are everyday/colloquial terms (e.g. linked to old age, forgetfulness and confusion) instead of or as well as medical terms.
- There is some degree of confusion amongst people from all ethnic groups about the difference between dementia (i.e. a syndrome) and Alzheimer's disease (AD), as well as other conditions (which can cause dementia). Recent changes in the conceptualisation of AD may add to this confusion.
- In some cultures, there is no concept of 'carer' in the sense of a person (usually a close relative) who provides care and support on a voluntary, unpaid basis. Providing such care and support is considered as natural or a basic responsibility of relatives.
- Minority ethnic groups may be difficult to reach but this does not justify ignoring them.
- Low levels of literacy, language difficulties and lack of trust need to be considered when developing communication materials and strategies.
- Many people with dementia from minority ethnic groups have some difficulties with the language used by the majority ethnic group and some are illiterate in their own mother tongue.
- People from the minority ethnic communities for whom communication methods and materials are being developed and implemented should be actively involved in that process.

Recommendations/points for reflection

- Culturally appropriate channels and means of communication must be developed and used to reach people with dementia and carers from minority ethnic groups. This should include written materials but also face-to-face and audio-visual approaches.
- Awareness raising materials targeted at specific minority ethnic communities should include images which reflect typical life in those communities (e.g. photos or images of environments, scenes and people) and use examples that people from those communities can relate to.
- People from minority ethnic groups should be involved in the development of culturally appropriate materials and messages.
- Collaboration between Alzheimer Associations should be considered when seeking to raise awareness about dementia amongst different minority ethnic groups, bearing in mind that local communities may have slightly different perceptions about dementia, different ways of talking about it and different cultural experiences.
- Efforts should be made to build up trust within ethnic minority communities before and as part of a proactive awareness-raising campaign or initiative.
- Awareness-raising materials should describe the typical progression of dementia and emphasise the potential benefit of support for various issues that might arise.
- More research should be carried out into the perceptions held by people from minority ethnic groups about dementia, health and care.

Promoting initial help seeking

Whether or not a person seeks help for symptoms (which might be an indication of dementia) depends on several factors which may be influenced by culture. Morhardt, Pereyra and Iris (2010, p. 42) describe this as follows:

> "Individuals' knowledge about an illness is generally linked to what they do about it. The literature looking at health behaviors (Leventhal et al., 1984) and mental health literacy (Jorm et al., 2000), suggest that people attempt to understand their symptoms based on what they know about an illness, and that in turn affects their recognition of a problem, whether to seek help, manage or consider prevention (Jorm, 2000; Jorm et al., 2000; Werner, 2003 and 2004). Culture influences how people define, perceive, and respond to illness and explains variations in illness related behaviors" (Andrulis, Brach, 2007; Chrisman, Kleinman, 1983).

This is echoed by Mukadam, Cooper and Livingston (2011) who concluded, on the basis of a systematic review of ethnicity and pathways to care in dementia, that beliefs about the aetiology of symptoms strongly influence whether people from minority ethnic groups access healthcare. The lower socio-economic situation of many people from minority ethnic groups in Europe may also influence help seeking. In deprived neighbourhoods, although there is a higher prevalence of unhealthy lifestyles and low self-management of disease. There is also a lower uptake of health-promoting services (van den Broeke 2017). Many people do not seek help when they first experience concerns. Some of the reasons for this are discussed below. This section focuses on issues linked to initial help seeking. Some of these issues are also relevant to accessing support and care but this is addressed in more detail in Section 4.

How different perceptions of dementia affect help seeking

As with various medical conditions and disability, the perceived cause of dementia often reflects what a person decides to do about it. So if dementia is considered as part of normal ageing (normal being understood as typical or common amongst older people or as non-pathological in the sense of not being abnormal for older people) rather than a medical condition, there may be little incentive to seek medical advice (Alzheimer Europe 2013). If a person starts to exhibit behaviour that relatives find more challenging, the family may start to question whether it is normal or perhaps something else that necessitates

medical attention but by then the family may already be in a crisis.

If the causes are believed to be spiritual, people may consider it more appropriate to pray or consult spiritual leaders or faith healers than their GP (Kenning et al. 2017, Mohammed 2017). In a study by Giebel et al. exploring differences between South Asians who did and did not consult their GP about dementia, there was a significant[19] association between not consulting and the belief that memory problems were given by God and that it was not appropriate to seek medical attention (Blakemore et al. 2018). Exorcism may also sometimes be considered a more suitable approach (APPGD 2013).

The perception of dementia as a mental disorder could have an impact on help seeking as it could be considered as a stigma, bringing shame on the family and affecting the marriage prospects of younger relatives (Rauf 2011). This may also be linked to dementia (or mental disorders in general) being considered as 'running in the family' (being genetically transmissible). In the case of arranged marriages, relatives of the bride and groom typically look into the backgrounds of the family they plan to marry into. Finding out about a mental illness (which may also be considered as hereditary) could result in the family honour being lost (Mohammed 2017). If dementia in a relative is believed to be caused by another's wrongdoing, then that person may be heavily criticised (as it was that person's fault) and this may result in extra strain on the family, on willingness to seek help and on subsequent coping (Adamson 2001). A study into attitudes of South Asians towards help seeking found that perceived social pressure was the strongest predictor for not seeking help (Hailstone et al. 2017).

Some of the other beliefs mentioned earlier surrounding the origin of dementia may also interfere with timely help seeking, leading to a focus on blame, bad luck or unavoidable life events (e.g. in the case of perceptions of dementia being due to retirement, bereavement, moving to a new house, loneliness, lack of proper care and support from the family, laziness or weakness of character).

Based on advice from South Asians in the UK, Mukadam et al. (2015) suggest trying to normalise help-seeking, breaking down stigma and emphasising the physical rather than mental nature of dementia. They also suggest using images of people from minority ethnic groups in information materials but there were different views

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[19] For a lay explanation of statistical significance, please see: https://digest.bps.org.uk/2010/08/16/statistical-significance-explained-in-plain-english/

about which age groups or section of the community the information should be targeted at.

Language barriers to help seeking

Language difficulties may result in health and social care providers often not being able to ensure that people from minority ethnic groups are aware of dementia, able to understand awareness-raising materials (even in their own language if illiterate), know where to obtain information and are able to ask for it (Moriarty 2015). In some areas, materials and bilingual care workers may be available but people do not always know about them and may wrongly assume that such support is not available. Some people with dementia from minority ethnic groups find it difficult to communicate potential symptoms of dementia to their families or their GP. This could be due to a number of factors such as not realising that the symptoms they are experiencing might be linked to a medical condition (such as dementia), not being sufficiently fluent in the language of the country and not having an appropriate vocabulary in their own language (Muhammed 2017).

Lack of knowledge about dementia and services

Limited knowledge about dementia and available services may serve as a barrier to seeking help. This may be changing but not everywhere. In the UK, for example, people from Hindu, Muslim, Jain, Sikh and Christian religions, as well as a small number not associating themselves with a particular religion, have obtained higher score for knowledge about dementia than in earlier studies (Purandare 2007, Hailstone et al. 2017). This may indicate that knowledge about dementia has increased in the UK amongst some minority ethnic groups but this is not necessarily the case amongst all minority ethnic groups, especially in other countries where efforts to increase awareness in general and amongst minority ethnic groups have not been made or have not been as successful. Also, differences may have been due to other factors such as an increase in general levels of education or specific features of the sample. Moreover, increased awareness about dementia needs to be accompanied by knowledge about the availability of services and this is something that is still lacking (Ahmed et al. 2017).

Health literacy

When trying to understand barriers to help seeking such as language difficulties and lack of knowledge, it is important

to avoid 'blaming' people from minority ethnic groups and to realise that communication is a two-way thing. Healthcare organisations have a responsibility to provide accessible information and care, and do not always succeed in doing so. Although health literacy is commonly defined as "the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker 2000 in Brach et al. 2012, p. 1), it is increasingly being acknowledged that healthcare organisations and the complexity of health care systems contribute towards health illiteracy. Brach et al. (2012) talk about 'health literate healthcare organisations' and emphasise their role in addressing health literacy as an essential part of providing person-centred care.[20] In the context of health literacy about dementia for people from minority ethnic groups, Ruud (2017, p. 230) suggests that in order:

> "to change people's health seeking behaviour, it is imperative that information is given early, is perceived as relevant, is clear, is easy to understand, and applies to a person's life situation."[21]

The 'personal budget' system, which operates in some European countries permits people to manage their own care and support and this can include paying relatives and friends to provide particular services. Whilst there has been some uptake of this option, language difficulties and poor health literacy skills may be obstacles. In the Netherlands, a whole network has evolved of people offering help to navigate through the system. In other countries, it is sometimes necessary to go through gate keepers in order to be entitled to some forms of support but people are not aware of this or of the existence of such support. A system which has the potential to promote autonomy and support a family-orientated approach to the provision of care will fail if it is too complex. Clearly, health and social care providers need to take measures to contribute towards health literacy, starting with simplifying their own systems of support and where necessary providing 'the support to gain support'.

In connection with communication problems and lack of healthcare literacy, Levesque and colleagues (2013) have stressed the importance of ensuring that people from minority ethnic groups are able to recognise potential health needs and know how to seek and obtain appropriate services (Suurmond et al. 2016). They emphasise not only barriers to initial and subsequent health seeking but also the corresponding abilities that people need to have in order to overcome those barriers.

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[20] For more information about health literate healthcare organisations and guidelines, please see article by Brach et al. (2012) at: https://nam.edu/wp-content/uploads/2015/06/BPH_Ten_HLit_Attributes.pdf

[21] For a detailed discussion about health literacy and tailoring information on dementia for migrants and ethnic minorities, please see Chapter 8 in the report by Sagbakken and Kumar: https://www.fhi.no/globalassets/dokumenterfiler/rapporter/2017/sagbakken-kumar-dementia-ethnic-minorities-and-migrants-nakmi-rapport-2-2017.pdf

Distrust of GPs and of the healthcare system

GPs are frequently consulted for a range of health issues and these consultations represent windows of opportunity to recognise and discuss problems or symptoms, provided that GPs are able to dedicate the necessary time for this. Practice nurses and community nurses may also have such an opportunity and having established a relationship of trust over time be able to detect signs of possible cognitive deterioration (Suurmond et al. 2016).

Unfortunately, distrust of GPs and the fear of racism may hinder help seeking within some minority ethnic communities (Shah 2007, APPGD 2013, Kenning et al. 2017). Even when people have contacted their GP (in the UK), they have not always been successful in obtaining a diagnosis from the memory assessment teams and some report feeling that they have been 'fobbed off' (Rauf 2011). In addition, some carers (African Caribbean and South Asian in the UK) have expressed the opinion that mental health services can only offer a diagnosis, not treatment, care or support and that consequently obtaining a diagnosis does not have great impact on people's lives (Mukadam, Cooper, Basit and Livingston 2011). African Caribbeans and South Asians in another study have stated the opinion that the knowledge basis of GPs varies considerably and feel that this has led to initial misdiagnoses and delays in accessing specialist services (Jolley et al. 2009). Finally, in some minority ethnic communities, people may fear that, should they be diagnosed with dementia, their diagnosis would not be kept confidential by their GP (Mohammed 2017).

Members of the traveller communities in the UK are sometimes distrustful of GPs, fearing that consultations may lead to members of the family being institutionalised, forced to settle or separated from the rest of the family. This, combined with past experiences of culturally inappropriate services and contact with insensitive healthcare professionals, results in members of these communities often not seeking help or only in cases of crisis (Dementia Action Alliance 2018, Rattigan and Sweeney 2018). However, when they find a trusted GP or healthcare professional who respects their culture, some people from traveller communities will travel to consult them and consider taking up the offer of care and support (MECOPP 2012, DAA 2018, Rattigan and Sweeney 2018).

Transnational networks

Some people from some minority ethnic groups do not seek help, either in relation to diagnosis or to the use of services and support, because they rely on transnational networks of support. In Finland, for example, some older people from minority ethnic groups linked to the former Soviet Union and Estonia have very strong ties with their children who travel to Finland regularly to help with all kinds of tasks and maintain social ties across the border (Heikkinen and Lumme-Sandt 2013). Whilst people from these communities may be involved to some extent in the Finnish community, their focus of attention and emotional ties are predominantly with people outside of Finland. Some people from the former Soviet Union speak some Finnish, but in many cases it is 'old Finnish' and they can only understand basic everyday terms. Their knowledge of social services is weak and it is challenging for them to find available help (Voutilainen, Manninen and Vaarama 2003).

Key points from the section "Promoting initial help seeking"

- There are several possible reasons why some people from minority ethnic groups do not seek help in relation to dementia (e.g. linked to language, poor health literacy and the way they perceive dementia).
- Language barriers and lack of knowledge about dementia and the availability of services and support may result in some people from minority ethnic groups not realising that support is available and that they are entitled to it.
- Even if aware of available support, some people from minority ethnic groups would not be able or know how to go about obtaining it.
- Some people from minority ethnic groups are distrustful of health and social care professionals and of the healthcare system. They may, for example, have fears of being put into residential care, of being misdiagnosed, of lack of confidentiality, of health and social care professionals not respecting their culture or of being offered inferior care.

Recommendations/points for reflection

- Health and social care professionals should have some awareness about perceptions of dementia and care which are common amongst people from particular minority ethnic groups (but not everyone in that group) and consider how this might influence the attitudes and readiness of the latter to seek help.
- Health and social care professionals should try to normalise help-seeking and discuss possible symptoms of dementia in a factual way, albeit taking into consideration a person's beliefs about the condition, as a means to reduce stigma associated with dementia and with seeking help.
- It should not be assumed that failure to seek initial help means that a person would not benefit from diagnosis or future support, or that people from minority ethnic groups "look after their own".
- Health and social care providers should consider how to reach out to 'grass roots' organisations and local cultural groups either as a means to reach members of minority ethnic group or in order to seek their advice on how to increase help seeking.
- Policies should be developed to promote better coordination between GPs and other health and social care providers as well as a better system to share knowledge about available services and support.
- It should be acknowledged that some people from minority ethnic groups lack trust in GPs and in the healthcare system. Efforts should be made to build up that trust. This might, in part, be addressed in awareness-raising campaigns about dementia for people from minority ethnic groups and involving people from minority ethnic groups in such campaigns.
- People who find it difficult to seek medical advice/help in case of concerns, such as many people from minority ethnic groups, should have access to a free care navigator/coordinator/link worker. The existence of such a service should be well publicised, easy to access and free of charge.
- Organisations providing health and social care should strive to promote health literacy and to ensure that their own practices and procedures are understandable and straightforward.
- Health agencies could conduct outreach work to leaders in the local community to help create grassroots knowledge and use this to help promote a positive understanding and attitude about help seeking and possible support.
- Support should be provided to people with dementia from minority ethnic groups to develop the abilities needed to seek initial help and to access possible future services.

4. Issues surrounding diagnosis, assessment and treatment

This section explores issues surrounding timely and accurate diagnosis. After an initial reflection about why and in what way timely and accurate diagnosis is a specific issue for people with dementia from minority ethnic groups, we consider some of the key barriers to such diagnosis, paying particular attention to the need for culturally appropriate assessment and diagnostic tools. This includes a description of some of the available tools and an overview of the key challenges to assessment and diagnosis such as language difficulties, limited or no education and problems

with interpretation. There are, of course, numerous people from minority ethnic groups who are literate, proficient in the language used by the majority ethnic group, familiar with the principles of testing and highly educated. However, the concerns and issues addressed in this section focus on those who are not and for whom culturally inappropriate and insensitive procedures and tools may result in inadequate assessment and diagnosis. The section ends with a discussion about possible inequalities in access to and use of treatment by people from minority ethnic groups.

The complexities of dementia diagnoses in minority ethnic groups

Potential barriers to the assessment and to the accurate and timely diagnosis of dementia

Ethnicity is unlikely to have an impact on pathological processes underlying the appearance and evolution of dementia syndromes (Khan and Tadros 2014) and the symptoms of dementia seem to be similar across different ethnic groups (Nielsen et al. 2011a). However, there are certain issues which render the timely and accurate diagnosis of people from minority ethnic groups more problematic compared to people from the majority ethnic group. Examples of potential barriers to timely and accurate diagnosis include difficulties with language and communication, cultural perceptions of dementia and health, stigma and taboo, prejudice, structural discrimination and failure of GPs to refer patients from minority ethnic groups (Beattie et al. 2005, Nielsen at al. 2011a and 2011c). Some of these barriers have been discussed in Section 2 of this report in relation to initial help seeking. However, the combined impact of these factors on initial help seeking and on receiving an accurate diagnosis may contribute towards people from minority ethnic groups being diagnosed at a later stage of dementia. This, in turn, may affect their quality of life in that they do not receive support and treatment in the earlier stage of dementia. This sub-section starts with a brief overview of issues related to under and over-diagnosis of people from minority ethnic groups and considers possible predisposing/risk factors for certain groups, before moving on to explore some of the key issues which may affect timely and accurate assessment and diagnosis.

Prevalence of dementia and certain symptoms of dementia in people from minority ethnic groups: under-diagnosis and misdiagnosis

As mentioned in the Introduction, the proportion of older people within minority ethnic groups living in Europe is increasing (Nielsen et al. 2011, Diaz, Kumar and Engedal 2015) and many will develop dementia in the next few decades (APPGD 2013, Prince et al. 2015, Nielsen et al. 2015, Parlevliet 2017). In the Netherlands, for example, non-Western immigrants accounted for 4.7% of the population in 2014, and it is estimated that this will increase to 8.5% in 2030 (Parlevliet et al. 2016)[22]. Timely consultation and diagnosis of dementia amongst minority ethnic groups is essential to ensure that people from these groups have access to support and treatment on the same basis as people from majority ethnic groups.

Whilst people from minority ethnic groups experience the same symptoms of dementia as people from the majority ethnic group, they may describe them differently and have difficulty doing so because of limited linguistic abilities and lower levels of education (Nielsen et al. 2011a). In addition, GPs may encounter difficulties understanding the person from a minority ethnic group (due to language and the way the person expresses him/herself) and correctly interpreting answers to questions about the person's cognitive and physical functioning. Some professional care workers in the UK have expressed the opinion that most GPs

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[22] Based on figures from Statistics Netherlands [Centraal Bureau voor de Statistiek].

lack the cultural and linguistic skills to diagnose people from minority ethnic groups (Beattie et al. 2005). However, in most cases, GPs and specialists do not have access to culturally and linguistically appropriate cognitive test instruments and dementia rating scales (see next sub-section on this topic).

Despite the diagnosis of dementia being a complex process, with additional challenges for the diagnosis of people from minority ethnic groups, many people are not referred by their GP to a specialist. In a Swedish study, for example, GPs estimated that they referred less than 20% of their patients to a specialist for a possible diagnosis of dementia (Olafsdóttir, Foldevi and Marcusson 2001). Most people with dementia do not receive a formal diagnosis, either from their GP or from a specialist (Diaz, Kumar and Engedal 2015). Nielsen et al. (2015) point out that in Denmark, only 11% of the expected number of older people from minority ethnic groups with dementia receive a formal diagnosis of dementia.

A UK-based study comparing the number of people from White, Black and Asian ethnic groups diagnosed with dementia in 2015 revealed differences in the proportions of people from White, Black and Asian ethnic groups receiving such a diagnosis (Pham et al. 2018). People from Asian ethnic groups had the lowest proportion of diagnoses, followed by people from Black ethnic groups, with a slightly higher proportion of diagnoses, and people from the White ethnic group having the highest proportion of diagnoses. In a Norwegian study, the diagnoses of over one and a half million people over the age of 50 were analysed (Diaz, Kuman and Engedal 2015). The researchers compared diagnoses of dementia and diagnoses of memory impairment (25,915 patients) within two groups, classified as Norwegian and immigrant (most immigrants having lived in Norway for more than two decades). They found a significantly higher proportion of diagnoses of dementia in the Norwegian group. The researchers involved in these studies acknowledge that whilst a lower prevalence of dementia in the immigrant groups cannot be ruled out, other explanations probably explain the findings. For example, general practitioners may sometimes overlook patients' difficulties using or finding the right words if those patients have never been able to speak the language fluently (Uysal-Bozkir 2016).

In addition to probable under-diagnosis of people with dementia from minority ethnic groups, evidence of over-diagnosis has also been found, with unusually higher rates of diagnosis in some minority ethnic sub-groups being recorded (Nielsen et al. 2011b). In a population sample consisting of 67,219 people from minority ethnic groups in Denmark, diagnoses of dementia were compared to rates observed in the overall Danish population. In the 40 to 59

age group, prevalence was similar to that of the general population for men but more than double for women from minority ethnic groups. In the 40–49 age-group, prevalence was twice as high for men and almost three times as high for women in minority ethnic groups. Rates for the 60+ age group suggested considerable under-diagnosis (one seventh of the general rate for men and one third the general rate for women from minority ethnic groups). Nielsen et al. (2011) point out that low prevalence rates in the under 65 age group of people from minority ethnic groups have been found in other studies in Sweden and the UK and suggest that the higher rates recorded in Denmark could reflect misdiagnoses.

Differences in the prevalence of behavioural and psychological symptoms of dementia (BPSD) in people from minority ethnic groups have also been reported. Diaz and Qureshi (2017) describe findings from a UK study which suggests that people with dementia from the Indian sub-continent have a lower prevalence of anxiety and phobias compared to the majority ethnic group. In a review of research into the prevalence of BPSD amongst different ethnic groups in a range of countries, several differences were found but none of these were based on European populations[23] (Shah, Dalvi and Thompson 2005). The exact reasons for these differences are not known.

There is also some evidence that people from minority ethnic groups do not receive the same quality of diagnostic evaluation for dementia. Nielsen et al. (2011c) evaluated the diagnostic workup for people diagnosed with dementia from minority ethnic groups in Denmark. They found that only 23% of patients had received an acceptable workup (i.e. consisting of well-conducted diagnostic tests and evaluations). Compared to the majority ethnic group, significantly fewer patients from minority ethnic groups received a detailed history of cognitive symptoms, a cognitive test, neuroimaging, blood tests and a test of activities of daily living, were significantly lower as part of their diagnostic workup. This suggests that they received a sub-standard diagnostic evaluation.

Nielsen et al. (2011b and 2011c) further point out that their results, as well as those of several other studies, suggest that many people from minority ethnic groups are misdiagnosed as having dementia, and that some may have psychiatric disorders. Beattie et al. (2005, p. 71) suggest that "there is a historical and pervasive racism in the mental health system that would lead black people to be mislabelled as having dementia when they really had a different mental health problem". Most of the people from minority ethnic groups involved in the Danish study mentioned above received a diagnosis with no specification of the type of dementia and without subsequent follow-up or treatment (Nielsen et al. 2011b).

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23 With the exception of one UK study.

Nielsen et al. (2011c) draw attention to linguistic and cultural factors affecting evaluations, to the way that interpretation is provided, with a heavy reliance on assistance from relatives, to compliance of patients from minority ethnic groups with the diagnostic process, to difficulties distinguishing depression from early dementia and to the lack of culturally appropriate assessment and diagnostic tools (these issues are discussed further in this section).

Predisposing/risk factors

When looking at different factors which might explain a higher or lower prevalence of dementia amongst people from minority ethnic groups, it is important to consider possible factors which might predispose or on the contrary protect people from certain ethnic groups from developing dementia. These factors are mainly linked to other medical conditions, to people's life experiences or to some of their lifestyle habits. In most cases, they increase a person's likelihood of developing dementia. For example, some minority ethnic groups are at greater risk of diabetes and vascular disease, and both of these conditions are recognised risk factors for dementia (Richards et al. 2000, Adelman 2011, Bhattacharyya and Benbow 2013, European Union 2014, Uysal-Bozkir et al. 2016). Higher rates of stroke in young adults in some minority ethnic groups and of depression, especially in women, have also been reported (see Nielsen et al. 2011b). A few studies have found high rates of hypertension amongst people of African origin living in the UK and the USA (Livingston et al. 2017).

Type 2 diabetes is up to six times more common in people of South Asian origin (of Indian, Pakistani and Bangladeshi descent) in the UK (Khunti, Kumar and Brodie 2009).

According to Sattar and Gill (2015), migrant South Asians seem to be more insulin resistant than White Europeans but there is no clear evidence suggesting genetic factors for increased rates of diabetes. Sattar and Gill suggest that epigenetic factors[24] may contribute considerably and that South Asians should be "encouraged and helped, by various culturally appropriate methods, to maintain a high physical activity level and low bodyweight across the life course to prevent diabetes". Given the relationship between diabetes and cardiovascular conditions within some minority ethnic groups and the increased risk of developing dementia, there is an urgent need to raise awareness about dementia, develop culturally appropriate diagnostic tools but also to develop preventive strategies specifically targeted at minority population which are at greater risk of dementia (Nielsen et al. 2011b).

A few recent studies suggest that non-medical factors such as social isolation, lower socio economic status and having a lower cognitive reserve[25] also increase the risk of developing dementia (Livingston et al. 2017). As pointed out by Qureshi and Diaz (2017), these factors are quite common amongst people who have experienced migration (and might also apply to many people from minority ethnic groups without a migratory background). Although people from some minority ethnic groups might be more affected by certain risk factors and hence at higher risk of developing dementia, some of those who migrated to Europe might also have more opportunities to reduce the risk of developing dementia (e.g. through increased awareness and knowledge about risk factors and healthy lifestyles, and perhaps through having the means to act on that information). However, the very factors which might increase risk, probably interfere with the ability to benefit from such opportunities.

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[24] "Whenever two genetically identical individuals are non-identical in some way we can measure, this is called epigenetics... epigenetics can be defined as the set of modifications to our genetic material that change the ways genes are switched on or off, but which don't alter the genes themselves" (Carey 2012, p. 6–7)

[25] This term is used to describe how some people can maintain normal cognitive functioning despite having damage to their brains. As they have a greater brain reserve in the first place, damage to the brain does not have as great an impact on their cognitive performance (e.g. language, reasoning and memory). It is believed that education/learning helps increase this reserve. For a more detailed explanation of cognitive reserve, please see: https://www.health.harvard.edu/mind-and-mood/what-is-cognitive-reserve

Key points from the section "The complexities of dementia diagnoses in minority ethnic groups"

- Certain factors such as diabetes, high blood pressure, depression, social isolation, lower socio-economic status and having a lower cognitive reserve, which tend to be more frequent amongst people from some minority ethnic groups, may increase the risk of developing dementia.
- Some people from minority ethnic groups have an increased risk of developing dementia and the population of older people from minority ethnic groups, who have or may eventually develop dementia, is increasing. The diagnosis of people from these groups remains problematic, often resulting in under-diagnosis and for some sub-groups in misdiagnosis.
- Language difficulties and lack of cultural awareness may result in symptoms of dementia not being detected by healthcare professionals (e.g. because some patients already have communication problems to start with, because they may describe symptoms in a different way and because they may express or deal with symptoms in different ways).
- GPs often fail to refer their patients to a specialist for a full diagnostic evaluation for dementia.
- Many people with dementia from minority ethnic groups receive a sub-standard diagnostic work up compared to that provided to majority ethnic groups (i.e. consisting of well-conducted diagnostic tests and evaluations).
- Some studies report a lower percentage of people from minority ethnic groups receiving a diagnosis with specification of the type of dementia that they have.

Recommendations/points for reflection

- Attention should be paid to the management of risk factors which are potentially modifiable (e.g. high blood pressure, obesity and diabetes) and more prevalent in some minority ethnic groups.
- Measures should be taken to improve timely and accurate diagnosis of dementia amongst minority ethnic groups. The fact that people visit their GP with complaints relating to dementia risk factors such as cardiovascular disease and diabetes may be helpful in initiating discussion about dementia.
- Further research is needed to explore challenges for general practitioners, neurologists, geriatric psychiatrists and other healthcare professionals involved in diagnosis and issues related to the under-diagnosis as well as misdiagnosis, especially resulting in the over-representation of dementia in younger minority ethnic populations.
- More research is needed into the prevalence of BPSD amongst people from minority ethnic groups and into how people from minority ethnic groups cope with these complex needs.

Challenges surrounding the development of culturally sensitive assessment and diagnostic tools

Language, literacy and lack of culturally appropriate diagnostic tools

Although biomarkers are increasingly playing a role in the diagnostic work up of AD dementia, dementia is still very much a clinical diagnosis which relies on verbal interaction, observation of behaviour and cognitive assessments (Fields, Ferman, Boeve and Smith 2011). Language difficulties and illiteracy may hinder the timely and accurate assessment and diagnosis of people from some minority ethnic groups. Although literacy is usually associated with schooling, the term is not dependent on a person having received formal education. A commonly cited definition is that provided by UNESCO in 1958 which was that "a literate person is one who can, with understanding, both read and write a short simple statement on his or her everyday life." In 2006, in an independent report commissioned by UNESCO, it was emphasised that literacy skills are independent of the context and background of an individual[26].

A high proportion of Arabic-speaking older people in the Eastern Mediterranean Region are illiterate (Chaaya et al. 2016), including many older people from Morocco, with people of Moroccan origin constituting the largest group of non-European migrants in Flanders (Berdai Chaouni and De Donder 2018). In the South Asian community in the UK, only 35% of older people over 65 years of age can speak English and only 21% can read and write English, often communicating in their first language, which for many is Urdu (Blakemore et al. 2018). A 2011 census of England and Wales further revealed that only 40% of people from traveller communities had any formal qualifications. In a study involving Turkish immigrants in Denmark, Nielsen and Jørgensen (2013) demonstrated how illiteracy can affect a person's performance on cognitive tests. Considerable differences were found between people who were illiterate compared to those who were literature. Appendix 3 (p. 88) provides examples of typical mistakes that people make when asked to copy four different line drawings of shapes and in filling in the numbers and hands on the drawing of a clock. When comparing the drawings, please note that none of the participants in the study had dementia. The drawings of the illiterate participants show how being illiterate might easily contribute towards the misdiagnosis of dementia by affecting scores on certain diagnostic tests.

In countries with a long history of migration (e.g. due to colonisation), people from minority ethnic groups tend to have fewer difficulties understanding the language and culture than in countries where migration is more recent (Nielsen et al. 2011a). Despite considerable linguistic and cultural diversity amongst members of minority ethnic groups in Europe, most countries in a cross-country comparison carried out by Nielsen et al. (2011a) used cognitive assessment instruments with people from minority ethnic groups which have only been validated in populations from the Western culture and relied on relatives for interpretation (as well as professional interpreters). The lack of access to culturally sensitive screening and diagnostic tools is a major challenge facing GPs and specialists, resulting not only in under-diagnosis of dementia in minority ethnic groups but also in over-diagnosis (Nielsen, Vogel, Phung, Gade and Waldemar 2011b).

Education

Whereas some people from majority ethnic groups, especially of the older generations, may have had little or no formal education, this is more common amongst some minority ethnic groups. Standard screening tests used for screening and diagnosing dementia have repeatedly been found to be biased with regard to education (Goudsmit et al. 2018). Education often involves learning things and doing tasks which are not necessarily considered important or relevant at the time but people (usually children) have little choice and become accustomed to doing such tasks. Lack of formal education (such as schooling) may result in people finding seemingly simple tasks, such as drawing a clock face or a cube, difficult. They might never have drawn geometric shapes or done much drawing in general. People get used to using and holding pens and pencils at school and continue to use pens and pencils to write and draw in their everyday lives. Good performance on some drawing or copying tests, for example, requires fine motor finger movements as well as visuospatial skills, and tests which involve visually guided motor behaviour (e.g. moving a cursor on a computer screen) may be biased by literacy (Ardila et al. 2010). People who are illiterate lack this kind of familiarity with pencils and pens and this may affect their performance on tests (Soumaya 2018). In addition, people with limited or no schooling may feel under stress and be totally unfamiliar with the concept of cognitive testing. According to Ardila et al. (2010), as little as 1 to 2 years' schooling can make a significant difference in performance on some neuropsychological tests.

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[26] For further information about literacy and illiteracy, including definitions from several countries, please see Chapter 6 of the 2006 report commissioned by UNESCO: http://www.unesco.org/education/GMR2006/full/chapt6_eng.pdf

People with no or low levels of education also tend to perform worse on tests involving naming, comprehension, verbal abstraction, figure recognition and orientation (Goudsmit et al. 2018). They also tend to be less 'test-wise', to be unfamiliar with the formal procedures associated with testing and sometimes to find line drawings difficult to interpret (Ardila et al. 2010, Goudsmit et al. 2018). It should also be noted that the content of formal education may be radically different in countries from which some people from minority ethnic groups migrated.

Education not only provides knowledge but also contributes towards the development of certain abilities and attitudes (Ardila 2003). According to Carreiras et al. (2009) and Castro-Caldas et al. (1998 – in Nielsen and Jørgensen 2013), lack of schooling as a child, resulting in people not learning to read and write, affects the functional and structural development of the brain and this is not limited to the language domain of the brain. Nielsen and Jørgensen (2013) also point out that being unable to read and write is often accompanied by a whole range of factors, especially linked to low socio-economic status of the person's family, which may have an impact on cognitive function in later life.

Cultural norms

The concept of cognitive testing was developed in Western society and represents a culture-dependent activity affected by different cultural conditions and idiosyncrasies (Ardila 2003 and 2005). Ardila (2005) describes eight approaches or strategies typically used in cognitive testing which may be unfamiliar to people from some ethnic backgrounds and even violate their cultural norms. These are:

1. a one-to-one relationship (in communities where tasks are carried out in a collaborative way in a social context, a one-to-one, one-off relationship between two strangers involving one performing a task may run counter to cultural norms),
2. background authority (the authority a person is perceived to have which allows him/her to make certain requests such as for the person to do various tasks. It might not be obvious why he or she has such authority and why the other person should comply with requests),
3. best performance (doing one's best may be well understood in competitive societies but in others restricted to important tasks. Some tests may seem absurd and pointless, resulting in the person not making a sufficient effort to 'do well'),
4. isolated environment (the person may be in a room, perhaps even locked, with a person he/she does not know, and this may be inappropriate in some cultures, especially for women),

5. special type of communication (possible lack of familiarity with formal language use in the testing situation),
6. speed (doing things quickly is not necessarily perceived by the people being tested as being better than taking longer and doing a better job),
7. internal or subjective issues (some questions may be perceived as inappropriate and invasive),
8. the use of testing elements or strategies (pictures, images and objects used in tests may be culture-specific).

People from minority ethnic groups may therefore sometimes find cognitive testing difficult and under-perform on tests that are not culturally sensitive. This may contribute towards misdiagnosis, unnecessary further examinations and inappropriate medical treatment.

Translation issues

Translating instruments for the assessment and diagnosis of dementia into the languages understood by members of minority ethnic groups may go some way towards more accurate and timely diagnosis of dementia amongst those groups. The points raised by Ardila (see above) suggest that this would not be sufficient on its own because there are also other cultural issues to consider. However, until more culturally appropriate instruments are developed, it is worthwhile looking at what the issues are linked to the translation of screening and diagnostic tools.

Translated versions of the MMSE exist in several languages from around the World. However, there is a shortage of translated versions of the MMSE that have been validated on relevant minority ethnic groups in Europe. It may not be sufficient to translate an assessment or diagnostic instrument. It should also be validated on the group with whom it will eventually be used and there may be differences in the way a language is used by minority ethnic groups in different settings or countries and of different ages. There are hundreds of different languages spoken by people from different minority ethnic groups, in some cases, several within the same group. As highlighted by Parker and Philp (2004), some people cannot read or write in their mother tongue:

"Many Gujarati women from rural areas of the sub-continent are unable to read or write in their own language. Indian Punjabi speakers comprise Sikhs from Punjab state, and Hindus from Punjab or East Africa. Pakistanis from provincial districts generally speak a Punjabi dialect and may be unable to read or write, while those from the cities speak, read and write Urdu. Immigration from Bangladesh has been more recent: the most common language

spoken is Bengali (also known as Bangla or Bangla-deshi), with some speaking Urdu" (Parker and Philp 2004, p. 447–448).

A major difficulty with some screening and even diagnostic tools for dementia, which might otherwise be suited to people from minority ethnic groups, is that they can only be used by clinicians who are bilingual or with the help of interpreters (Ahmed et al. 2017). Another issue which can be problematic is that healthcare professionals sometimes have difficulty obtaining consent for various investigations (e.g. blood tests and lumbar punctures) which may be needed for the diagnostic procedure (Nielsen et al. 2011a).

Interpretation issues

Assessment and diagnosis may be improved in some cases if good quality interpretation is provided. In some countries or healthcare authorities, people who are not fluent in the language of a country have the right to request an interpreter (Plejert et al. 2015, Majlesi and Plejert 2018). However, interpreters are not always available when needed (e.g. due to a shortage of suitably qualified interpreters in a particular language or dialect, practical issues linked to accessing one when needed and lack of funding for their services). Relatives are often asked or expected to fulfil the role of interpreter and in many cases, given the choice, some members of the family, would prefer a relative to interpret.

Relatives/informal interpreters

There are pros and cons to the use of relatives as interpreters. On the positive side, relatives are often familiar with the person's situation and already know what the person is trying to communicate, they are in many cases trusted (i.e. they will not reveal what the person says outside of the family) and in some cases may be familiar with a particular language that is not spoken by many people and with a dialect that the person speaks. Moreover, at a recent meeting of the Race Equality Foundation (in Bristol in 2018), a healthcare professional from the African-Caribbean community drew attention to the changing nature of some languages whereby the language or dialect spoken by an older person having been born in a different country may be radically different (different words, different ways of using language to express a point etc.) to that currently used (e.g. by second or third generation members of the community). This issue is also relevant to the use of professional interpreters. However, there may be conflicts and family interests which impact on the type of information and details that the relative is willing to convey, resulting

in censorship. Also, some interpreters might not translate a particular comment because they do not think that it is medically relevant (Bolden 2000). Acting as an interpreter may also have an emotional impact on relatives in that it may result in them putting their energy into providing interpretation when they actually need to focus on coping with their own emotions.

Involving relatives in interpretation also means overriding the general principles of respect for privacy and confidentiality. Younger, second or third generation members of the family are more likely to have a relatively good command of the national language and may therefore be expected to fulfil the role of interpreter. Depending on their age and role within the family, they may sometimes have little say in the matter. The use of informal/family interpreters may also mean that the person with possible dementia might be uneasy talking about certain issues which could call into question their standing within the family or lead to personal embarrassment (e.g. having a grandchild interpret information about intimate matters).

Finally, interpretation is a complex skill which requires specialised training. Being fluent in more than one language does not make someone an interpreter. People who are bilingual but have not received interpreter-specific training are more likely to add or omit information in exchanges with the user and have a tendency to interject their own opinions and assumptions, resulting in the transmission of incomplete and/or inaccurate information (NHANES 2006). When using relatives for the purpose of translation, healthcare professionals have no guarantee with regard to the accuracy of the information the latter conveys to the person with possible dementia and to healthcare professionals. Relatives should not be used as interpreters simply to reduce costs or because it is quicker and easier to ask a relative than to find a professional interpreter. This does not mean that they should be totally excluded during the process of obtaining a diagnosis (unless the person seeking diagnosis is opposed to their presence) as they may be able to convey useful information about their relative's difficulties and behaviour.

Professional/trained interpreters

One of the reasons for using relatives as ad hoc interpreters is that it is difficult to find professional, trained interpreters in the relevant languages, dialects and varieties[27], and at the exact time that they are needed. In some countries in Europe certain dialects, with limited numbers of older speakers, are gradually dying out, but in most European and non-European countries many dialects and

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[27] There are numerous varieties of a given language. A dialect is often considered as a variety of a language connected to a specific geographical area, with features on all levels of language, including lexical, phonological, and grammatical ones. It is generally (but not necessarily) mutually intelligible by speakers of a language. Other varieties include style (level of formality) and register (adaptations to particular contexts and participants). What counts as a dialect is also heavily dependent upon cultural and political issues (Schilling-Estes, 2006).

varieties are spoken. In such cases, it is essential that interpreters speak and understand the actual dialect that a person uses. In addition, some people from minority ethnic groups would prefer to have an interpreter of their own age and background (Mohammed 2017). Due to a general shortage of suitable and qualified interpreters, and in some cases the limited number of interpreters who are fluent in a particular dialect, there is a risk of professional interpreters being members of the same minority ethnic community and of people in need of their services not wanting to have them as interpreters or to disclose certain details to them.

Plejert (2018) has drawn attention to the increasing practice in some countries of fast-track/crash courses for interpreters and of under-estimating the practical and professional skills needed for effective interpretation. Even with professional, well-qualified interpreters, their use in the context of the assessment and diagnosis of dementia raises certain challenges. In many cases, interpreters are not sufficiently knowledgeable about dementia and cognitive testing (Plejert et al. 2015). Similarly, many healthcare professionals lack experience working with interpreters. In the context of memory assessments of people from the Somali community in Finland, Jaakson (2018) points out that it has been necessary to remind interpreters that it is not their role to help the person do the test but just to translate the instructions and what was said. Sometimes, however, a certain degree of flexibility and ad hoc adaptation from interpreters may be helpful. In clinical practice, when tests of cognitive functioning are not culturally appropriate, clinicians often find that they need to skip parts of the test or use interpreters to find a solution, sometimes replacing an element of the test or adapting it in situ to make it more suitable for a person from a minority ethnic group (Plejert, Antelius, Yazdanpanah and Nielsen 2015). Such approaches are adopted on a daily basis because most of the tests being used are not optimal for practitioners, patients or interpreters.

Majlesi and Plejert (2018) provide a detailed case study of the interaction between a professional interpreter, a Kurdish-speaking elderly lady and a Swedish-speaking occupational therapist in the context of cognitive testing. They conclude that the completion of cognitive testing was the outcome of a collaborative approach in which the interpreter not only provided oral translation but co-facilitated the task by responding to posture and body language, prompting, rephrasing/reformulating the instructions to facilitate understanding, simplifying responses and directly answering requests from the person without going through the tester etc.[28] In this way, the interpreter played a role

of monitoring and walking the person through the test, which could be seen as co-production between the interpreter, the person taking the test and the tester. Majlesi and Plejert (2018) emphasise the need to pay attention to such issues which may affect the reliability of interpreter-mediated tests and their implications for the diagnosis of dementia in people from minority ethnic groups. Plejert et al. (2015) describe a dialogical approach[29] whereby the interpreter is considered as an active agent, engaged in an interplay with and between those involved and the environment (a visible co-constructor of an interactional event), in contrast to a more traditional approach whereby the interpreter is considered as merely transmitting a message in a neutral manner (i.e. without influencing in any way its content or formulation). They point out that the perception of interpreters as co-participants in cognitive testing encounters is perhaps less widespread amongst clinicians and conclude that:

> "when it comes to the training of clinicians in working with interpreters, it would be beneficial if the 'myth' of the interpreter as a neutral message transmitter could be broken. That would hopefully help clinicians understand and be prepared for practices that go beyond the interpreters' pure renditions of what has been said only. It might also encourage clinicians to dare to interfere and ask about information that is being negotiated, but not rendered" (Plejert et al. 2015, p. 183).

In sum, interpreter-mediated dementia assessments pose many challenges that may be related to the lack of appropriate tests for particular patients, and to interpreters frequently being asked to translate tests in situ, which may be necessary, but is in conflict with the interpreters' professional codes of conduct. Clinicians may also sometimes put too much trust in the interpreters' abilities, and therefore refrain from interfering, even in cases when the interpreter apparently does not report sequences of talk between the patient and themselves. Many interpreters are very skilled at what they do, but the term "professional" is sometimes complicated, since it may be associated simply with authorisation and medical specialisation, with no guarantee of the quality of the service provided. In addition, the interpreter may in some cases primarily have been trained to interpret medical interviews but not, specifically, formal tasks. Furthermore, they may not have been trained to work with people with cognitive or mental health conditions. Some fairly simple measures can, however, improve the situation for interpreters as well as for clinicians, and increase the security of interpreter-mediated medical encounters (please see recommendations box below).

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[28] In another study reported by Plejert, Lindholm and Schrauf (2017), an interpreter changed an open question to a closed question with 4 responses to choose from (which changes the nature of the test and makes it somewhat easier).

[29] Please see Wadensjö's (1998) seminal work on this perspective.

Key points from the section "Challenges surrounding the development of culturally sensitive assessment and diagnostic tools"

- The lack of access to culturally sensitive assessment and diagnostic tools for dementia is a major challenge facing GPs and specialists in Europe.
- Some tools have been translated into a range of languages used by minority ethnic groups but this alone does not make them culturally appropriate.
- Most assessment and diagnostic tools for dementia, which are used for people from minority ethnic groups, have not been validated for use with those groups.
- Language is not the only factor affecting the appropriate use of assessment and diagnostic tools. Other issues, such as cultural and educational bias, need to be considered as well as literacy levels.
- Education is not just about acquiring knowledge and facts. It is also about learning attitudes, becoming 'test-wise', complying with requests to do tasks and becoming familiar with writing tools.
- Lack of schooling as a child and illiteracy may have an impact on the development of the brain.
- The concept of cognitive testing was developed in and reflects the values of Western society. This bias is reflected in many tests and puts people who were not brought up Western countries at a disadvantage.
- It would not be sufficient to translate every test into every existing language. Apart from the sheer number of languages used in some countries by people from minority ethnic groups, as mentioned above, language is not the only obstacle.
- Interpretation can be useful when conducting assessments with people who are not proficient in the language of the country in which they live. In some countries, people have a right to request an interpreter if they feel that they will not be sufficiently able to speak or understand the language used during the clinical encounter.
- In practice, it is not always possible to find a suitable interpreter and sometimes there may be linguistic or cultural issues (e.g. finding an interpreter who speaks a specific dialect or an interpreter of the same sex etc.), which make this more difficult.
- Relatives are frequently asked to act as interpreter. This is not ideal, either for the relatives concerned or for the people being assessed.
- Healthcare professionals who work with interpreters for the purpose of assessment and diagnosis do not always fully understand the difficulties involved in interpretation, such as differences between languages and dialects, and the fact that words and expressions in one language are not easily translated into another language, or the goals of interpretation. This may affect their assessment of a person's performance on tests.
- Inadequately trained interpreters may inadvertently influence a person's performance on tests.

Recommendations/points for reflection

- Every person should have the right to be assessed and diagnosed in his/her best language.
- Tools used for the assessment and diagnosis of people from minority ethnic groups should be culturally sensitive and have been validated for use with those groups.
- More research is needed to develop culturally appropriate assessment and diagnostic tools for dementia.
- To ensure effective assessment and diagnosis, people from minority ethnic groups should be informed of their right to have an interpreter and access to an interpreter should be free of charge.
- Relatives should not be asked to act as interpreters. They should, however, be consulted during the assessment process if required and subject to the agreement of the person being assessed.
- More interpreters are needed in different languages and dialects, who are authorised and have a medical specialisation, including training in person-centred language, in different activities and formal clinical tasks, and with people with different conditions such as dementia. Training in this respect varies greatly across Europe.
- Clear standards for the training, accreditation and operation of professional interpreters should be developed and implemented across Europe.
- Clinicians and interpreters should meet before an assessment in order to ensure that the interpreter is familiar with the instruments to be used and is informed about certain aspects or regulations with regard to why and how the test is to be carried out.
- Skilled interpreters should, if possible, be re-appointed for the same patients over time.
- Many clinicians are trained in working with interpreters but may sometimes rely too much on interpreters. Clinicians should be encouraged to make sure that they maintain the medical and overall responsibility for the task for which interpretation is needed. This would also facilitate the work of the interpreters.

Overview of existing assessment and diagnostic tools

Little research has been dedicated to the development of culturally sensitive (or culturally fair) tools despite the huge increase in the number of older people from minority ethnic groups likely to develop dementia in the next few decades (Khan 2015, Næss and Moen 2015, Nielsen et al. 2015, Sagbakken et al. 2018). This is starting to change, with several assessment/diagnostic tools having been developed or tested in the last five years on people from minority ethnic groups with and without dementia in memory clinics in Denmark (Nielsen et al. 2013), in Berlin, Brussels, Copenhagen, Malmö, Oslo and Thessaloniki (Nielsen et al. 2018a & 2018b) and in Amsterdam (Goudsmit et al. 2016), as well as on illiterate Turkish immigrants in Copenhagen (Nielsen and Jørgensen 2013). People from a range of minority ethnic groups have been involved in these studies, including but not limited to people from Turkish, Moroccan, Surinamese, Polish, Pakistani, Albanian, Indian, Serbian, Bosnia-Herzegovinian, Macedonian and Russian ethnic communities. The pros and cons of some of the key tools are described below.

The Mini-Mental State Examination (MMSE)

The Mini-Mental State Examination (MMSE) was developed by Folstein and colleagues in the 1970s and remains one of the most widely used cognitive screening tests in Europe (Nielsen et al. 2011a). It has become a kind of gold standard as an initial test for possible signs of dementia and has been translated into numerous languages. Despite its high level of accuracy in identifying people with dementia and the fact that it is quick and easy to administer, it has been criticised for having a cultural, social, ethnic and educational bias (Parker and Philp 2004). The test requires arithmetical ability as well as reading and writing skills. For this reason, it is not suitable for people with a low level of education. Chaaya et al. (2016), suggests that it is not suitable for Arabic-speaking populations from the Eastern Mediterranean Region where a high proportion of older people are illiterate (hence also to many people from those regions having moved to Europe). As pointed out by a GP in relation to the use of the MMSE:

> "It stops there already ... I have to invent half of the test. Which day are we today? Does every Moroccan illiterate housewife have to know that it is the 23rd of February? Does she have dementia because she cannot count backwards from 100?" (Berdai Chaouni and De Donder 2018, p. 7).

There is a risk when using the MMSE of misdiagnosing people from minority ethnic groups. Consequently, researchers and clinicians have tried to develop or adapt other instruments for use with these groups of people.

Clock Drawing Test (CDT)

The Clock Drawing Test (CDT) requires people to draw a clock and fill in the numbers and draw the hands of the clock in the right place, sometimes using a pre-drawn circle. It is a measure of visuospatial functioning. Drawing a clock is often included in other cognitive screening tests. According to Schulman (2000), the CDT is quick and easy to administer and hence quite popular with busy physicians. However, educational level does have an impact on its accuracy. If people are not used to writing/drawing, or don't use a clock regularly, they would be at a clear disadvantage. Some studies have reported low education being associated with lower specificity (i.e. the percentage of people without dementia correctly being identified as not having dementia) and an unacceptably low level of sensitivity (the percentage of people who are correctly identified as having dementia) (Schulman 2000). Whilst this is a drawback to the test, it can be useful in cases where language, but not education, is a serious barrier to cognitive testing (Silverstone et al. 1993 in Schulman 2000). Also, it has been found to be useful in helping people to understand that they have cognitive problems (e.g. in cases where they lack awareness or may be in denial).

Rowland Universal Dementia Assessment Scale (RUDAS)

The Rowland Universal Dementia Assessment Scale (RUDAS) is a short cognitive screening instrument which was developed in Australia in a multi-cultural setting (Storey et al. 2004). RUDAS is considered as being at least as accurate as the MMSE (in distinguishing between people with and without dementia) (Rowland et al. 2006). It was designed to minimise the effects of cultural learning and language diversity on the assessment of cognitive performance. RUDAS contains six short tests and takes about ten minutes to administer. Minimal training is required to use it and it is available in more than 30 languages (Naqvi et al. 2015). The tests include an assessment of body orientation, praxis (alternating hand movements), drawing (copying a cube), judgement (linked to crossing a busy road), memory (recalling four items from a shopping list) and language (naming animals) (Nielsen et al. 2018a).

The tests are generally considered as being relatively unaffected by gender, cultural background and language use (Naqvi et al. 2015). However, some studies have found that people with limited or no education do not perform well on the cube drawing and alternating hand movement tests (Nielsen et al. 2013 and 2018a, Chaaya et al. 2016). In a recent study involving people with normal cognition, people with MCI and people with dementia from the non-Western migrant population in the Netherlands, an

alternative visuospatial test was used for the RUDAS, which consisted of using matchsticks instead of a pencil to draw/copy the cube (as developed by Matute and colleagues in 2000). The researcher found that literacy did not significantly affect performance of the alternative task amongst the people with normal cognition and suggests that this test might be less challenging for people who are illiterate (Soumaya 2018).

On the basis of a five-country European assessment of RUDAS, Nielsen et al (2018a) suggest using an education-adjustment of scores when testing people with low levels of education. In addition, a study comparing the diagnostic accuracy of the RUDAS compared to the MMSE by Goudsmit et al. (2018), amongst a wide range of people from minority ethnic groups who had been referred to a geriatric outpatient clinic, recommended the RUDAS for use in a highly illiterate, culturally diverse geriatric outpatient population.

Cross-Cultural Dementia (CCD) screening tool

The Cross-Cultural Dementia (CCD) screening tool was developed in a general hospital in the Netherlands. It consists of three sub-tests designed to measure memory, mental speed and executive functioning. Goudsmit et al. (2016) recently tested this screening tool on people from six different ethnic groups, including Dutch. The series of tests measures memory (using coloured pictures of everyday household items), mental speed and inhibition (using line drawings of the sun and the moon) and mental speed and divided attention (using images resembling domino pieces). The various tasks involve recognising images that have been presented, naming as quickly as possible images of the sun and moon in the person's own language, saying the word for sun when a moon is presented and vice versa (to measure the Stroop effect)[30] and linking up domino pieces according to the number of dots or by colour.

The CCD does not require knowledge of facts or the ability to read and write. It can be administered without the need for an interpreter or for the tester to speak the language of the person being tested as the test instructions are given to the person by a computer. Currently, instructions can be given in six languages: Dutch; Turkish; Moroccan-Arabic and Tarifit (two languages that are commonly spoken by Moroccans in the Netherlands); Sranantongo and Sarnámi-Hindustani. The influence of ethnicity, age and education on performance has been found to be small (Goudsmit et al. 2016). There were some differences in performance between the ethnic groups but when matched for age and education, the apparent ethnic differences were no longer significant. A difference in performance between ethnic groups on the Sun-Moon test was, according to the

researchers, perhaps due to the words for sun and moon being longer in some languages (e.g. the word for sun is two syllables long in Turkish and only one syllable in Surinamese) (Goudsmit et al. 2016). Only a small number of people with dementia were included in the study and many found one of the tests (the dots test) too difficult, as did a few illiterate people in the control group. The researchers nevertheless conclude that the CDD is a promising and culture-fair test for the screening of cognitive impairment in older immigrants.

European Cross-Cultural Neuropsychological Test Battery (CNTB)

The European Cross-Cultural Neuropsychological Test Battery (CNTB) consists of a series of tests covering a range of functions (Nielsen et al. 2018b), namely:

- RUDAS for the assessment of global cognitive function.
- The Recall of Pictures Test (RPT), Enhanced Cue Recall (ECR) and recalling a semi-complex figure for the assessment of memory.
- Picture Naming Task, and animal and supermarket fluency (naming, within a minute, as many animals as possible or naming, within a minute, as many things as possible that can be bought in a supermarket) for the assessment of language.
- The Colour Trails Test (CTT), The Five Digit Test (FDT) and the Serial Threes Test (STT) (counting down from 20 by threes) for the assessment of executive functioning.
- Copying of Simple Figures, The Clock Drawing Test (CDT) (completing the drawing of a clock from a predrawn circle), the Clock Reading Test (CRT) (reading the time on a series of drawn clocks on which the clock hands show the time but there are no numbers) and copying a semi-complex figure for the assessment of visuospatial functioning.

The CNTB takes about an hour to administer and can be done with or without an interpreter. It was tested on different ethnic groups in five European countries. The tests were carefully designed to minimise the need for translation and reading skills. Significant differences in performance were observed between the different ethnic groups on all measures except the RPT. Some groups performed better on some tasks than others. The Serial Threes Test, for example, was particularly difficult for the Turkish people (who had lower levels of education) but they performed better on the RPT. The RPT and ECR were unaffected by education. The RUDAS, however, was the only test that was not affected by ethnic group. The researchers suggest, based on their analysis of

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[30] The Stroop effect is what happens when someone is asked to say the colour that a word is written in but not the word itself (e.g. if the word 'blue' is printed in red ink, the person should say 'red'). This test was described in an article by JR Stroop (1935).

the findings, that the significant differences in performance between different ethnic groups were most likely due to educational differences rather than ethnicity or different levels of acculturation. They also concluded that further work was needed to develop a more effective assessment of language function within the CNTB (Nielsen et al. 2018b).

To conclude, individual test results obtained using such various tools should not be considered as stand-alone measures of cognitive function or to determine whether or not a person has dementia. There is, as yet, no tool or set of tools that is perfectly suited and completely adapted to the needs of people from minority ethnic groups, but great progress has been made. Ideally, a battery of tests should be used and the findings should be considered along with other elements of a complete diagnostic evaluation conducted by the relevant and qualified healthcare professionals.

Key points from the section "Overview of existing assessment and diagnostic tools"

- A range of tools are used to assess and diagnose dementia. Most of these are not suitable for use amongst people from minority ethnic groups. There is, as yet, no tool or set of tools that is perfectly suited and completely adapted to the needs of people from minority ethnic groups.
- In recent years, researchers have looked at the pros and cons of some of the most commonly used tools with the aim of determining which are culturally fair, appropriate or neutral and hence suitable for use within minority ethnic communities. This research has involved people from several minority ethnic groups in Europe.
- The Mini-Mental State Examination (including translated versions) is one of the most widely-used cognitive screening tools in Europe. However, it has been criticised for having a cultural, social, ethnic and educational bias.
- The Clock Drawing Test is quick and easy to use but scores tend to be affected by educational level.
- The Rowland Universal Dementia Scale (RUDAS) is considered to be at least as accurate at the MMSE in identifying people who do or do not have dementia. The various sub-tests are generally unaffected by gender, cultural background and language. Educational level may influence scores on some sub-tests, but scores can be adjusted for education. An adapted version of one of the sub-tests may also be helpful in reducing educational bias. The RUDAS can be used with people from all ethnic groups and is particularly suited to the assessment of people from minority ethnic groups.
- The Cross-Cultural Dementia screening tool (CCD) does not require knowledge of any facts or the ability to read and write. Ethnicity, age and education have a very small influence on performance. The tool has not yet been tested on many people with dementia and many of those were involved in a study to evaluate the tool found one of the sub-tests too difficult, as did people who were illiterate.
- The European Cross-Cultural Neuropsychological Test Battery (CNTB) includes a series of tests including the RUDAS and the Clock Drawing Test. The tests can be done with or without an interpreter and with minimum reading skills. With the exception of the RUDAS, there were considerable differences in performance between different ethnic groups. The researchers suggest that this was most probably linked to different levels of education between the groups. Further research will be carried out to determine whether this might have been the case and to improve the battery of tests.

Recommendations/points for reflection

- Further research (together with necessary funding) is needed to develop culturally appropriate and assessment and diagnostic tools for dementia.
- Pending the results of further, ongoing research, the RUDAS should be considered for the assessment and diagnosis of dementia in people from minority ethnic groups, perhaps in combination with other tests currently being developed.
- Individual test results from various tools should not be considered as stand-alone measures of cognitive function or to determine whether or not a person has dementia.
- The results of various tests need to be combined with a complete diagnostic evaluation conducted by qualified healthcare professionals.

Inequalities in access to and use of treatment by people from minority ethnic groups

The whole issue of timely and accurate diagnosis is closely linked to gaining access to appropriate care and support, not only in the form of services (which is addressed in the next section), but also in the form of anti-dementia drugs. A study involving patients who were registered on the Norwegian national registry for primary health care reported differences in the proportion of native Norwegians or immigrants receiving treatment for dementia (Diaz, Kuman and Engedal 2015). A smaller proportion of immigrants, especially from low income countries, had received a diagnosis of memory impairment or dementia, and significantly more immigrants were diagnosed with memory impairment as opposed to dementia. According to the researchers, this may have been partly due to challenges diagnosing people from minority ethnic groups and the lack of culturally appropriate services. Amongst patients who had received a diagnosis, a significantly lower proportion of the immigrants from the low income countries had purchased anti-dementia medication. Having had an interpreter was associated with immigrants purchasing anti-dementia drugs, whereas the opposite was the case with regard to having consulted a GP with an immigrant background (although it is difficult to draw conclusions regarding GPs due to the small number available).

Another study by Stevnsborg et al. (2016), also based on a national registry, looked at the use of anti-dementia drugs amongst people born in Denmark, Western immigrants and non-Western immigrants. They also found that a lower proportion of immigrants had received anti-dementia drugs (25–30% less compared to the people born in Denmark). The non-Western immigrants had the lowest use of anti-dementia drugs.

Stevnsborg and colleagues (2016) suggest the following possible explanations for the lower anti-dementia drug use described above:

- Anti-dementia drugs are licensed for the treatment of Alzheimer's dementia, as well as for dementia due to Parkinson's disease and Lewy body dementia. There is some evidence that some minority ethnic groups have higher rates of vascular risk factors and vascular dementia.
- People from minority ethnic groups are often diagnosed at a later stage of dementia (most of the anti-dementia drugs are most effective in the earlier to middle stages).
- Lower standards of diagnosis experienced by some people from minority ethnic groups result in higher rates of unspecified dementia. This may result in doctors not prescribing anti-dementia drugs.
- The cost of anti-dementia drugs is mainly covered by the state (in Denmark and perhaps in many other countries in Europe). Many people from minority ethnic groups have limited financial resources so even a small cost may be a barrier for purchasing anti-dementia drugs.
- Language barriers make it difficult to navigate the healthcare system.
- The belief that dementia is a normal part of ageing may result in lower levels of use of anti-dementia drugs.

Possible explanations for the disparities in the use of anti-dementia drugs by different ethnic groups suggest a lack of equity, which in many cases may be linked to structural discrimination.

Key points from the section "Inequalities in access to and use of treatment by people from minority ethnic groups"

- Timely and accurate diagnosis should contribute towards people from minority ethnic groups being offered the same standards of care, support and treatment as that offered to people from majority ethnic groups.
- Recent studies in Norway and Denmark found that people from minority ethnic groups were not being prescribed anti-dementia drugs on an equal basis as people from majority ethnic groups.
- The non-Western immigrants in the Danish study and those from the low-income countries in the Norwegian study had the lowest use of anti-dementia drugs.
- For people from minority ethnic groups with limited financial resources even a small cost may be a barrier for purchasing anti-dementia drugs.
- Possible explanations for the lower anti-dementia drug use include people from minority ethnic groups not having been diagnosed with a specific form of dementia and/or a form that is suited to anti-dementia drug treatment, being diagnosed at a later stage, not having had an interpreter, being deterred by costs (however small they might be), finding it difficult to navigate the healthcare system and perceiving dementia as natural and hence, not requiring treatment.

Recommendations/points for reflection

- Measures should be taken to improve the quality of diagnosis of people from minority ethnic groups so that they receive a diagnosis of a specific form of dementia (e.g. dementia due to Alzheimer's disease, vascular dementia or Lewy Body dementia).
- Healthcare professionals responsible for diagnosing dementia should have training in cultural awareness and to develop the cultural competence needed to ensure timely, accurate and differential diagnoses of dementia amongst members of minority ethnic groups.
- The role of interpreters in the diagnostic procedure and reasons for low uptake of anti-dementia drugs should be further explored.

5. Support and care

A large proportion of care and support for people with dementia is provided by informal carers, such as relatives and close friends. In many cases, those carers, irrespective of the ethnic group with which they identify, do not receive sufficient, appropriate and timely support, and in many cases struggle to combine their other personal and professional responsibilities with that of providing care and support. Caring for a person with dementia or coping with dementia (i.e. as the person who has the condition) is often more challenging compared to other chronic conditions. For people from minority ethnic groups, there can be additional challenges which further hamper their opportunities to access the care and support, not only that they need and are entitled to, but that is culturally appropriate.

In this section, we look at a few broad issues related to the provision of care and support (namely person/relationship centred care and whether or not services should be mainstream) and discuss some of the possible reasons for limited uptake of services by people from minority ethnic groups. This is followed by a look at specific aspects of intercultural care and support. The section ends with a discussion about issues faced by different people, mainly members of the minority ethnic groups, who provide care and support to people from minority ethnic groups.

Different approaches of relevance to the provision of intercultural care and support

Person/relationship-centred support and care

From the 1990s onwards, based on Kitwood's work, a person-centred approach to care and support came to be recognised as the gold standard in the field of dementia care, gradually becoming more of a basic requirement for good care. In some care settings, the philosophy of 'person-centred dementia care' has now become a stated norm for many services, even when it is not entirely clear what standard that implies. Within this approach, the focus is on supporting the wellbeing, dignity and autonomy of the whole, unique person regardless of the extent of cognitive impairment rather than on a collection of symptoms or behaviours to be controlled and rather than assuming that one service will suit everyone. A person-centred approach therefore benefits people with dementia by respecting their human rights and individuality, and by contributing towards quality of life and wellbeing. However, whilst there is general consensus on the need for a person-centred approach, the actual practice of person-centred care varies considerably (Alzheimer Europe 2015). Many people from minority ethnic groups do not receive timely and appropriate support and care. Attempts to provide person-centred care all too often occur within a framework which reflects the cultural traditions, norms and awareness of the majority ethnic group.

In 2010, the Swedish National Board of Health and Welfare (SBHW) produced guidelines in which it is specifically stated that person-centred care should involve consideration of the different cultural or linguistic backgrounds and needs of people with dementia (Antelius and Plejert 2016). It is further stipulated that respecting cultural needs should be interpreted as "giving persons with dementia disease the opportunity to practice their religion, being served culturally appropriate food, keeping their cultural traditions and customs, and having access to nursing staff that communicate in the same native tongue as the person with dementia". Linguistic needs were described as being linked to being cared for by nursing staff who communicate in the person's native language and who also have cultural competence to give people with dementia with a different ethnic background a sense of security, increased well-being and a sense of feeling 'at home' (SBHW, 2010:21, based on translation by Antelius and Plejert).

The term 'person-centred' is increasingly being extended to take into consideration everyone involved in the act of giving and receiving care and support. Nolan et al. (2004), have proposed a shift from individualistic notions of person-centredness to relationship-centredness, which is particularly relevant in minority ethnic groups in which the focus is often more on the family unit than the individual[31]. A relationship-centred approach reflects the interdependence between carer and care receiver and the importance of interpersonal interactions in creating a basis for care and support (Walsh and Shutes 2013).

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[31] Please see sub-section on 'filial piety/responsibility' (p. 46) in Section 5 on Support and Care.

The ability to communicate with others in meaningful ways is part of any person/relationship-centred approach to care. It contributes towards the promotion of autonomy and towards maintaining a person's sense of self, identity and well-being. Much has been written on the topic of communication in the context of dementia but Plejert, Lindholm and Schrauf (2017) point out that very little research has been done in the area of multilingual[32] interaction and dementia despite the fact that multilingualism is more the norm than the exception in many countries.

Communication should also involve asking people with dementia and their carers themselves about their preferences and involving them in creating culturally appropriate care and support. This should occur on a one-to-one basis but also at the level of small groups in order to help healthcare professionals and service providers develop intercultural care and support that is also appealing to people who are not yet using it. In the Netherlands, for example, Smits et al. (2018) set up a working group of Turkish carers, most them who were daughters of a person with dementia. Together with the researchers, the carers developed their own criteria for culture sensitive care through co-creation. They then used this successfully to lobby for culture sensitive dementia care in their town. A similar approach could also be used with people with dementia from minority ethnic groups, albeit with some adaptation and appropriate support.

Mainstream or separate/ specialised services

Recognising dementia as a potential disability[33] and the importance of a person/relationship-centred approach to care and support should help ensure that everyone with dementia is treated on an equal basis with respect for their individuality and rights. Providing such care and support within the context of interculturalism requires attention to certain challenges but can be achieved in different ways. There is an ongoing debate about whether intercultural care and support for people with dementia from minority ethnic communities should be part of the mainstream provision or separate. The provision of person/relationship-centred care and support should be possible within mainstream care where respect for each person's language, religion and other cultural needs should be possible.

The issue as to whether services should be mainstream or specific depends on what is considered as sufficient versus merely symbolic or inadequate add-on measures within mainstream care and also whether or not people from specific minority ethnic groups prefer specialised services. In

terms of the principle of either approach, Johl et al. (2016) raise the issue of some service providers having concerns, when proposing specialised services for certain minority ethnic groups, about singling out a particular group and of appearing 'racist'. There may also be differences between first and second or third generation members of minority ethnic communities with regard to the extent to which they are comfortable with the local culture and generic health services (Bhattacharrya and Benbow 2013).

It is sometimes assumed that people from the same ethnic group prefer to use services where they can have social contact with people of a similar age, class, background and ethnicity (covering language, food, music and games) (Beattie et al. 2005). It is important to avoid making assumptions about interactions between people from the same minority ethnic group. Bhattacharyya and Benbow (2013) point out that there are hierarchies and caste systems in some minority ethnic groups. The example given is the South Asian community in the Bradford area of the UK, which is described as being culturally and socially fragmented with divisions based on caste, status, gender and generational hierarchies. Such divisions can be traced back to the place of origin of the first migrants and are reproduced in the current setting.

Some services such as day care centres come to be used predominantly either by members of minority ethnic groups or by members of the majority ethnic group on the basis of living in the proximity. Even when they have been set up primarily for people from a particular ethnic group, people from other groups sometimes attend and fit in well (Beattie et al. 2005). For people who wish to go to a centre where there are more people from their own culture, the overall lack of dementia-specific services, especially in rural areas, may sometimes make this impossible as it would be too far away, making it impractical to get there and for relatives and friends to visit. In the UK, where there is a large ethnic minority voluntary sector, people sometimes prefer to use services provided by such groups, which are not specifically for dementia but which are tailored to their ethnic group (APPGD 2013).

Most probably, the response to the question "should care and support for minority ethnic groups be mainstream or specialised?" is that it depends. As with the development of intercultural care and support in general, it is essential that people from the different minority ethnic groups are involved in discussions about the development of new services and whether existing services are acceptable. There seems, nevertheless, to be a slight emphasis in the literature on adapting mainstream services to make them more appropriate for people from a wide range of ethnic

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[32] The use of more than one language in a given context.
[33] Please see the Introduction (p. 5) for more details.

groups. Kenning et al. (2017), for example, point out that the usual approach is to try to tailor existing services to specific ethnic groups (i.e. making mainstream services more inclusive). However, a study by Söderman and Rosendahl (2016), which involved the comparison of two care homes in Sweden with native Finnish-speaking residents, describes the one with native Finnish speaking staff as being superior to the one with native Swedish-speaking and bilingual staff in terms of the perceived impact on residents' wellbeing. More details of this study can be found in the section on Issues related to language and communication (p. 52).

Key points from the section "Different approaches of relevance to the provision of intercultural care and support provided to people with dementia"

- A person-centred approach to care and support is often considered a basic requirement for good care.
- The emphasis with person-centred care is on the individual and his/her relationship to other people. By definition, this should respect the cultural and linguistic needs of each person (as well as his/her family or network).
- There is, however, a risk of person-centred care occurring within a framework which reflects the cultural traditions, norms and awareness of the majority ethnic group.
- Good communication is essential when providing person-centred care but there has been surprisingly little research in the area of multilingual interaction and dementia.
- The provision of person/relationship-centred care and support should be possible within mainstream care or a specialised separate service.
- Specialised services might sometimes be preferred because of practicalities (e.g. being able to cater more fully for the dietary requirements/preferences of people from one or two specific ethnic groups and having staff who are fluent in a particular language).
- On the other hand, many people are used to and enjoying living in multicultural communities and would therefore prefer mainstream services.
- There are arguments for and against each approach both from the perspective of service providers and service users. Preferences may also differ depending on the type of support needed, the stage of dementia and the individual concerned.

Recommendations/points for reflection

- People with dementia and their carers from minority ethnic groups should be directly involved in the development of person/relationship-centred intercultural care and support.
- Mainstream and specialised intercultural care and support should be developed taking into consideration a range of factors (e.g. the availability of suitable staff, the needs of people from minority ethnic groups, proximity to potential service users and costs).
- Local, voluntary sector organisations providing generic culturally-sensitive services should have access to training from specialist dementia staff so as to be able to better support people with dementia.
- Intercultural care and support should be widely available, not just in cities and urban areas but also in rural areas.

Challenges related to the uptake of services and support by minority ethnic groups

A diagnosis of dementia should enable people from minority ethnic groups to access care and support. However, minority ethnic groups are less likely to use dementia services and social care services in general compared to majority ethnic groups and may in addition present later to services (APPGD 2013, Segers, Benoit, Colson, Kovac, Nury and Vanderaspoilden 2013, Greenwood et al. 2015, Jutlla 2015, Mukadam et al. 2015, Hailstone et al. 2016, Pham et al. 2018). Although in some countries, many are registered with GPs, they do not necessarily access dementia services (Shah 2007). In the Nordic countries, especially in Finland, very few older people from minority ethnic groups live in care homes (Söderman and Rosendahl 2016, Stevnsborg, Jensen-Dahm, Nielsen, Gasse and Waldemar 2016, Sagbakken et al. 2018), although an increase is likely in the coming years. Several reasons have been put forward to explain the late or reduced use of dementia services amongst minority ethnic groups. Some of these are discussed below.

Lack of post-diagnostic support

Ideally, every person diagnosed with dementia should receive post-diagnostic support. In its local delivery plan (LDP), the Scottish Government (2018) declares its commitment to offering people newly diagnosed with dementia a minimum of one year's post-diagnostic support, coordinated by a named Link Worker. The aim is to enable people with dementia and their families to better understand and adjust to a diagnosis, connect better and navigate through services and plan for future care including anticipatory care planning. A systematic review carried out by Parveen (2018) revealed a complete lack of research covering post-diagnostic support of people with dementia from minority ethnic groups in the UK. Considering that there is a substantial body of work that has been carried out in the UK into intercultural care and support for people from minority ethnic groups and that the concept of post-diagnostic support exists in the UK, this is a worrying lack which is unlikely to be much better in other countries and which needs to be urgently addressed.

Lack of trust in the healthcare system

As with initial help seeking, lack of trust in the healthcare system affects the use of services (Ahmed et al. 2017). Jolley et al. (2009) found that carers from African Caribbean and South Asian communities in the UK doubted the capacity of mental health services to address language barriers and cultural differences and feared that they would be culturally stereotyped. Distrust of the healthcare system has also emerged in studies involving African Caribbeans and South Asians (Bhattacharyya and Benbow 2013) and involving members of the Chinese community in the UK (Truswell et al. 2015), as well as amongst the Norwegian-Pakistani community, perhaps according to Næss and Moen (2015), based on their earlier experience of prejudice and discrimination. Some people from traveller communities have expressed fear about being taken away to a home ('locked away') and being forced to curtail travelling (Dementia Action Alliance 2018, Rattigan and Sweeney 2018). Fear of help seeking resulting in institutionalisation has also been expressed by some South Asian carers in the UK (Mukadam et al. 2015).

Some degree of mistrust and perceived discrimination may be linked to cultural and linguistic issues which result in a person misinterpreting the way they are treated. They may be unfamiliar with the healthcare system and have difficulty understanding the role of different healthcare professionals and what to expect from them. For example, they may fail to understand why they cannot see a specialist directly (without having to pass through a GP, why they are left to wait for 4 or 5 hours in the emergency department of a hospital and then sent home after a brief exchange with a doctor, or why people who arrive at the GP surgery after they do, see a doctor first (possibly due to triaging systems). Such experiences may leave people feeling disempowered and alienated from the system (Cally et al. undated). Some of the negative feelings about being unfairly denied certain services and support may be linked to earlier experiences of prejudice and discrimination (Jutlla 2015).

Discrimination and prejudice against people from minority ethnic groups does nevertheless still happen (APPGD 2013). Many older Irish people with dementia, for example, experienced considerable prejudice, open hostility and discrimination following migration to the UK. Although this is fortunately less common nowadays, many still complain about stereotypes held by healthcare professionals (e.g. that regardless of the illness, alcohol is the problem) (Tilki et al. 2010).

Services not considered appropriate

Dementia services that are available are often not used by people from minority ethnic groups to the same extent as by the majority ethnic group, which means that the needs of the former may go unmet (Daker-White et al. 2002). People with dementia and carers from minority ethnic groups often complain of a lack of choice (Kenning et al. 2017) and some assume that services and support will not respect their culture and religion, and that there

will be no linguistic support (Bhattacharyya and Benbow 2013). This is sometimes the case. In some communities, services are considered inappropriate because they do not respect cultural or religious norms such as it not being considered appropriate for someone of the opposite sex to provide personal care and same-sex carers not being available (Kenning et al. 2017, Golan-Shemesh and Lahav 2018). According to Rattigan and Sweeney (2018), a significant number of people from traveller communities (in the UK) would not even attempt to access support for a person with dementia based on the assumption that the support offered would not be culturally appropriate. The kinds of services that people from some minority ethnic groups would most appreciate (e.g. day and night sitting services) are often not available (Beattie et al. 2005) or do not correspond to a person's interests and way of life.

Group discussions involving people with dementia, carers and members of the general public in the UK from Indian, African Caribbean, and Eastern and Central European communities revealed a heavy reliance on support from relatives, social workers and GPs. They also had a distinct preference for services and support provided by third sector organisations such as charities, local day centres and churches. Parveen et al. (2017), who conducted this research, suggest that such organisations might be more readily trusted and better able to meet the cultural needs of the local minority ethnic communities (Parveen and Oyebode 2018).

Language-related issues

Language-related issues for people with dementia and carers

It is sometimes difficult to navigate the healthcare system in one's own mother tongue. Trying to do this with limited knowledge of the system and the language can be a significant barrier (Kenning et al. 2017). In some countries, materials might be available and bilingual staff or interpreters, but this is often not the case or has to be organised in advance. People from minority ethnic groups may fear or just assume that no one will speak their language (La Fontaine et al. 2007). Difficulties with language have been found to be related to limited use of home care services (Denktas et al 2009) and to a perceived lack of power to insist on one's right to support. Jutlla (2015) provides the example of a Sikh male carer who linked failure to obtain certain support to being uneducated and illiterate, comparing his own situation to that of middle class, educated people who can obtain information (e.g. in leaflets that are available) and use it as means to obtain the same services that he is refused.

It has already been mentioned that in some ethnic communities, there is no awareness of and sometimes even no word for dementia. The same applies to the term 'carer'. In some languages, such as Bengali, Gujarati, Urdu and Punjabi (Greenwood et al. 2015) and Russian (Jaakson, Hemmilä and Jaakkola 2017), there is no word for carer, which may result in carers not realising that support is available for them and not being able to relate to information about available support. For some, what others would call being a carer is simply seen as an extension of an existing responsibility to care for a relative with dementia[34] (Adamson and Donovan 2005, Lawrence et al. 2008, Rauf 2011, Jaakson, Hemmilä and Jaakkola 2017, Rattigan and Sweeney 2018). Some people are reluctant to label themselves as a carer, stating that it is "a huge step and shifts the dynamic in the relationship" (Ahmed et al. 2017, p. 46). They may also consider the concept inappropriate as (almost) everybody in their community acts as a carer for somebody else (Groen-van de Ven and Smits 2009).

Financial barriers

Many people from minority ethnic groups have a lower socio-economic status than people from the majority ethnic group. In countries where healthcare is free at the point of delivery or covered by health insurances, small costs linked to accessing services may sometimes be overlooked. However, for people who are on a low income and struggling to make ends meet, having to use the telephone to make appointments or to pay for public transport to get to a day care centre or for petrol and parking to attend memory clinics, may be enough to deter them from using services. People may also be afraid of having to sell their homes to pay for residential care or losing their social security benefits (Ahmed et al. 2017, Pharos 2018).

Stigma

Diagnosis may open the door to support and care but benefiting from this often means letting other people know that a person or one of his or her relatives has dementia. Stigma deters people from some minority ethnic groups from using services associated with dementia (Mackenzie 2006, Rauf 2011, APPGD 2013, Antelius and Kiwi 2015, Jutlla 2015, Kenning et al. 2017). Some feel that there would not be as much stigma in their home country (Mukadam et al. 2015), while others clearly state the opposite. In some countries, such as South Africa, for example, it is quite common for people with dementia to be considered as witches and to be excluded from society, persecuted and even killed (Mkhonto and Hanssen 2017). Some researchers also report that dementia is considered a stigma in Arabic-speaking Eastern Mediterranean countries, where the term for dementia is 'Kharaf', which means 'unravelled' or

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[34] See sub-section on filial piety/responsibility (p. 46).

'lost in his/her mind' (Cipriani and Borin 2014, Yaghmour, Bartlett and Brannelly 2018). Stigma is a powerful and complex social phenomenon which can interfere with people seeking diagnosis, subsequent support and care, and to them hiding the person with dementia from other people out of fear of what people might think of them. In the general literature on stigma, the emphasis is very much on a personal attribute that is socially salient (Goffman 1963, Jones et al. 1984) and leads to negative labelling and stereotyping, cognitive separation ('them' and 'us'), devaluation and discrimination, all within the context of unequal power relations (Link and Phelan 2001 and 2006).

Within many minority ethnic groups, the social saliency of the stigma is mainly linked to dementia being perceived as a mental disorder or a punishment from God (and hence shameful), and the stigma may sometimes be extended to other members of the family (which is known as courtesy stigma or stigma by association). In some minority ethnic groups, it may be another member of the family who is believed to be the one who is being punished by God. In their study into the experience of dementia across ethnic groups, Lawrence et al. (2011) found that some men with dementia from the South Asian community considered dementia as threatening their position within the community but not within the family where the emphasis was on a collective identity. The stigma may also be attributed to the whole family, as a unit, based on their perceived failure to fulfil their religious or cultural duties to provide care for a dependent relative (see next sub-section on filial piety/responsibility).

The issue of responsibility for the stigmatised attribute and subsequent blame is central to some theories of stigma (Jones et al. 1984, Weiner et al. 1988, Stangor and Crandall 2003), with lack of perceived responsibility being linked to lower levels of stigma (Kurzban and Leary 2001). Perceived responsibility of people with Alzheimer's disease[35] has been found to be low or moderate in several quantitative studies involving majority or non-specified ethnic groups (e.g. Cohen et al. 2009, Crisp 2004, Werner 2005, Werner 2008) but beliefs about personal or family responsibility for dementia may be one factor resulting in higher levels of stigma in some minority ethnic groups.

Filial piety/responsibility

Power relations and responsibility for care

In some minority ethnic groups, especially African, Middle Eastern and South Asian, male relatives are considered as the decision-makers and 'spokesmen' for the family and therefore decide whether and how to access support services. The actual physical/hands-on care is provided by women, usually wives, daughters-in-law and daughters (Rauf 2011, APPGD 2013). Female members of the household may make a lot of the decisions which precede the involvement of the male members of the household (Rauf 2011).

There are differences between minority ethnic groups with regard to which person (i.e. which woman in most cases) should provide care. Botsford et al. (2011) found a greater expectation amongst Greek Cypriot communities for daughters to provide care than within the African Caribbean community. In the Turkish and Moroccan ethnic groups in the Netherlands, it is usually the eldest daughter or the wife of the eldest son who provides care whereas in the Surinamese Creole group it is usually a daughter but not necessarily the oldest (van Wezel et al. 2018). Turkish or Moroccan men in the Netherlands do not generally provide physical care but when they do, it tends to be a man from their own family line such as a father or uncle.

There are several ethnic communities in Israel and differences with regard to who provides care and who makes care-related decisions (Golan-Shemesh and Lahav 2018). In the ultra-orthodox Jewish community, for example, the entire family takes responsibility for care. The primary care is mainly carried out by female members of the family, but male members of the family will often provide personal/intimate care for male relatives and take them to the synagogue. There is a strict separation between men and women within the orthodox community. In the Druze community, women also have main responsibility for care but with some gendered division of responsibilities in that daughters care for their mothers, whereas sons may provide some care to their fathers (intimate care and helping the relative to fulfil his religious duties). In the Arabic Muslim community in Israel, daughters, especially if single, care for their parents and the oldest son is responsible for healthcare decision making.

It has been noted in research carried out in Finland that intergenerational relationships are particularly important in the everyday lives of older migrants from the former Soviet Union. These relationships provide a feeling of safety and wellbeing, helping compensate to some extent for the social and emotional exclusion that some experience in their host country (Heikkinen 2011). A similar phenomenon may also occur in relation to older people who move to another country in Europe when they retire.

Women from minority ethnic groups who have been given sole responsibility for the care of a person with dementia often struggle to cope. Some may be angry about having been given this responsibility (Ar and Karanci 2017).

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[35] The studies are about Alzheimer's disease but bearing in mind the dates of the articles, it is most probable that they are about dementia caused by Alzheimer's disease (as opposed to preclinical or prodromal Alzheimer's disease).

They may, however, hesitate to ask for professional help for fear of criticism that they are unable to fulfil their role, of angering other members of the family or of being excluded because "only bad women complain" (Tonkens, Verplanke and De Vries 2011). This may sometimes be balanced by the satisfaction that providing care brings in terms of recognition and praise from other members of the family (Van Wezel et al 2016). However, cultural perceptions of care responsibilities often result in women from minority ethnic groups caring for people with very advanced dementia with little or no support, and waiting until a crisis occurs or terminal care is required before seeking help (Mukadam et al. 2011 and 2015).

Religious duty

The gender-based power relations in families may also be based on or accompanied by religious beliefs about relatives having a duty to care for their dependent relatives (e.g. within Hinduism, Islam and Sikhism), especially within the South Asian communities in the UK (Rauf 2011) but also amongst Turkish and Moroccan groups in the Netherlands (van Wezel et al. 2016). Some studies have also reported Christian beliefs about caring for older dependent relatives such as in the study by van Wezel et al. (2016) of female Surinamese carers of people with dementia in the Netherlands[36]. The duty to care is in some cases accompanied by the belief that someone has done something wrong and is being punished (as mentioned in the sub-section on stigma) or that they are being tested. Turkish and Moroccan female carers, who were Muslim, interpreted providing care as a test from God, which if successfully accomplished, would pave the way to paradise (van Wezel et al. 2016). The person or family concerned may wish to show acceptance of the test (by being patient and providing the care needed) rather than evidence of failure (by accepting outside help) which would put them at risk of criticism (Rauf 2011).

Criticism and pressure on the female carer normally comes from outside the immediate family (e.g. from the in-laws, the extended family and neighbours as well as spiritual leaders). In some cases, relatives who are not responsible for providing care interpret the need for support not as being related to a person's increased cognitive deterioration but as the carer's inability to manage (Sagbakken et al. 2018). Spiritual leaders in some religions may play a decisive role in care decisions. In Islam, for example, Muftis (senior Muslim scholars) can be asked to provide an Islamic ruling on whether it would be acceptable to accept certain support or place a relative in residential care (Mohammed 2017).

It is often assumed that people from certain minority ethnic groups 'look after their own' and do not want any support

(Moriarty et al. 2011, Ahmed et al. 2017). Those who do seek outside help may have negative experiences because of such assumptions (APPGD 2013). Jutlla (2015) warns against stereotyping people from minority ethnic groups as being oppressed by cultural norms and community expectations. She points out that some carers do decide to face possible criticism and disapproval in order to access support which they feel is justifiable and corresponds to their own personal situation and needs. Some carers and service providers from Chinese and Indian communities expressed the view, when asked about dementia care, that it may not always be practical in the UK for families to maintain the tradition of providing care themselves (in the absence of extended families living together in one house, older people living on their own and children moving away for employment reasons) (APPGD 2013).

Practices linked to the provision of care within the family and the use of outside support may be gradually changing as a result of changing family structures, more women taking up paid employment outside the home and different perspectives on care especially amongst second and third generation groups (Lawrence et al. 2008, Bhattacharyya and Benbow 2013, Golan-Shemesh and Lahav 2018). A Dutch study found that in Turkish and Moroccan communities, families recognised that professional support, including residential care, was sometimes necessary but would only be justifiable in extreme cases (van Wezel et al. 2016). Surinamese Creole carers in the same study considered family care to be better than professional care. They were more inclined to see their role as directing the provision of care, which would ideally be provided at home but if necessary and in the interests of their relative, could include residential care. They did not fear criticism from the family or community for using services and support.

Changing attitudes towards the use of services may sometimes lead to conflict within families, especially between younger and older generations and between male and female relatives. It may, however, also lead to sharing of care responsibilities within the family (e.g. moving the person with dementia between different relatives' houses due to health problems or work commitments) (Sagbakken et al. 2018). In the study by Sagbakken et al. (2018), the difficulties managing work and care commitments, within the context of a deep-rooted commitment to provide care at home and a smaller or scattered circle of relatives, were emphasised. Whilst beliefs about religious duty often influence decisions about the organisation of care within families, spirituality and religion are also often experienced by carers as a source of strength and support (van Wezel et al. 2016, Parveen and Oyebode 2018).

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[36] These carers were all from the Creole ethnic group. There are also Surinamese ethnic groups in the Netherlands from Hindustani and Chinese communities. They might have different views.

The perspectives of people with dementia

The views of people with dementia themselves are often overlooked. Lawrence et al. (2010) found, in the context of a qualitative study involving Black Caribbean, South Asian and White British people with dementia, awareness of the need for support. Some felt that outside support was necessary but undesirable. Some were not sure that support from the family was available or likely to be sufficient over time. Whereas some South Asian and Black Caribbean people with dementia described the provision of care by relatives in terms of reciprocity (their children simply returning the care they had previously received from their parents), most of the White British participants were concerned that they were burdening their relatives and both they and some Black Caribbean people with dementia felt that there were constraints affecting the level of care their children could provide (see subsequent section on reciprocity).

Pride, honour and shame

Religious beliefs about filial responsibility are linked to the concepts of pride, honour and shame, which are themselves interrelated. A person may, for example, feel a sense of pride, in being able to provide the care and support needed. It brings honour upon the family. Failing to provide care, by contrast brings shame on the family. In South Asian communities, it is often the actions of women that are considered to result in honour or shame on the family (Rauf 2011). Within some minority ethnic groups, honour and shame have far-reaching consequences. As mentioned earlier, knowledge that family has a person with dementia (often perceived as a hereditary mental condition) may affect marriage prospects of younger relatives and even the standing of the wider family which might be living thousands of kilometres away.

The flip side of the coin is that managing to fulfil care obligations may result in a sense of accomplishment and pride, which can be personally rewarding. Helping others, including people outside of the immediate family, is often highly valued and considered as a means to ensure respect, especially within Christian, Sikh and ultra-orthodox Jewish communities (Lawrence et al. 2011, Golan-Shemesh and Lahav 2018) or to obtain blessings from God (Mackenzie 2006). In Israel, this has led to successful projects involving female volunteers helping provide care in the homes of people with dementia (Golan-Shemesh and Lahav 2018).

Similarly, Black Caribbean and South Asian people in the UK often consider the provision of care as a sign of virtuousness in contrast to many native English carers who consider it restrictive and requiring them to put their lives on hold (Institute of Psychiatry cited in Rauf 2011). In the Netherlands, Turkish and Moroccan carers also saw providing care as a means to acquire respect with the family and community (e.g. from the parents but also from brothers and sisters and the wider community), whereas for the Surinamese Creole carers, such recognition was just from the close family, not the wider community (van Wezel et al. 2016).

Reciprocity

A recurring theme in the literature on care giving traditions is that of reciprocity, namely providing care in recognition of acts of kindness and out of gratitude for having been cared for oneself (e.g. as a child). Mackenzie (2006) found that some Sikh and Hindu carers in her study saw care as a way to repay parents for their previous acts of kindness. In two studies carried out in Norway involving carers having migrated to Norway from Pakistan, Afghanistan, China, Vietnam, Turkey, Lebanon, Sri Lanka and Chile (Næss and Moen 2015, Sagbakken et al. 2018), carers described the provision of care to parents as a moral question and a matter of reciprocating the care they had received as children throughout their upbringing. Female Turkish, Moroccan and Creole Surinamese in the Netherlands expressed similar views (van Wezel et al. 2016). In one of the Norwegian studies, the participants linked the issue of reciprocity to beliefs about normal ageing and the need for tolerance, coupled with hope and some degree of worry about whether their children would do likewise:

> "The day will come when also we will be shuffling aimlessly around the house, banging the walls and slamming the doors. I hope that then our children will not be so tired of us that they send us off to a nursing home. I have been brought up to put up with behaviour like this. It is natural that people do these kinds of things when they get old" (Næss and Moen 2015, p. 1723).

The perceived superiority of family care

Alongside beliefs about the duty to care and paying back older relatives for the care they once provided is the belief that relatives would not be as well cared for by outsiders (e.g. they would not be understood, would not receive individualised care, would not receive enough food and exercise and might even be sexually abused) (Sagbakken

et al. 2018). Reasons for the perceived superiority of family care include claims that it is more loving, offers more security and recognises who the person with dementia is. This is contrasted against negative images of residential care in the media, summarised by a Moroccan carer as being places where people are left suffering, with no contact, just waiting to die (van Wezel et al. 2016). Carers from the Turkish, Moroccan and Surinamese Creole communities in the Netherlands also mentioned family care as providing a familiar and trusted environment amongst people who speak the same language.

Responding to religious, cultural and gendered roles and responsibilities

On the one hand, it is important to respect cultural traditions with regard to power relations and gendered care roles. On the other hand, it is important to consider the physical and mental wellbeing of relatives providing care without any support. One possible approach, suggested by Mukadam et al. (2015), is to reframe outside support as living up to cultural expectations to enable the person with dementia to live as fulfilling a life as possible rather than as relinquishing care. It may also be beneficial to gain the support of spiritual leaders and male members of the communities in which filial piety is a tradition.

Healthcare providers need to be aware of the cultural traditions within some minority ethnic communities to provide care within the family but also to avoid stereotyping and considering this as reflecting the wishes of all members of the community (Turner et al. 2005, Brooke et al. 2018). Moreover, the acceptance of help is not necessarily all or nothing and there may be differences in the kinds of services that individuals and groups consider acceptable. It is also important to avoid assuming that people from minority ethnic groups all have the support of a family. There are also people with dementia, within groups which typically do not use outside support, whose relatives are not willing or able to provide support, who do not have children or

whose families were divided when they migrated (Parveen, Morrison and Robinson 2013, Næss and Moen 2015, Sagbakken et al. 2018). Also in the context of working with rather than against traditions, it is important to support women in their role and offer them the possibility to enjoy the same rights and opportunities as other women without challenging their perceptions of duty or of virtue and pride linked to their caregiving activities.

Finally, Næss and Moen (2015) report an interesting practice in the Norwegian-Pakistani community regarding the financial burden on the principal carer, which may arise due to loss of income and the absence of state subsidies. This consists of pooling the pensions of the parents requiring care and support into the family economy. Næss and Moen (2015) point out that all Norwegian citizens are entitled to a standard minimum pension even if they have never been in paid employment. In other countries, where a minimum standard pension does not exist and where this practice is not common, carers may be financially disadvantaged by providing care, through potential loss of income, the costs of any outside help used and lost pension contributions. However, in some countries such as the Netherlands where it is possible to obtain a 'personal budget', some minority groups are increasingly using this option as a means to compensate family members for the costs incurred as a result of providing care even though, as mentioned earlier, it can often be difficult to navigate the personal budget system.

In her evaluation of the impact of religion on dementia care service uptake amongst people from some minority ethnic groups, Regan (2014) suggests looking at how religion could be used to help promote service use. She describes a two-phase approach: first, to use scriptures and teachings of faith to promote care-giving within members of the community; second, for religious leaders to increase understanding of dementia as a biomedical condition to reduce stigma and promote access to health and social care services.

Key points from the section "Challenges related to the uptake of services and support by minority ethnic groups"

- People from minority ethnic groups do not use support and services to the same extent as people from majority ethnic groups.
- People from minority ethnic groups sometimes assume that available support will not be suited to their cultural needs and preferences.
- Some fear that nobody will speak their language and they or their relatives would not be able to cope.
- In many cases, intercultural care and support services are not available. Where they exist, people do not necessarily know about them or think that they would not be entitled to them.
- Difficulties with language and lack of knowledge about how the healthcare system works may result in some people not being able or being hesitant to ask about services and support.
- Many people from minority ethnic groups have limited financial resources and struggle to make ends meet. Even a small cost, such as a bus fare, parking fee or the cost of a phone call (especially if kept on hold for several minutes), may be enough to deter a person from using a service.
- The stigma of dementia, of mental disorders and/or of the family not providing care may result in people hiding the fact that they or a member of their family has dementia and in not using services and support which they might otherwise find helpful.
- In some minority ethnic groups, people with dementia are usually cared for by female relatives. In the context of religious beliefs and traditions, it is often considered their duty to care. They may be reluctant to seek outside help as this might be interpreted as a rejection of that duty or as failure to fulfil it, which could be considered as bringing shame on the family.
- The concepts of pride, honour and shame are interrelated. Fulfilling care obligations can also bring recognition and a sense of accomplishment or pride.
- Sometimes the tradition of providing care is not directly linked to religion but to values and traditions which reflect the principle of reciprocity (i.e. providing care as a means to repay kindness, love and care previously received oneself).
- Although women often provide informal care, male relatives may be the official spokesperson for the family. Consequently, women are often not asked or do not have the opportunity to discuss their possible need for support with health and social care professionals or service providers, and their physical and mental health may sometimes suffer.
- Some people believe that care provided by the family is superior and that provided by professional carers.

Recommendations/points for reflection

- People from minority ethnic groups should be offered culturally sensitive post-diagnostic support, if at all possible from a person who speaks the language they are most proficient in.
- Awareness raising materials should challenge negative stereotypes and address fears that people from minority ethnic groups might have about services and support.
- Services and support should be presented in the context of ways to provide better care and support rather than as involving handing over or relinquishing care.
- Health and social care professionals should seek to establish a relationship of trust and mutual respect with members of minority ethnic groups through the acquisition of cultural awareness and the development of cultural competence. They should be provided with training in providing intercultural care and support.
- GPs should be provided with the necessary means and support to enable them to take a more active role in ensuring access to intercultural care and support for their patients from minority ethnic groups.
- Religious duties and traditions may influence attitudes towards the use of services and support but it should not be assumed that people with dementia and families from particular minority ethnic groups do not wish to receive appropriate services and support.
- Commissioners (those who are responsible for assessing needs, planning and purchasing health and social care services) should consult and where appropriate work in partnership with organisations which have been successful in meeting the care and support needs of people from minority ethnic groups.
- Where and when possible, prominent people from the community who have had personal experience with dementia could be encouraged to be spokespeople to help dispel stigma.

Aspects of intercultural care and support provided to people with dementia

This section is about aspects of intercultural care and support which have a direct impact on the daily lives of people with dementia from minority ethnic backgrounds, and in some cases of their carers. It covers a range of issues such as language, food and drink, appearance and dress, religion, understanding life histories and end-of-life care. A lot of the information covers issues which are specific to minority ethnic groups. Minority ethnic groups are made up of people who may have a lot in common but whose thoughts, feelings and behaviour are not determined solely by their culture. They are unique individuals. The aim is therefore not to emphasise differences between minority and majority ethnic groups but rather to serve as a starting point to develop cultural awareness by highlighting some of the things that are important to many, but not all, people from minority ethnic groups. This should, hopefully, promote reflection and the desire to better understand people from difficult cultures. Often, behind the apparent differences (e.g. related to appearance, traditions and religious practices), there are similarities and shared values. Culture is one aspect of a person's identity which needs to be recognised but should not overshadow their individuality. An understanding of shared cultures needs to be balanced with knowledge of the individual so that people are not regarded merely as members of 'other' groups with collective norms (Mackenzie 2007).

As Rauf suggests (2011, p. 16):

> "It is important that people are respected as individuals and individual families rather than seen as generalised conceptions of stereotypical groups."

Issues related to language and communication

It is important for all people with dementia to have the opportunity to communicate in their own language, not only for the purpose of getting across their needs and wishes and of understanding those of other people but also as means to develop relationships and to establish and maintain a sense of self and identity. The social as well as functional aspects of language are particularly important in the context of intercultural care. Professional carers should not underestimate the huge importance of mundane, social talk when providing care (Plejert et al. 2017). The ability of professional carers to get to know and understand people who are often from very different cultural backgrounds to their own is essential and yet often hampered by language difficulties. Based on their experience of developing cultural sensitivity in memory work, Jaakson, Hemmilä and Jaakkola (2017) emphasise the importance of core steps that include reaching out, engagement, dialogue, building a relationship based on trust and constant reflection about one's own work. Poor communication between professional carers and people with dementia from minority ethnic groups can also result in the latter being considered as having more cognitive deterioration than they actually have and being incorrectly medicated (Söderman and Rosendahl 2016). A common language can make it easier to understand cultural values and traditions that are important to people:

> "Language difficulties, then, constitute a central challenge in intercultural geriatric care, particularly in relation to dementia, either when minority elders lose whatever of the majority language they once knew or when ethnic minority health care personnel's majority language skill is limited" (Hanssen 2013, p. 234).

A major problem in ensuring that people from minority ethnic groups can receive care from professionals who speak and understand their language is that there are so many languages and dialects. In some countries, there are already two or three national languages (such as in Luxembourg, Belgium and Switzerland) on top of which it would be necessary to add further languages. It would be ideal to have bilingual professional carers who reflect the local demography (Bhattacharyya and Benbow 2013). This would, in theory, be possible provided that sufficient numbers of people from the relevant cultural groups wished to work in this area. If this were not the case, measures would need to be taken to increase interest in this type of work and perhaps training possibilities for people from the relevant minority ethnic groups. It is questionable, however, how practical this solution would be for services covering people from a wide range of minority ethnic groups speaking several languages.

This brings us back to the issue of mainstream or specialised services raised earlier. In Sweden, Söderman and Rosendahl (2016) compared the pros and cons of residential care for Finnish-speaking older people either in a home in which all the staff were Finnish speaking or in a home where there was a mixture of Swedish speaking and bilingual staff. The findings seem to show very clearly the superiority of the Finnish-speaking staff home in providing person/relationship-centred care (some of which is mentioned in the sections below). This might seem to suggest that where resources are available, the number of people from the minority ethnic group is sufficiently high and there is sufficient demand within that group, it might make sense to develop specialised services. For example, in the Northwest of England, there are several residential homes for people from the Jewish community (Ahmed et al. 2017). This approach is sometimes called 'ethnic matching' or 'linguistic matching'. Plejert et al. (2017) draw attention to earlier studies carried out by Jansson (2014) and Ekman et al. (1993 and 1994) which further support the conclusion that linguistic (as well as cultural) competence of professional carers is essential for creating a trusting relationship and promoting well-being amongst people from minority ethnic groups in residential care.

Whilst it may often be beneficial to match staff from the same cultural background with service users, some families would prefer to have someone from outside their community because of stigma (APPGD 2013). Looking at this from an ethical perspective, a typical Western European response, based on a focus on individual autonomy, might be that the decision should be based on the wishes of the person with dementia, if known. This could be interpreted as failing to respect the role of the family within that person's culture with regard to healthcare decision-making. At the same time, care must be taken to avoid making assumptions about care arrangements based on stereotypes about people from certain minority ethnic groups and failing to seek the views of the person with dementia.

In cases where linguistic matching is not desired or feasible, other approaches are possible to try to ensure that people are understood and feel valued in their interactions with professional carers and, in the residential or day care setting, with other residents. Plejert et al. (2018) report strategies observed by Jansson (2012ab, 2014) which involve learning frequently-used words, repeating words just used by the resident and singing phrases in the person's mother tongue. This playful use of language helps establish social relations with residents and can be helpful in gaining their cooperation when carrying out care tasks that the residents do not particularly like. It might also sometimes be helpful, as a form of distraction, to defuse difficult situations or manage anxiety.

Technical communication aids, may, to some extent help. Free online translation tools, for example, could, if used with some caution, aid and support communication, as could some other low-tech solutions such as communication boards with pictures. Applications for iPads are also currently being developed for mono- as well as multilingual communication support in Europe, but research on their usefulness is still primarily based on the monolingual setting.

Bhattacharyya and Benbow (2013) suggest that professional carers could be encouraged to learn languages or at least key words to show families and residents that they are making an effort and are interested in them as people. The ability to learn some of the basic words and gain a basic understanding of languages used by residents and service users can be enhanced with the help of bilingual colleagues (as happened in the study by Söderman and Rosendahl) or visiting relatives or interpreters (Bhattacharyya and Benbow 2013).

However, communication is more than mere verbal exchanges. Small et al. (2015 cited in Plejert et al. 2017) emphasise the importance of 'embodied conduct' (e.g. pointing, the use of gaze, touch, body-contact, helping a person stand up, walking with them etc.) in developing positive affective relationships and in promoting independence. There are, however, limits in the sense that professional carers may be aware of the importance of verbal and non-verbal communication but still have difficulty managing some situations because they perhaps pronounced a word wrong or did not understand something that was said. This is similar to the problem sometimes experienced by migrant care workers. In many cases, it is not as important what is said but rather how it is said or how a person is received and this can again be communicated through non-verbal means such as gaze, turn-taking and facial expression (Plejert et al. 2017). Non-verbal communication is also particularly important in view of the fact that some people lose the ability to speak and understand their mother tongue.

Food and drink

Food and drink can be seen as having practical functions (i.e. to nourish the body and sustain life) but also as being linked to certain religious requirements, having a social purpose and affecting wellbeing. Religious requirements differ considerably from one religion to the next and also within certain minority ethnic groups (which sometimes consist of groups of people from different religions). With regard to such requirements amongst members of the South Asian community in the UK, for example, Rauf (2011) explains:

"Muslims for example eat only Halal meat, with the prohibition of pork in any form. They will also not drink alcohol. Sikhs on the other hand may well choose to eat meat, but not Halal meat. Hindus are almost always vegetarian, with a large majority being vegan. Not only will Hindus not eat meat, but cows are sacred in their religion" (Rauf 2011, p. 12).

Aside from their religious justification and significance, the key differences between dietary requirements in different religions are about which foods are allowed, which are not and how animals should be slaughtered (the Islamic requirements are called Halal and the Jewish requirements are called Kosher)[37]. In some religions there are periods of religious fasting, the most well-known perhaps being Ramadan. However, Ramadan is not just about fasting. It involves strict fasting from dawn to sunset but also a period of prayer and reflection, self-control and thinking about others. To prepare for the fast, Muslims eat a pre-dawn meal of power foods to get them through the day.

Religious dietary requirements may differ geographically and change over time. In the Eastern Orthodox, Roman Catholic, Anglican and Methodist traditions, there is a tradition of Friday fasting. This consists of fasting or not eating meat on Fridays, often resulting in people eating fish on Friday. In the last few decades, Friday fasting has become less common, often being restricted to the period of Lent. In England and Wales, however, in 2011 the Bishops' Conference sought to revive this tradition (Oddie 2011), which emphasises the possibility of religious traditions fluctuating over time.

To respect cultural and religious dietary requirements, it is therefore important to make an effort to understand everything involved so that they can be practiced in a meaningful way. People with dementia themselves may at some point forget certain requirements but, in keeping with what has always been important to them throughout their lives, might appreciate support to be able to continue to practice them. This is in keeping with Dworkin's 'integrity' view of autonomy which emphasises the importance of critical interests (Alzheimer Europe 2009). These, in contrast to experiential interests which are things that people do just because they like doing them, are about interests which are deeply meaningful. They reflect critical judgements that were made and are the kinds of things that make people think, had it not been so, their life would have been worse or wasted (e.g. having a close relationship, accomplishing a particular task or fulfilling a duty). Most religions are quite tolerant towards people who are unable rather than unwilling to fulfil their religious obligations. Nevertheless, professional carers can play an important

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[37] A table providing a brief overview of religious dietary restrictions is available at: https://www.chapman.edu/about/fish-interfaith-center/religious_dietary_restrictions.pdf

role in helping people with dementia to keep up their religious practices (e.g. regarding food and drink) if they so wish. It may be necessary to consult families, if available, and local religious leaders to clarify certain issues if information is not readily available.

Professional carers should also try to understand traditions surrounding the way that food is served, how it is offered as a display of hospitality and whether it is customary for families to prepare and eat food together. Rauf (2011) comments on the way that older South Asian people can sometimes be quite pushy in offering refreshments and explains that this is a sign of hospitality. People with dementia from a wide range of ethnic groups may have traditions surrounding food and hospitality and few opportunities to engage in them (e.g. towards visiting relatives and friends), especially in residential care settings where access to food and drink may be controlled by staff. There may be certain constraints affecting what professional carers can do but staff need to have an understanding of the social or relational function of food amongst people from different minority ethnic groups and try to support them to maintain their customs and traditions surrounding food.

Finally, food can be enjoyable and contribute towards quality of life. People from minority ethnic groups in residential or day care should have the same right to good food as those from the majority ethnic group. In a qualitative study of people with dementia from the Sami community in Norway (Hanssen 2013), nurses commented on the positive impact on residents when traditional Sami food was served and regretted that this only occasionally happened. In the Swedish study mentioned earlier for Finnish-speaking residents, the Swedish-speaking/bilingual home only served traditional food on special occasions and managed this through a large-scale catering company, whereas in the home with Finnish-speaking staff, several traditional meals were cooked and served by the staff every week and staff felt that residents ate more when given a traditional meal. Yet another approach is to regularly order in food for residents from minority ethnic groups (e.g. a Chinese or Indian take away) (APPGD 2013). There are some good examples of care providers being creative in finding solutions to provide people from minority ethnic groups with traditional food that they enjoy, but when it comes to religious requirements, this is perhaps not sufficient. Talking about different specialised homes for Jewish people in the UK, a Jewish carer stated:

> "Because if you don't fit into Beenstock and you don't fit into Heathlands, you have to go to one of the other homes which… It's difficult to organise Kosher food and prayers and… So, that is a big hole" (Ahmed et al. 2017, p. 35).

Appearance and dress

Some people from minority ethnic groups wear traditional clothing on a regular basis. Others choose to dress in the same way as people from the majority ethnic group. There are many forms of traditional dress worn by people from minority ethnic groups in everyday life. Examples include the traditional long heavy dresses worn by Roma women in Finland and the salwar karmeez (worn by Sikh and Pakistani Muslim women), saris (worn by Bangladeshi, Hindu and Muslim women) and turbans (worn by Muslim and Sikh men). Some of these garments, and the way they are worn, are linked to religious requirements whereas others reflect geographical or historical norms (Rauf 2011). For some women, it is important that the clothes they wear cover their head or body. Many Muslim women, for example, wear Niqab, Burka and Chador, in keeping with Hijab, an Arabic term which means to put on, to cover or a curtain, veil or covering, symbolising a modest dress code. Doing so is often an assertion of religious and cultural identity (Soni 2013).

It is important that people with dementia from minority ethnic groups are given the opportunity to dress in a way that reflects their religious and cultural identity as well as their personality. Professional carers should be familiar with and respect each person's preferences, and when necessary help the person to dress appropriately. They should also be aware of religious and cultural traditions linked to personal grooming and washing, and of personal, symbolic items that people may wish to have on them at all times (e.g. certain items carried by some Sikh men).

Twigg (2010) is critical of the emphasis on physical comfort in many residential homes, on clothing restrictions linked to laundry requirements and on the frequent problem of residents ending up wearing other people's clothes. As Twigg points out, comfort in dress is a complex and socially determined concept but all too often, it is more about convenience for staff than the wellbeing of residents. There is a certain comfort derived from feeling socially presentable. Sitting around in 'comfortable' loose fitting clothes does not necessarily provide that comfort. The Roma women in Finland, for example, still wear traditional heavy velvet skirts, which are known to be damaging to their health (leaving traces on their hips and internal organs). They are probably far from comfortable but the skirts are a big part of the Roma women's identity (Jaakson 2018).

Twigg (2010, p. 6) argues in favour of the continuing relevance of clothing for people with dementia. Speaking about clothes, she states:

> "They represent a continuation of cultural and personal traditions; they are located in social relations that respond to and acknowledge the clothed self,

and in which the person is directly embedded, in the sense of being the wearer and bearer of clothing; and they form part of the continuing narrative of self through which the people express their position within particular social worlds."

This may be particularly important for people from ethnic groups with very different dress codes for whom not being able (and not being assisted when necessary) to dress as they wish may be particularly disturbing for them (e.g. when clothes get mixed up or people don't have the chance to choose what to wear and end up wearing clothes they find embarrassing or out of character). Encountering one's relative with dementia in someone else's clothes can be disjunctive and distressing, threatening the sense of continuity of self (Twigg 2010).

Religious obligations

Many people with dementia from minority ethnic groups will wish to continue practicing their religion by praying, attending a place of worship or taking part in various religious festivals. Consequently, there may be certain times and dates when it would not be convenient to receive care services (Rauf 2011) and others when culturally appropriate support would be particularly welcome (i.e. to promote social inclusion). In some minority ethnic communities, it may be problematic for people with dementia to continue attending their place of worship. Depending on the level and nature of their dementia, there is a risk that they might disrupt the service, not be able to join in communal prayer and perhaps fail to respect certain religious requirements. Sometimes their families will try to stop them attending in order to save face, preserve their dignity or protect their standing within the community. The extent to which a person with dementia is encouraged and assisted to continue attending public places of worship and engaging in communal prayer may be partly influenced by the family but also the spiritual leaders of a particular place of worship.

Cognitive abilities tend to be highly valued by members of the ultra-orthodox Jewish community and cognitive decline likely to result in loss of family honour. However, the Alzheimer's Society of Israel was successful, together with ultra-orthodox care services and rabbis from the community, in changing attitudes and improving awareness and knowledge about dementia. As a result, men with dementia now often continue to go to the synagogue and engage in communal prayer (a capacity which is often retained when others have already been lost) (Golan-Shemesh and Lahav 2018). Some people may still be hidden though in order to protect their honour, so attitudes have not completely changed. Nevertheless, this emphasises the importance of creating links with spiritual leaders as a means to gradually change perceptions of dementia and promote social inclusion.

In the case of services and care provided in the person's home, health and social care professionals should understand that they might be asked to respect certain traditions such as taking off their shoes on entering a person's home. This is because in some religions, it is common to have a place of worship in the home. Walking around a person's home with outdoor shoes on would make it unclean. Professional carers who provide services in a person's home should also consider the way they dress and whether this might be considered offensive to service users from some minority ethnic groups (Rauf 2011). Continence problems may also result in the home being considered as unclean and interfering with home prayer (Bowes and Wilkinson 2003), which might also disrupt family life and lead to embarrassment.

A safe and stable environment

Intercultural care and support should provide people with dementia from minority ethnic groups with a feeling that they are in a safe and stable environment. Being amongst people who speak and understand a person's language is likely to be important. At the most basic level, people need to feel able to summon assistance in case of perceived danger and to understand what is being said around them. This applies to people with dementia (whose possible difficulties with language and communication would be exacerbated by being in a situation in which they were not proficient in the language) but also to carers trying to make sense of various care situations and options, and needing to communicate with care staff. To some extent, the perception of being in a safe place or in a trusted environment is based on a subjective feeling, to some extent it may be more tangible. The ability of professional carers to establish a good relationship with their clients from minority ethnic groups is important. Söderman and Rosendahl (2016) emphasise the importance of language in creating a good relationship between professional carers and people with dementia, pointing out how the lack of a common language can lead to misunderstandings and minor issues being blown out of all proportion resulting in anger, frustration and aggression. Such incidents may be unpleasant for those involved but also create unease amongst fellow residents.

A lack of traveller sites with adequate facilities may result in people with dementia and carers from those communities having difficulties with laundry, bathing, toileting and continence care (DAA 2018). Services aimed at providing assistance in these areas for the majority ethnic group are likely to be wholly unsuited to the traveller community and require more than a minor adaptation to make them culturally appropriate. Another problem for traveller communities is that people with dementia may be at greater risk of getting lost in unfamiliar surroundings, sometimes in areas where metal is being recycled. The perceived or real prejudice of nearby inhabitants may result in travellers not

seeking outside help in such cases. It seems likely that various assistive technology devices might be useful in this context and there are various systems in place in some areas of Europe to facilitate the work of the police in finding people with dementia rapidly when they get lost. However, it is not known whether people from traveller communities would be informed about or entitled to AT devices and some travellers may be hesitant to initiate contact with the police or the local authorities (e.g. based on a past negative experience or anticipated discrimination).

Reminiscence and possible trauma

Reminiscence work is often considered helpful as a means to understand a person with dementia. However, according to Ahmed et al. (2017) national historical and cultural reference points tend to be used which may make it inappropriate for people from minority ethnic groups unless suitably adapted. It has been suggested that the use of life stories and family biography workshops may help healthcare professionals to learn about the unique individual in the context of that person's experience within a particular minority ethnic group (Jutlla 2015), to see "the person beyond the dementia" and to consider people "as part of a family history" (Grøndahl et al. 2017, p. 9).

Some researchers emphasise the importance of understanding a person's individual experience of migration and where appropriate of settling into a different culture, particularly as this may be relevant to that person's expectations and attitudes towards receiving care and support. The issue of possible trauma needs to be considered though. There are many refugees in Europe who have recently experienced trauma as well as people from minority ethnic groups who experienced trauma when they were younger (e.g. survivors of the Holocaust, people who lived through the India-Pakistan Partition and people who experienced childhood sexual abuse) (Birchard 2009, Herz 2017, Doshi and Mehdi 2017). The experience of trauma is not limited to people from minority ethnic groups but it may be more common amongst older people who originate from certain countries and have lived through periods of conflict.

Dementia will hopefully be diagnosed at an earlier stage amongst people from minority ethnic groups as progress is made developing culturally-appropriate assessment and diagnostic tools. Consequently, in the next few decades, there may be increasing numbers of people living with dementia with a history of trauma which professional carers will need to deal with. It might not always be necessary to know all the facts about what happened.

It may sometimes be sufficient for professional carers to realise that they are not necessarily doing something wrong, to understand what is going on and why somebody might be behaving in a particular way, to be empathic and to be willing to listen if a person wishes to talk about their experience

End-of-life care

Very little research has been carried out into the needs and wishes of people with dementia (and their families) from minority ethnic groups living in Europe regarding end-of-life care, and of their knowledge and awareness of palliative care services at the end of life (Koffman 2018). Research has been conducted in non-European countries, particularly in North America, which provides valuable insight into certain issues, but the findings are not necessarily representative of the situation experienced by people from minority ethnic groups in Europe. A few general findings, which might nevertheless be worth considering when developing and delivering end-of-life care, include the need to pay attention to equity in referrals for palliative care, to awareness about and the use of advance directives, to issues related to the assessment of pain, including communication issues and cultural attitudes towards the experience of pain, to cultural variation in attitudes towards autonomy in end-of-life decision making and to understanding attitudes and decisions related to the use of life-sustaining treatments (Koffman 2018). People may also have concerns about the period after their death. Some older people from the former Soviet Union, now living in Finland, who are reliant on their families in the former Soviet Union for support, worry about where they will be buried, who will look after their graves and how to avoid this task becoming a burden to their relatives (Heikkinen and Lumme-Sandt 2013).

Some information is available about religious practices and beliefs, as well as traditions, which are common amongst different minority ethnic groups in Europe but these are not directly linked or limited to the situation of people with dementia. They may nevertheless contribute towards increasing awareness and cultural sensitivity amongst health and social care providers. For example, information was provided, in the context of a project called "Demenz und Migration"[38], which highlighted several rituals and practices commonly followed by Turkish Muslims living in Germany. Examples include relatives deciding whether to contact an Imam[39], praying together for the dying person, watching over the person's body after death, communicating the death by word of mouth, sometimes followed by an announcement in the newspaper, and organising a big

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[38] For more information (in German) please see: http://www.demenz-und-migration.de/kulturelle-besonderheiten/islam-und-tuerkei/

[39] The imam is a leadership position in some branches of Islam. A person is hired or selected by members of the community. Sometimes this person has had special training, but this is not required.

prayer ceremony 40 days after the person's death. Details are also provided about various rituals surrounding the preparation of the body of the deceased.

In a UK project, cultural beliefs and taboos surrounding death and dying were reported amongst people from African and South Asian (mostly Punjabi Sikh) ethnic communities (Smith, Moreno-Leguizamon and Grohmann 2015). Some members of the African community were reluctant to talk about death. It was a taboo subject linked to fears about "inviting" death. The same reluctance was noted in relation to discussions about making a will amongst some members of the South Asian community. Many from both communities declared that they would want to return home to die or to be buried in the country of their birth. Differences between people from the Sikh and Muslim faith were described surrounding the ritual bathing of the body, including the respective roles of men and women. Members of both communities seemed to have a limited knowledge about what palliative care is.

It is common amongst some minority ethnic groups (e.g. within some traveller communities and some Muslim communities) for large numbers of the close and extended family, including children, as well as members of the wider community, to call or visit the dying person in hospital as a sign of respect or as part of a religious duty[40] (Smith, Moreno-Leguizamon and Grohmann 2015, Baktit Abbasi 2018). Within some traveller communities it is also common to cover mirrors when a person is dying and to light a fire outside when the person has died (Smith, Moreno-Leguizamon and Grohmann 2015). Rules and regulations often interfere with members of these communities respecting their customs and this may sometimes lead to situations of conflict with professional carers and with other residents in the hospital.

In some minority ethnic groups, there may also be cultural differences linked to beliefs about the purpose of end-of-life care. De Graaf et al. (2012) found that Turkish and Moroccan minority groups in the Netherlands considered disease and dying as family issues and that relatives often expect doctors to try to cure patients until death, which may clash with doctors' aims to promote quality of life.

It is beyond the scope of this report to cover the customs and practices of all the minority ethnic communities and the rituals and beliefs associated with all religions. At the same time, even if it were possible to do so, this would not guarantee intercultural end-of-life care and support. Such information can be extremely helpful as a means to improve intercultural awareness and as a broad guide for health and social care professionals. However, the needs and wishes of the individual are paramount. The period surrounding death calls for great sensitivity to religious practices and rituals. However, as pointed out by Koffman (2018):

> *"Formal religion is a means of expressing an underlying spirituality, but spiritual belief, concerned with the search for existential or the ultimate meaning in life, is a broader concept and may not always be expressed in a religious way."*

Koffman warns against approaches which more or less focus on facts or 'recipes' for the experience of death and dying across different faiths, pointing out that there are significant differences between different branches of most religions (e.g. between Orthodox and Liberal Judaism or between Anglican and Pentecostal Christianity). A broad knowledge and understanding of different religious and spiritual beliefs and practices would nevertheless provide a solid basis for such a personal enquiry.

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[40] See also section on Carers from minority ethnic groups in the Section 6 (p. 62).

Key points from the section "Aspects of intercultural care and support provided to people with dementia"

- Intercultural care and support promotes awareness of and respect for cultural difference. However, people from different ethnic groups also have a lot in common and are individuals in their own right. Culture needs to be recognised but should not overshadow recognition of people's individuality.
- It is important, especially in the context of dementia care, for people to be able to communicate in their own language. However, non-verbal communication (e.g. touch, tone of voice, body language etc.) is also important.
- People from minority ethnic groups may have dietary requirements which are sometimes influenced by religious beliefs and traditions. Food can also be a source of pleasure and serve a social function. Not having access to familiar food may have a negative impact on people's perceived quality of life.
- Appearance/dress often reflects a person's personality as well as their cultural and religious identity.
- The importance of clothing is often underestimated (e.g. in residential care homes where the main concern is sometimes linked to ease of dressing, assumed 'comfort' and washing of clothes). For people from some minority ethnic groups and their families not being able to dress in a culturally appropriate manner may be disturbing.
- For many people from minority ethnic groups, religion is an important part of their lives. They may wish to practice their religion by praying alone or with others and to take part in religious festivals. They may eventually need support to do so and support from religious leaders may vary.
- People from minority ethnic groups may appreciate/expect others to observe or respect certain religious practices and traditions (e.g. taking off shoes when entering their home and greeting members of the opposite sex in the appropriate manner).
- Like anyone else, people from minority ethnic groups receiving care and support for dementia need to feel that they are in a safe and stable environment. Being able to speak and be understood in one's own language can be helpful in this respect. As dementia progresses, some people revert to the language of their childhood.
- Sometimes, the physical environment is unsafe and ill-suited for the provision of good quality dementia care (e.g. for people with dementia from traveller and other nomadic communities).
- Reminiscence work (e.g. involving life stories) may help professional carers to understand people from different ethnic groups as unique individuals and as members of a particular culture. There is a risk, however, of sometimes reviving memories of traumatic experiences which may be difficult to manage.
- Cultural awareness about traditions and practices linked to end-of-life care within different communities is important but only as a basic framework within which to enquire about the wishes, needs and preferences of individuals, their families and close friends.

Recommendations/points for reflection

- Intercultural care and support should be developed in cooperation with people from the specific communities who currently or may eventually use it. Basic issues should be addressed such as how to enable people to practice their religion and enjoy culturally appropriate food and activities and how to ensure respect for cultural traditions and customs. The best way to address these issues is likely to differ from one minority ethnic group to the next.
- People from minority ethnic groups should, to the extent that it is practically possible, have access to health and social care professionals who can speak their mother tongue.
- Where bilingual professional carers are not available, efforts should be made to learn some of the most commonly used words and to involve visiting relatives, bilingual colleagues and interpreters, both for practical reasons and to communicate an interest in the person receiving care or support. The use of technical communication aids should also be considered.
- Interpreters should be more readily available and budgeted into the cost of providing intercultural care and support.
- Key professional carers working with minority ethnic groups should have some training in managing trauma in the context of dementia care (in the sense of protecting the wellbeing of their clients as well as staff).
- All professional carers (including auxiliary/support staff) should be aware of significant historical conflicts and issues which may have led to trauma amongst people with dementia from minority ethnic groups.
- Professional carers should try to understand the spiritual and religious needs and wishes of people with dementia from minority ethnic groups who are approaching the end of their lives (and of their families and close friends), and to ask rather than make assumptions about beliefs and practices to which they may or may not adhere.
- Professional carers and service providers/commissioners should seek feedback from people with dementia and carers from minority ethnic groups about services and support, and how these do or do not correspond to their needs and expectations.
- Professionals should be provided with the tools and abilities to support people with dementia and their families at times when the person might no longer wish to adhere to their previous traditions.

6. Issues and challenges encountered by professional and informal carers

People from minority ethnic groups are under-represented as recipients of dementia care services but in some areas are largely over-represented as providers of such services (Beattie et al. 2005, Moriarty, Sharif and Robinson 2011). In addition to professional carers from minority ethnic groups already living in a particular country (in many cases having been born and having grown up there), carers with a migratory background are increasingly being employed in Europe as professional carers (Doyle and Timonen 2009). This is especially the case in some European countries with regard to live-in carers for dependent older people, including people with dementia (Ungerson 2003, Degiuli 2007, McGregor 2007, Doyle and Timonen 2009, Romero 2012). Overall, people providing dementia care are more likely to be female, from a minority ethnic group and, if employed, on a temporary contract (Prince et al. 2015).

To date, there has been little research about the personal experience of people from minority ethnic groups who provide dementia care and support, either professionally or informally (e.g. relatives and friends). The experience of

care and support is closely linked to the experience of those who provide it. Satisfaction with care and support tends to be greater when it is provided by people who are motivated and skilled, physically and mentally able to provide such care, and feel valued, supported and engaged (Royal College of Physicians 2015). Consequently, although the wellbeing of the person with dementia must be the central concern when providing care and support, this must be balanced against other concerns related to the wellbeing and rights of other people such as professional and informal carers (Alzheimer Europe 2015).

In this section, we look at the experience and some of the challenges encountered by:

- Health and social care professionals
- Informal carers (from minority ethnic groups)
- Migrant carers (focusing on care professionals with a recent migratory background)
- Live-in carers (mainly people who have recently migrated to a country).

Health and social care professionals

Health and social care professionals providing dementia care to people from minority ethnic groups have their own understandings of dementia and may also have beliefs about people from minority ethnic groups which have an impact on the care they provide. It might be assumed that most professional carers in Europe have a reasonable understanding of dementia, are able to recognise dementia and consider it as a medical condition. However, a study by Emilsson (2011) into dementia care staff in Portugal, France and Sweden revealed that all perceived the needs and behaviour of residents with dementia through the lens of ageing rather than dementia.

Many health and social care professionals, from all ethnic groups, are not sufficiently aware of services for people with dementia, and especially not of specific services for people from minority ethnic groups. In addition, some have limited or no understanding of the culture of people from specific minority ethnic group to whom they provide care or of their particular needs and wishes. There may,

however, be situations in which health and social care professionals are aware of cultural practices but need to insist on certain issues (e.g. to enter a person's home in a crisis situation without taking off their shoes). A particularly difficult situation is where the social services have received a 'note of concern' from neighbours and need to check the wellbeing of a member of the family but are refused entry by relatives (Sagbakken et al. 2018). There are also many situations in which health and social care professionals are restricted with regard to the support that they can provide to people from minority ethnic groups by procedures, hierarchies, structures, funding and lack of training opportunities.

Some of the other issues described in this subject may also apply to both groups. Language difficulties may impact on the ability of professional carers to provide good quality, person-centred care. In a Norwegian study, staff in home-based dementia services complained of not being able to understand their clients from minority

ethnic groups, of having to rely on relatives for translation and of not feeling that they understood the situation and needs of their clients (Sagbakken et al. 2018). This was combined with frustration about finding ways to involve relatives in care (as the latter often express an interest in being involved) and their efforts being ignored (e.g. relatives not attending meetings to discuss how to coordinate care). However, the researchers noted that some people felt uncomfortable and disloyal "talking about everything" in front of strangers, whereas others appreciated the proposed family meetings and yet others, women in general, wanted to attend but were unable to do so because they could not leave the person with dementia alone. So this is a complex issue which probably requires more flexibility and perhaps a different approach to involving the family. As many people from minority ethnic groups are often diagnosed at a later stage of dementia (if at all), relatives and friends supporting them are unable to leave them at home alone whilst they go out to organise the support they need. The way that support is organised sometimes prevents the very people who need it from obtaining it.

Another problem experienced by professional carers is how to communicate effectively with families and provide appropriate support for the person with dementia and carers without creating conflict between male and female relatives. Some staff in Norway report differentiating between the information given to male and female relatives to avoid conflicts which nevertheless sometimes occur and then being shut out and not knowing what is going on (Sagbakken et al. 2018). Issues surrounding communication difficulties are central to the development of cultural competence. Seeleman (2014) emphasises the need for cultural awareness, awareness of one's own prejudices and tendency to stereotype, the ability to transfer information in a way that it will be understood, knowing when to seek external help and having the ability to adapt to new situations in a flexible and creative manner, all of which are skills that can be learned through appropriate training.

Situations may arise when professional carers lack information about something that might be important for a person from a particular minority ethnic group, need more information or are unsure about how a course of action might affect other people. Because of the dynamic nature and multitude of different cultural groups, the provision of intercultural care and support is likely to be an ongoing process of continuous learning and collaboration with those directly concerned and with others who have the relevant expertise and knowledge. Jutlla (2015) suggests that possible lack of confidence of staff to provide care to a person from a minority ethnic group is something that can be overcome with training.

Health and social care professionals occasionally encounter ethical dilemmas. When trying to determine what is

ethical (i.e. morally good and right), people tend to rely on shared norms and understandings of right and wrong. This involves drawing on values which have been defined by society as a whole and picked up from other people (e.g. from parents, through education, through relationships with other people and through culture). Ethical dilemmas can involve people from any ethnic group but in the case of people from minority ethnic groups, part of the dilemma and the ways to address it may be influenced by conflicting cultural values and perspectives, as well as communication problems. A person might, for example, refuse intimate care from a healthcare professional of the opposite sex or insist on seeing a doctor or having an interpreter from the majority ethnic group (or even vice versa). Someone may wish to observe religious traditions which are either difficult to arrange or which disturb the wellbeing of other people (e.g. in residential care settings). There may also be issues with relatives' requests seeming to be in contradiction with an individual's own interests, which he or she might not necessarily be able to express. A person with dementia might also act in a way that seems to be out character with what seem to have been his/her long-standing cultural habits and values (e.g. a Hindu lady asking to be served beef for dinner, a Sikh man not wanting to wear a turban etc.). Issues surrounding changes of behaviour which are not congruent with long-held values, particularly in relation to people who have dementia, have attracted intense philosophical debate and no clear consensus.

In addition, whilst health and social care professionals may wish to comply with various requests, they are often faced with practical, financial and procedural constraints. It is not always possible, for example, to obtain a Polish interpreter at three o'clock in the morning and it might be considered abusive to leave a person in soiled continence pads until a female professional carer comes on duty. In some cases, requests may clash with ethical principles and cultural values held by professional carers themselves (e.g. certain requests or behaviour could be interpreted as discriminatory or as overriding a person's right to autonomy). The cultural values and wellbeing of more than one stakeholder need to be considered and each situation is unique. It is not possible or even desirable to make general statements about who or what is right or wrong and about what should be done.

Ethical dilemmas need to be addressed within an ethical framework, in a systematic manner, with the support of the organisation responsible for care, taking into account the unique nature of the situation and of everyone involved. This will help ensure that whatever action is taken (if indeed action is to be taken), health and social care professionals can defend their decision as being what was right/ethical in that particular situation, at that time and for the people involved, including themselves.

There are several possible ethical frameworks which may be helpful such as the "dignity-enhancing framework" developed by Chris Gastmans (2013) and the concept of

"conscience-guided reflection" developed by Julian Hughes and Clive Baldwin (2006).[41]

Carers from minority ethnic groups

Children and grand-children of people from minority ethnic group often feel as if they were caught between two cultures, being in a kind of mixed culture. A 'cultural mix' may offer some benefits but also lead to certain disadvantages and even dilemmas. Carers of people with dementia from minority ethnic groups may sometimes feel over-burdened and in an awkward position, having to negotiate the demands and expectations of the person with dementia and their relatives on one side with those of health and social care professionals on the other, with their own expectations sometimes being yet different.

One potential challenge results from different cultural perspectives of health, sickness and care. The tradition within some minority ethnic groups of the family caring for the person with dementia (and looking after his or her every need) does not coincide with the current philosophy of care in many parts of Europe which increasingly seeks to promote remaining capacities and help people to live as independently as possible. This may challenge established cultural understandings of what it means to be 'sick' and what it means to provide care. Carers may find it difficult to coordinate the family's cultural expectations with those of the healthcare professionals.

Many minority ethnic groups are structured around the principles and values of 'familism', which emphasises the family as the central unit governing personal and social life and reflects social norms, personal attitudes, and behaviours. Typically, this includes respect for elders, obedience to parents and mutual support (e.g. filial piety), overriding the interests of the individual. In many Western European countries, principles and values reflecting individualism are more common amongst majority ethnic groups. Individualism emphasises individual freedom and autonomy, and on respecting and promoting the interests of the individual.

Through the process of acculturation, some people from minority ethnic groups move on and away from the culture of their parents and grandparents, having had a different life and exposure to different experiences and opportunities compared to their older relatives. As this is a gradual process, however, they may sometimes find themselves in a difficult situation, not feeling comfortable with certain decisions and in certain interactions with members of their

family and outsiders. In Dutch society, for example, a fairly individualistic perspective of health care predominates (a so-called 'I-culture' as opposed to the 'we-culture' which predominates in many other cultures). According to Baktit Abbasi (2018) the religious duty of Muslims to visit a dying person means that a lot a relatives visit the hospital and hospital staff sometimes find this disturbing. Although cultural awareness raising may help hospital staff to be more understanding when this happens, younger generations from the Muslim community who can see the issue from both sides may feel uncomfortable and isolated, not feeling fully able to identify with either perspective.

In some families, younger people from minority ethnic groups might be better able to access and act on information, as they are likely to have a better command of the language of the country, be able to use the latest information technology and be familiar with the national healthcare system. Whilst this know-how could be of benefit to the older generations, some cultural traditions may place greater emphasis on respect for older people and on the importance of valuing their knowledge and experience (i.e. whatever Grandpa or Grandma says, holds). This may sometimes bring them into conflict with the wider family and represents lost opportunities to support older relatives. Measures to help bridge this gap might therefore be beneficial in promoting the potential for learning and support within families, without jeopardising cultural traditions based on respect for one's elders, which is still prevalent in many minority ethnic cultures (Parveen and Oyebode 2018).

Some carers experience psychological problems years after the person with dementia has died even though appropriate support may have a positive impact on helping them to cope (e.g. to deal with behaviour and symptoms that they find difficult to manage) (Spijker et al. 2009). A greater 'burden' has been reported amongst informal carers from minority ethnic groups whose families may have high expectations related to caring for a relative and some reluctance to accept outside help (Berdai Chaouni and De Donder 2016, Parveen and Oyebode 2018). However, according to Parveen, Morrison and Robinson (2013), recent evidence suggests that familism does not always have negative consequences and may sometimes be beneficial to carers.

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[41]   For a brief overview of these frameworks, please see Alzheimer Europe's report on ethical dilemmas faced by professionals providing dementia care: https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2015-Ethical-dilemmas-faced-by-professionals-providing-dementia-care-in-care-homes-and-hospitals

Also, spirituality and religion may help some people to cope with caring. In the UK, spirituality and religion tends to be used more by people from minority ethnic cultures as a means of coping than by people from the majority ethnic group (Parveen and Oyebode 2018).

As mentioned earlier, care is often provided by one person and that person is often a daughter or daughter-in-law. Several key issues linked to lack of use of services were discussed in the section "Challenges related to the uptake of services and support by minority ethnic groups" (sub-sections of filial piety/responsibility and religious duty). That discussion described challenges experienced particularly by female carers. Another issue is that daughters and daughters-in-law who provide care are often younger than carers from majority ethnic groups (who are often spouses or partners). Parveen and Oyebode (2018) describe them as the 'sandwich generation' as they are often responsible for the care of older parents as well as children. They may find it difficult to coordinate their jobs

and care responsibilities. It is often assumed that people from minority ethnic groups benefit from the support of an extended family network. In some cases, certain care responsibilities may be shared amongst different members of a family. However, there is some evidence of a tendency towards fragmentation of families from minority ethnic groups (e.g. due to changes in immigration laws, the need to move away to find employment and the gradual process of acculturation), which means that family support is increasingly lacking.

Communication with people outside the family is often already hampered by shame (Van Wezel et al 2016). Female carers often feel that they cannot communicate with other members of the family or outsiders (such as their GP) about difficulties coping and about the possible need for help (Tonkens et al. 2008, Tonkens et al. 2011). In addition, assumptions about the existence of support from the family have sometimes led to carers not being offered support (Parveen and Oyebode 2018).

Migrant carers

Whereas practically all migrants might identify with a minority ethnic group, many people from minority ethnic groups would not consider themselves as migrants. It has been difficult to obtain information about issues related to health and social care professionals who are clearly from minority ethnic groups (but not necessarily migrants). In some of the studies about migrant and live-in carers mentioned in this and the next sub-section, it is not clear whether a) they are solely about people having recently (e.g. in the last 10 years) moved to a country and become a carer or b) also include people from minority ethnic groups who have lived for long periods in a particular country, were born in that country (e.g. second or third generation) or have no migratory background. Some of the issues described in the section below may apply to professional carers from minority ethnic groups but it cannot be assumed that they do. As elsewhere in this report, we will use the terms used by the researchers whose findings we are reporting.

Reasons for and issues surrounding migration

Migrant carers are likely to have different reasons for having moved to another country to take up paid employment. Not all necessarily set off with the aim of becoming a carer. Some may have arrived as asylum seekers. Most Iranian migrants in Sweden, for example, came as a result of the 1979 Revolution, the Iran–Iraq war of 1980–1988 or to seek a higher education (Antelius and Kiwi 2015).

Migrant carers are not just part of the workforce but also people with lives and families of their own (Kröger and Zechner 2009). People (usually women) who leave their countries to work elsewhere as carers sometimes leave behind them children, disabled or older relatives who also need care. This is sometimes referred to as the 'global care chain concept' which highlights the relationship between globalisation, migration and care, whereby a need for care in one part of the world is resolved through the employment of migrant carers which results in a shortage of care in another part of the world (Weicht 2010). Zontini (2007) and Yeates (2009) (see Kröger and Zechner 2009) warn against stigmatising migrant carers who have care responsibilities at home or the families or organisations who employ them, pointing out that migrants are not victims of circumstances beyond their control and have not 'abandoned' their own relatives (as they make arrangements for care and continue to provide emotional support). They suggest instead that policies should be developed to better support them.

In Bulgaria, the Alzheimer Association reports a situation consisting of working age adults leaving the country to work abroad (not necessarily as carers) resulting in people with dementia being left responsible for the care of children and also vice versa. Migrants with a higher level of education tend to be better able to provide for the care of those they leave behind than those with lower levels of education or skills. Some formal care arrangements are not 'all or nothing'. Ungerson (2003, 2004) describes a situation in Austria where Hungarian and Slovakian carers are

employed on a two-weeks-on/two-weeks-off basis. It is not known whether this facilitates care arrangements in the country of origin.

There are sometimes obstacles to gaining employment as a carer such as having to undergo training (sometimes at their own cost) and to work initially on a voluntary basis in order to gain experience (Doyle and Timonen 2009). Language may also be a big obstacle with certain jobs necessitating a high level of proficiency in the official language of a country. Some migrant carers find that their professional qualifications are not recognised in the country where they are working and are obliged to take less-qualified jobs.

Racism, stereotyping and prejudice

Once in employment, migrant carers may experience racism and prejudice. Migrant carers often face the worst conditions in the care market, resulting in a 'racialised' divide between the tasks given to migrant and non-migrant carers and the types of contract and working hours offered (McGregor 2007). In a qualitative study of the experience of the multi-cultural care workforce in Ireland (Doyle and Timonen 2009), almost all African carers reported having experienced some form of racism or prejudice. In most cases, perceptions of unfairness and discrimination were not, in that study, associated with the person to whom they were providing care but rather to their co-workers and managers. In another study, migrant dementia carers reported prejudice and stereotyping from residents as well as colleagues (Egede-Nissen et al. 2016).

Training on how to deal with negative remarks and actions from care recipients may be helpful but the discrimination from co-workers and management may nevertheless affect morale and self-esteem, especially where there are no official channels for complaint (Doyle and Timonen 2009). In a study of migrant carers in Ireland and the UK (Walsh and Shutes 2013), carers reported cases of older people refusing to be cared for by a 'black' or 'foreign' care worker. Often such refusals came at the first encounter but sometimes in the context of an existing relationship of care. Sometimes, care workers were shocked by the attitudes and behaviour of the clients but looked for explanations such as the lack of experience of the clients with other nationalities. The European migrant workers in this study reported much lower levels of racism and prejudice.

Employers and care recipients are sometimes influenced by cultural stereotypes when taking on or appraising migrant care workers, with some carers being perceived as being particularly caring or warm. According to Doyle and Timonen (2009), this leads to the perpetuation of racial and ethnic stereotypes, the consequences of which are not yet fully understood and may well be extended to minority ethnic groups. Romero (2012) suggests that in Spain, in the context of employing migrant workers, women are "considered as natural (biological) caretakers for dependent older people par excellence". Walsh and Shutes (2013) report references to a 'caring culture' in the Philippines and India and to a 'hard working culture' in Eastern Europe.

Such stereotypes are an obstacle to seeing the real person and whilst on the surface, they may seem positive, they may also lead to negative stereotyping about other assumed characteristics and towards other migrant carers who are perceived as lacking the valued characteristics. Negative stereotyping is part of the process of stigmatisation which also involves devaluation and discrimination (Link and Phelan 2006). Migrant workers may be reluctant to make a formal complaint about working conditions or attitudes and behaviour towards them if they are in a vulnerable legal position (i.e. their residency rights being dependent on the care recipient or employer being satisfied with their work, being dependent on the employer for accommodation and their right to seek alternative employment being limited or non-existent) (Doyle and Timonen 2009, Walsh and Shutes 2013).

Developing a positive relationship with care recipients

Despite many migrant carers experiencing racism, prejudice, negative stereotyping and discrimination, many report a positive experience of caring and describe the importance of a positive relationship with the people for whom they care. Migrant carers of older people (including people with dementia) in Ireland and the UK emphasised the importance of developing a reciprocal relationship with the older person and of feeling that they were making a difference (Walsh and Shutes 2013) and migrant carers of people with dementia in Norway also reported enjoying their work and finding it rewarding (Egede-Nissen et al. 2015). Clients with neurodegenerative diseases such as Alzheimer's disease were considered by some migrant carers as being more abusive which may indicate the need for better dementia training and more support so as to enable migrant carers to manage certain situations, practically and emotionally, and to maintain a good care relationship with clients who have dementia (Walsh and Shutes 2013).

Cultural awareness and language proficiency

The ability to develop a positive care relationship with clients can be hindered by the lack of a shared cultural outlook with residents such as being aware of significant historical events that they have lived through, sharing or at least understanding their religion, being able to prepare

traditional food and drink properly and understanding humour, gestures, accents and colloquial expressions. Walsh and Shutes (2013) conclude that the ability to communicate, understand cultural norms and deliver care in a culturally appropriate manner is fundamental to the development of relational aspects of care which both clients and migrant carers in their study considered to be a core determinant of quality of care.

Sometimes cultural awareness can be as basic as knowing about certain food that people from the host country like, how to greet visitors and dress codes and this can probably be picked up quite easily through observation and interaction. Within increasingly multi-cultural societies, it should of course not be assumed that there is just one culture and with regard to religion, it may be more difficult to understand people's beliefs and religious practices as they are rarely explained.

Language can be a considerable obstacle in that a high level of langue proficiency is not only a question of vocabulary and grammar but also of understanding accents, medical terminology, slang, colloquialisms, humour and non-verbal communication (such as facial expressions, gestures and body language). Language is therefore extremely important but it is not always sufficient to perfect one language. As mentioned earlier, in some countries, such as Luxembourg, Switzerland, Belgium, Spain and Italy, there may be more than one national language and in parts of the UK and Ireland, Gaelic and Welsh may be spoken in addition to English. Added to this, the people with dementia receiving care may speak other languages, being themselves migrants or from minority ethnic groups with different languages.

The need to perfect at least the main language or languages of the host country is important for the provision of quality care and for good relationships with residents, co-workers and employer but also for migrant workers to integrate into a new society, make friends and become active members of the community. Migrant carers are not always aware of the availability of language lessons or of how to access them (Egede-Nissen et al. 2016). They may also find it difficult to fit the lessons into their working schedule and might not be able to afford them. Efforts should be made by local governments and employers to ensure that migrant carers have the opportunity to improve their language skills. Brooke et al. (2018) suggest the need for open access training and education to cover the broader aspects of communication such as accents, behavioural and facial communication etc.

Cultural differences in the perception of dementia and dementia care

Migrant carers may have very different attitudes towards the care of older people, including people with dementia, to those of most of the people they are caring for. However, migration also influences this view. Similar to the beliefs about filial piety amongst some minority ethnic groups, some migrant carers consider it the moral duty of families to care for their older relatives and that the relatives of people in residential care homes have abdicated their moral responsibility by leaving the care of their parents, for example, to people they do not know and are being paid to provide care. Dementia carers from a Middle Eastern background in Sweden (caring for people with dementia from the same background) emphasised that people from their native countries consider the care of older relatives as a religious obligation which is enforced by relatives as well as through pressure from mosques, churches, associations, distant relatives and even neighbours (Antelius and Plejert 2016). On the one hand, some migrant carers may be critical of families of people with dementia in residential care based on their own beliefs about filial piety; on the other hand, some migrant carers may need a better understanding of filial piety but also to be aware that families which have migrated to Western cultures may have adapted their beliefs through the process of acculturation (Antelius and Kiwi 2015, Brooke et al. 2018). This has been reported with regard to families of Middle Eastern descent in the Netherlands who may have a more positive view of professional care, and who may interpret caring as ensuring that care is provided rather than providing it all themselves (Van Wezel et al 2016).

Migrant carers may use the term dementia in the care setting but are nevertheless usually aware of the beliefs about dementia in their country of origin where in some cases, the term dementia is not used at all (or at least not by lay people) and if used may have a different meaning because there is no concept of dementia. Iranian carers in Sweden, for example, used the Swedish terms for dementia or memory loss when interviewed but explained that in Iran the term Alzheimer's would be used but not necessarily with the same meaning. In Kurdish, a term would be used which means crazy or lunatic. Other terms mentioned included 'fool' and 'senile' (Antelius and Kiwi 2015). In some cases, it is the cultural perceptions of ageing rather than dementia which influence how migrant carers respond to the needs of people with dementia (Brooke et al. 2018). Behaviour may also be attributed to daydreaming or to the person just being 'burdensome' and 'troublesome', sometimes with the assumption that they have always been like that (Antelius and Kiwi 2015). In the study by Antelius and Kiwi, migrant carers highlighted a general lack of understanding about dementia:

"Shervin, 52 years old: I honestly do not know if either staff or relatives have any idea what dementia is.

Ayeh, 57 years old: Frankly, none of us know what dementia is" (Antelius and Kiwi 2015, p. 86).

A good understanding of cultural differences between migrant carers, people with dementia receiving care and their families is important in ensuring that people with dementia receive good care, that families receive appropriate support and understanding and to avoid judging and making assumptions about desired care arrangements.

The concept of residential care is not always familiar to migrant carers prior to them taking up their work (McGregor 2007, Antelius and Kiwi 2015, Antelius and Plejert 2016). Some have never heard of nursing homes and residential care. When they realise what is involved, some carers find the work 'dirty', 'low' and 'cheap' and feel ashamed of being part of that process (McGregor 2007) even though they may decide to continue with the work (sometimes as a perceived stepping stone to a better job). Ow Yong and Manthorpe (2016) also highlight the ambitions of some migrant dementia carers to move from the residential care setting to take up a more qualified post.

Perceptions of traditional gender roles may also lead to feelings of shame. In societies where the provision of care is still considered 'women's work', some male migrant carers feel ashamed of their work, feeling that it challenges their masculinity and this may result in conflict or re-negotiation of gender roles at home (McGregor 2007). Romero (2012) highlights the feminised and ethnified nature of much of the care provided to dependent older people in Europe, calls for social workers to challenge the situations and inequalities that are inherent in public policies and advocates for a higher level of social justice.

Brooke et al. (2018) suggest the need for all care workers to understand dementia from a biopsychosocial perspective, that it is not a natural consequence of ageing and to understand the importance of preventive interventions, early diagnosis and that symptomatic treatments are available. Whilst the emphasis may often be on migrant dementia carers adapting to the culture of the host country, it should not be overlooked that there is not a single culture but many cultures within any country.

The process of acculturation

The process of acculturation (mentioned earlier) means that migrant care workers from a particular country and carers from minority ethnic groups will not necessarily have the same values and perceptions as people who migrated from a particular country many years ago. Antelius and Plejert (2016) argue that it is important to try to understand dementia care, in a migratory context, more in relation to the healthcare system and culture within the new society (i.e. how people feel about dementia and dementia care in their current setting). This could apply to migrant care workers as well as to migrants with dementia. Brooke et al. (2018) suggest the need for migrant dementia care workers to adapt both to the

new country and to the workplace culture and point out that validated, robust tools to understand the process of acculturation in relation to the provision of culturally competent person-centred dementia care are lacking. However, understanding and openness to different cultures is perhaps also needed from members of the host country. In their review of the intersection of culture in the provision of dementia care, Brooke et al. (2018, p. 10) conclude:

"Successful acculturation is essential to enable migrant care workers to provide culturally appropriate person-centred dementia care, understanding care workers' culture is equally important and needs to be considered when developing care provisions for people living with dementia."

Cultural and ethnic matching

Being a professional carer from the same minority ethnic group as person with dementia can sometimes be challenging. Professional carers who share some of the same cultural values might find that these are in conflict with their professional knowledge, training and identity, and with established care philosophies, procedures and time constraints. The demands of the profession may make it impossible to respond to the wishes and expectations of people with dementia and their families and result in inner conflict as well as conflict with the person with dementia and his/her family. Some professional carers are one of a few, if not the only person, in an organisation who is either from a minority ethnic group or who just speaks the language of some of the residents.

Sometimes, this results in professional carers from minority ethnic groups being given sole responsibility for the care and support of people from minority ethnic groups and having to deal with special requests from relatives, which at times go beyond their professional responsibilities. As was mentioned earlier in relation to informal carers, people who have adapted to the culture of a particular country, through the process of acculturation, or were born and brought up in that country, may find themselves in an awkward position with assumptions being made about their values and traditions which may not correspond fully or at all to them as an individual. This practice also reflects an attitude that all minority ethnic groups are the same and that by virtue of belonging to a particular minority ethnic group, a person would be able to better understand or relate to a person from any other minority ethnic group. It could also be interpreted as implying that a professional carer from a minority ethnic group is less able to work with people from the majority ethnic group. The following quote highlights some of these issues:

"The employment of minority ethnic staff applies across services (Akpaffiong et al., 1999; Alzheimer's Disease

Society 1998; Department of Health, 1998). However, Patel et al., (1998) highlight the potential of such staff being 'dumped on', e.g. in having to see all non-White or non-English speaking service users. It is important to stress, as Patel et al., (1998) do, that employing

minority staff is only part of an overall strategy, and just because a worker is of the same ethnicity as the target group, it does not necessarily follow that they will be accepted by the target community (Alzheimer's Disease Society, 1998)" (Daker-White et al. 2002, p. 105).

Live-in carers

Live-in carers, as the term suggests, live in the home of the person to whom they provide care. In many cases, live-in carers offer a more affordable alternative to residential care, enabling family carers to better coordinate their personal and professional obligations, and enabling people with dementia to continue to live in their own homes and communities. Live-in carers are sometimes described as belonging to the 'grey' care labour market.

> *"Grey market care refers to care work which is paid outside the formal economy thus avoiding taxes and social insurance fees. It also means that none of the parties involved are insured against unexpected events like accidents, illnesses, mistreatment or unemployment" (Kröger and Zechner 2009, p. 20).*

The consequences of such care arrangements and the impact on the lives of the live-in carers need to be considered. Limited research has been carried out on the experiences of such carers in the context of dementia. Often, studies exploring the experiences of live-in carers are not focused on dementia care but cover the care of children and older dependent people, as well as people with dementia.

Some live-in carers benefit from certain rights and protection (e.g. having been registered as employees, had their social contributions paid and/or simply being aware of their rights, especially those who are European citizens) (Doyle and Timonen 2009). Herz (2018) has compared different systems of live-in care in a range of countries, including some in Europe. In Austria, for example, live-in care arrangements were regulated in 2007 and are now formally recognised as part of the Austrian social care system, with possibilities for means-tested financing of such care. Known as 24-hour care, two live-in carers are usually employed on two-week rotating basis. Almost all are self-employed (Herz 2018). In the German-speaking part of Switzerland, live-in carers are usually taken on for periods of two to twelve weeks. In the UK, on the other hand, live-in carers are employed on a private basis, with no funding from the state and no official policies governing their terms and conditions of work

(Herz 2018). Nevertheless, there are care agencies in the UK, which are regulated by the Care Quality Commission and provide live-in carers, as well as training, security checks and arrangements for leave and hours off.

Live-in carers employed on the grey market are becoming increasingly common in the Mediterranean countries such as Italy and Spain (Herz 2018). They are not formally registered as residents or employees. Even when official registration of their work and residency status would be possible, live-in carers are sometimes still taken on illegally and paid in cash by the care recipient or their family. Many live-in carers are not entitled to social benefits or minimum periods of time off, receive insufficient payment in exchange for their services, may lose their jobs in an instant, not receive their pay and would be in a difficult situation if they became ill. There are also implications for their future wellbeing and even survival if their pension contributions are not paid. Live-in carers with no residency rights (e.g. non-European citizens) are at greater risk of exploitation (Ungerson 2004, Degiuli 2007). However, even for Europeans, certain conditions must be met in order to have the right to reside in a different EU-country on a long-term basis[42] so even European live-in carers may find themselves in a difficult situation if employed on the grey market.

People receiving care as well as their relatives may also have concerns about the care arrangement and even experience abuse. People with dementia may at times have difficulty understanding or communicating various forms of abuse and there is a risk that they will not be believed if they report it (Ayalon 2009b in Herz 2018). People with dementia and their relatives may also be concerned about retribution from the live-in carer, should they complain and for this reason, might prefer to suffer in silence or take measures to keep the live-in carer happy (Herz 2018).

Different cultural backgrounds and languages may well make it difficult for live-in carers to adjust to their new environment. Families may also find it difficult to adjust to having a stranger in their homes at first. In some countries,

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[42] Extract from: EU freedom of movement and residence – "EU citizens with a valid identity card or passport may (.../...) live in another EU country for longer than 3 months, subject to certain conditions, depending on their status in the host country. Those who are employed or self-employed do not need to meet any other conditions. Students and other people not working for payment, such as those in retirement, must have sufficient resources for themselves and their family, so as not to be a burden on the host country's social assistance system, and comprehensive sickness insurance cover" https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM:l33152

certain nationalities are preferred over others because they are perceived as being more similar in terms of language and religion and as having certain positive personal characteristics. In Spain, for example, there is a preference for Latin American women, particularly Dominican, Ecuadorian, Bolivian, Colombian and Peruvian (Romero 2012). Very often, though, live-in carers come from countries with very different cultures, values, languages, and religions than the people they care for. Moreover, the choice of a live-in carer on the basis of ethnicity or nationality reflects the stereotyping of groups of people (e.g. people from one country or ethnic group are perceived as hard-working, those from another as being gentle and caring) (Herz 2018). Live-in carers are generally required to provide care and assistance but are sometimes also expected to have certain characteristics such as being kind, sensitive and affectionate (Romero 2012) which seem to be more in keeping with a search for a life partner than an employee. This raises the issue of relationships and emotional attachment. It also reflects an emphasis on personal qualities rather than on knowledge and skills (Herz 2018).

Due to the long hours that they are expected to work, they seldom have time off and therefore spend almost all their time with the person in their care and the family. Some become almost a member of the family rather than just an employee. Karner (1998 in Weicht 2010) has described how migrant carers, especially live-in carers, are sometimes practically adopted by families and treated as 'fictive kin'. This total emersion in the family life may be positive in some ways but could also lead to emotional strain, differences of opinion, limited opportunities for social interaction outside the family, social isolation and lack of opportunity to maintain contact with their own family and friends in their country of origin.

Some Alzheimer Associations have recognised the need to support both live-in carers and the families who employ them so that they can have a better understanding of each other's needs and cultural background. The Alzheimer Society of Israel, for example, provides training for live-in migrant carers and families so as to promote a better understanding between the two. Alzheimer Uniti also provides language training as a means to empower live-in carer and promote their adaptation to the Italian culture. At the level of the State, Weicht (2010) and Romero (2012) describe State provisions for the care of dependent older people in Austria and Spain as being very male orientated, reflecting a male-breadwinner, female-carer ideology, with the majority of people being cared for at home. The ideology of family responsibility for care, which is frequently associated with minority ethnic groups, may also contribute towards the employment of female migrant workers by some majority ethnic groups. Live-in carers may be a mutually beneficial arrangement for many people but an approach that is open to abuse and the unethical treatment of live-in carers due to its largely unregulated nature.

Key points from the section "Challenges encountered by people providing dementia care and support (from or to people from minority ethnic groups)"

- It is important to consider the rights and wellbeing of the people, from all ethnic groups, who provide dementia care and support.
- Language difficulties can affect the wellbeing of professional carers, leading to frustration and ethical concerns, also limiting the quality of care and support that they would like to provide.
- Procedural, organisational and economic constraints, as well as lack of training, may limit the ability of professional carers to provide good quality intercultural care and support.
- Professional carers are sometimes faced with ethical dilemmas which arise from cultural differences and misunderstandings.
- Carers from minority ethnic groups, especially from the younger generation, may find themselves in an awkward position, caught between the demands and expectations of two different cultures.
- Because of cultural traditions or religious duty, some female carers may find it difficult to discuss problems coping and to seek support. Doing so could be perceived as a refusal or failure to accomplish their religious duty or lack of respect for elders, which could, in turn, be considered as bringing shame on the family.
- Stereotypes about people from minority ethnic groups 'looking after their own' and having extended family networks of support sometimes result in services not being offered.
- Migrant carers may have care responsibilities in their country of origin. As reflected in the 'global care chain concept', the need for care in one part of the world may create a care shortage elsewhere.
- Language difficulties and lack of recognition of non-European training and qualifications may result in migrant carers having to accept care positions for which they are over-qualified.
- Professional carers from minority ethnic groups are sometimes given sole or main responsibility for clients from a range of minority ethnic groups. In some cases, this might reflect ethnic stereotyping and limit a person's opportunities choice and development within the profession.
- Stereotypes linked to perceptions of race and ethnicity continue to have an impact on employment opportunities, favouring some employment candidates at the expense of others.
- Migrants' perceptions of dementia and dementia care sometimes differ to those of the people they are caring for and may have an impact on the care they provide but also on their own self-esteem.
- The concept of the live-in carer is relatively new. It involves a person living in the home of another who is in need of care, and providing that care more or less round the clock.
- There is a disproportionately high number of people from minority ethnic groups employed as live-in carers, most of whom are considered as migrants, sometimes having no stable residency rights.
- Very few countries have regulated the situation of live-in carers. Consequently, live-in carers are usually vulnerable to exploitation and abuse of various kinds. Equally, there is little protection for the potential abuse of clients and their families.

Recommendations/points for reflection

- Professional carers (from all ethnic groups) should be provided with:
  - training in cultural awareness and the provision of intercultural care and support
  - training and support in managing ethical dilemmas
  - training and support in managing discriminatory/racist comments and behaviour from clients
  - linguistic support or training to facilitate the establishment of a good relationship with clients.
- The situation, living and working conditions of live-in carers should be regulated. The rights and wellbeing of all concerned should be promoted (i.e. of live-in carers, of people receiving such care and of those living in the same household).
- Measures should be taken to promote acculturation (e.g. through language courses, information about the majority ethnic group's traditions and habits, initiatives to promote involvement and engagement with other members of society, combined with a reasonable salary and sufficient free time).
- Policies should be developed to help migrant carers to combine working as a paid carer with care responsibilities they may have for a person in their country of origin.

7. Conclusions

Intercultural care and support for people with dementia and their carers should be developed as a means to respond to increasing numbers of people from minority ethnic groups in Europe who have dementia or may develop it in the coming years. This is an ethical and human rights issue, reflecting important principles such as distributive justice, non-discrimination and respect for dignity and autonomy, all of which have an impact on the quality of life of people from minority ethnic groups across Europe.

Throughout this report, we have highlighted key issues which are central to the promotion of care and support in the context of cultural awareness and cultural sensitivity. The provision of intercultural care and support could not be considered as ethical if it did not consider the wellbeing of everyone involved. We have therefore tried to consider the needs, challenges and concerns not only of people with dementia from different ethnic groups but also those of informal and professional carers, including those who may themselves identify with a minority ethnic group.

We hope that this report will encourage greater openness to cultural diversity and an increased awareness of the key issues which need to the addressed if people with dementia and carers from minority ethnic groups are to receive the same quality of care and support as that available to people from majority ethnic groups. In drawing attention to issues that are important to people from one or more specific groups, there is a risk of over-emphasising difference, stereotyping and thereby jeopardising the right of people from all ethnic groups to care and support that is truly person-centred. However, awareness and acceptance of cultural differences does not need to over-shadow awareness of what people from all ethnic groups have in common, and can provide a solid basis from which to explore and understand the needs and wishes of each person (i.e. in his/her own right as a unique individual).

Governments, commissioners, service providers and health and social care professionals in Europe are not all at the same point with regard to developing or providing intercultural care and support and do not all have the same resources. However, in some countries, there are already structures in place, materials, training and consensus about the importance of developing intercultural care and support. In addition to this report and in keeping with the goal to improve intercultural care and support for people with dementia, Alzheimer Europe, its member associations and the expert working group on dementia and minority ethnic groups have developed a simple database which provides details about initiatives and materials related to the provision of intercultural care and support, which have been developed in Europe. Please see: https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice

People from various minority ethnic groups might on the surface seem to share many cultural beliefs, practices and values (e.g. people from the Syrian community living in Denmark and others living in Greece) but their actual needs and wishes may be slightly different. Initiatives and materials developed for one minority ethnic group or for minority ethnic groups in general in a particular country might reflect or respond to certain issues which are unique to particular groups or places. Nevertheless, provided that people from the minority ethnic groups concerned are consulted and involved in their development, initiatives and materials that have been developed, tried and tested in one country for one or more minority ethnic groups, can in many cases be usefully adapted to other groups and situations.

We hope that this report and the above-mentioned database will contribute towards the improvement of intercultural care and support for people with dementia in Europe and we welcome any feedback or details of initiatives and materials from Europe for the database.

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9. Appendix 1 – Background information about the members of the expert working group

Alzheimer Europe would like to thank the members of the expert working group who graciously donated their time and expertise, and drafted this report. Please find below a brief overview of their backgrounds.

Dianne Gove, PhD, is Director for Projects at Alzheimer Europe and Honorary Visiting Research Fellow at the University of Bradford. She chaired the working group addressing minority ethnic groups and dementia. Her background is in psychology, education and psychotherapy (analytical Gestalt therapy). In 2013, she was awarded a PhD for her research into general practitioners' perceptions of dementia and stigma.

Jean Georges has been the Executive Director of Alzheimer Europe since 1996. Prior to this, he worked as a journalist and as a parliamentary assistant to members of the Luxembourg and European Parliament. He was responsible for setting up the European Dementia Ethics Network in 2008 and has since contributed towards several ethics projects in that context.

T. Rune Nielsen, Neuropsychologist, PhD, has worked as a clinical neuropsychologist and researcher in the Danish Dementia Research Centre, University of Copenhagen, Rigshospitalet, Denmark, since 2007. His main research interests have concerned dementia diagnostics, treatment and care among minority ethnic groups in Europe as well as populations in low- and middle-income countries. Recently, he was initiator and PI of an international collaborative study on development of adequate cross-cultural cognitive assessment methods for minority and majority ethnic groups in Europe.

Charlotta Plejert, PhD, is an Associate Professor of Linguistics at Linköping University, Sweden. Her primary research interests are language and interaction in dementia, multilingualism and dementia, and children and adults with speech and language impairments. Charlotta is main editor of the volume Multilingual Interaction and Dementia (Plejert, Lindholm & Schrauf, 2017) and co-editor of the International Journal of Interactional Research in Communication Disorders.

Mohammed Akhlak Rauf, MBE, is currently working through a PhD at the University of Bradford, where he is studying the coping strategies (manage transitions) of South Asian carers of a relative with dementia. He is the founder of the Meri Yaadain (My Memories) Community Interest Company, which seeks to raise awareness of dementia and facilitate culturally appropriate service provision amongst BAME communities. He was awarded an MBE in recognition of his work with people with dementia and their families.

Debi Lahav, BA OT, MA Expressive Therapy, has been working in the field of dementia for over 35 years in clinical settings, programme development, training and support groups. She is Head Therapist at the Psychogeriatric Day Center at Tel Aviv Medical Center. She jointly developed the Activities for Health programme and kit with EMDA Israel Alzheimer Association.

Siiri Jaakson, MA of Social Services, is working as Head of Culture-sensitive Memory Work in Society for Memory Disorders Expertise in Finland. She used to work as a memory adviser for ethnic minority individuals in Finland. Since 2015, she has been working in the development project ETNIMU in which she promotes the brain health of older people from different ethnic backgrounds and works to increase culture-sensitive awareness among professionals. She is currently developing a training programme for interpreters in memory tests situations.

Ripaljeet Kaur is a Senior BME Dementia Worker at Touchstone, a mental health organisation. She has over 10 years' experience working within BME communities, with the last five years specialising in dementia. Ripaljeet delivers awareness talks within community groups, supports people on the diagnosis pathway, provides post-diagnostic support and also facilitates a South Asian Dementia café 'Hamari Yaadain'. Ripaljeet was invited to 10 Downing Street to attend Vaisakhi event, which is a Sikh religious celebration, in recognition of her dementia work within BME communities.

Michal Herz, PhD, has been working for nearly two decades with people living with dementia, their loved ones and service providers, both in the UK and Israel. She recently completed a PhD exploring a triadic care relationship, between a person living with dementia, their spouse and a live in caregiver. She is currently starting a post as a consultant with the World Health Organisation on the Global Dementia Observatory and is an independent trainer in Israel.

Sahdia Parveen, PhD, is a Senior Research Fellow at the Centre for Applied Dementia Studies, University of Bradford, UK. Sahdia's background is in Health Psychology and her main research interests include exploring the influence of ethnicity and culture on how people with dementia and families cope and manage with dementia. Sahdia is currently leading on the Caregiving HOPE study which explores how cultural obligation, willingness and preparedness to care influence family carer outcomes.

Daphna Golan-Shemesh (MA in Expressive Art Therapy, BA in Social Work) is a Geriatrics Expert and Pet-assisted Therapist. She has been associated with Emda, the Israeli Alzheimer's association, since its establishment. She was the establisher of the Alzheimer's Aid Dog project and is both founder and manager of Beith-Hashemesh, which is a Geriatric Hospital linked to nature for people living with dementia.

Carolien Smits, PhD, is a professor at Windesheim University of Applied Sciences, in Zwolle, the Netherlands. Her chair is in Innovating with Older Adults. Her research contributes to the Windesheim Expertise Centre on Dementia for Professionals. It focusses on the care of people with dementia and their carers, in particular the interaction, shared decision making and co-creation leading to care innovations.

Alzheimer Europe would also like to thank the following for having commented on an early draft of the report:

- **Saida Baktit Abbasi,** Islamic spiritual nurse at the Radboud University Medical Centre, Nijmegen (Netherlands)
- **Gözde Duran,** MSc (Psychologist), Co-ordinator of Windesheim Expertise Centre on Dementia, Windesheim University of Applied Sciences (Netherlands)
- **Sari Heikkinen,** PhD (Gerontology), Senior Lecturer at the Laurea University of Applied Sciences, Järvenpää (Finland)
- **Lars-Christer Hydén,** Professor of Social Psychology and Director of CEDER (Centre for Dementia Research) at Linköping University, Linköping (Sweden)
- **The CEDER (Centre for Dementia Research) interdisciplinary research team** at Linköping University, Linköping (Sweden)
- **Jennifer van den Broeke,** PhD, Senior Project Leader, Pharos Dutch Centre of Expertise on Health Disparities, Utrecht (Netherlands).

10. Appendix 2 – Terms and concepts linked to intercultural care and support

In this Appendix, we look a bit closer at race, highlighting the continued use of the term despite widespread criticism of the concept. We then provide a few more details about some of the common characteristics of minority ethnic groups, including the relationship between ethnicity and both vulnerability and power, as well nationality and religion, ending with a few words about other terms often used in connection with minority ethnic groups.

More about race

Race is a concept which categorises groups of people on the basis of biological differences (often including visible physical traits or characteristics), which it is claimed have been passed down from generation to generation (i.e. genetic differences). The concept of race is often associated with the belief that some races are inferior and even 'less human' than others, with devastating consequences for certain groups of people (e.g. discrimination, colonisation, slavery and genocide). According to Smedley and Smedley (2005), two main beliefs about race have persisted since the 20th century, namely race as consisting solely of human bio-genetic variation (prevalent amongst scientists) and race consisting of a combination of physical and behavioural differences (a folk perception, also prevalent in some policies and laws). The concept of race has been challenged with opponents of this concept pointing out that so-called racial groups are not genetically discrete, measurable or scientifically meaningful and that there is more genetic diversity within 'races' than between them (Smedley and Smedley 2005, Mersha and Abebe 2015).

Nevertheless, the terms race and ethnicity (or racial group and ethnic group) are often considered and used as if they were interchangeable or, alternatively, included in lists of possible causes of discrimination separately but without defining either term. Despite terminology surrounding the concept of race being fraught with ambiguity and misuse, measures designed to offer protection against 'racial' discrimination often use the term in a way which does not seem to challenge the concept of race, merely stipulating that it should not be used as a basis for discrimination.

Article 1 of the UN International Convention on the Elimination of All Forms of Racial Discrimination, for example, merely states that 'racial discrimination' shall mean "any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life." The EU Charter of Fundamental Rights prohibits discrimination on 'any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation'. The Racial Equality Directive (2000/43/EC) prohibits discrimination on the grounds of "race or ethnic origin".

The underlying meaning and explicit assumptions made when the term 'race' is currently used are not always clear. It seems that whilst the term is widely acknowledged as lacking any scientific or genetic basis, it is now increasingly being interpreted within a wider scope including issues related to cultural differences, as can be seen from the following quote:

> "A racist practice or rule is one that distinguishes, excludes, restricts or gives rise to a preference based on 'race', colour, descent, or national or ethnic origin. Racist practices and rules make it more difficult for members of some groups to attain the human rights, to which they are entitled. Racist practices or rules may be practiced by individuals (for example through name-calling, racist graffiti, excluding people or using violence against them), or by institutions (for example, though the application of rules or regulations which do not make allowance for cultural difference)" (National Council for Curriculum and Assessment 2005).

In the context of research, the two terms often appear side by side with no explanation about their meaning. Typical statements include:

- Caregivers indicated their age, gender and primary racial or ethnic group.
- Participants were grouped into 5 racial/ethnic groups.

It is not always clear whether the two terms are really considered interchangeable. Researchers might sometimes feel that it is irrelevant (for the purpose of their studies) whether people identify with a particular group on the basis of race or ethnicity or are taking into consideration possible differences in the way that these terms are understood by participants. Whatever the reason, the two terms have different meanings and using them in this way may perpetuate the current ambiguities surrounding their use.

Mersha and Abebe (2015) question this tendency within research to use the two terms in this way. They point out that there are valid reasons in the context of healthcare for being aware of genetic differences between groups of people but that the concept of 'race' (based on observed differences in biology, physical appearance and behaviour) is not useful in establishing such differences[43]. They argue in favour of using 'ancestry informative markers' (AIMs). These are a "set of genetic variations for a particular DNA sequence that appear in different frequencies in populations from different regions of the world" (2015, p. 4). They do, however, recognise that whilst genetic ancestry might describe genetic relatedness more accurately than race or ethnicity, the interaction of biological and social factors in relation to health must still be considered.

More about some of the common characteristics of minority ethnic groups

In each country, there is usually a group of people who share a common culture and language, and form the largest proportion of the population. These people usually speak the official language of the country and have ancestors who have lived there for generations. They are more likely, compared to people from other ethnic groups, to receive culturally appropriate services and support, which can be readily adapted to their individual needs and preferences, because these are more compatible with the standard cultural norm (e.g. in terms of food, language, cultural activities, pastimes, religion, traditions and festivals). In

this sense, they differ from cultural groups who are the native inhabitants of a particular country (e.g. the native Indians in the United States and the Sami communities in Norway, Sweden, Finland and Russia) but who have become a minority ethnic group.

People who identify with other groups, which share a different culture, are often described as being from minority ethnic groups, ethnic minority groups or as being members of minority ethnic communities. Barth suggests that the shared cultural features are "an implication or result, rather than a primary or definitional characteristic of ethnic group organization" (Barth 1998, p. 15). Some writers opt for the term 'minority ethnic group' in order to emphasise that everyone belongs to an ethnic group (which is an inherent assumption reflected in many official documents). Mohammed (2017), for example, states:

> "I also use the term 'minority ethnic' in preference to 'ethnic minority' because it stresses the fact that everyone belongs to an ethnic group, rather than an ethnic group's minority status" (2017, p. 6).

Being asked to identify one's ethnicity in an official document, for the purpose of research, when filling out official documents or when being offered services or support suggests that a person is expected to belong to an ethnic group, irrespective of whether they feel any kind of identification with a particular group. This seems to run counter to the concept of ethnicity as involving voluntary self-identification with a cultural group.

Power relations and vulnerability

The issue of power cannot be ignored as members of minority ethnic groups very often have a vulnerable status and lack of political power, with many having experienced racism and prejudice (Moodley 2005, APPGD 2013). Berdai Chaouni and De Donder (2018) describe the situation of Moroccan older people who migrated to Belgium in the 1960s and 1970s under a guest worker program and, counter to the expectations of the Belgian state and even their own plans, ended up staying in the host country. Many (approximately 70%) have no formal education and their socio-economic status resembles that of many minority ethnic groups in other European countries with a similar migratory history (Liversage and Jakobsen 2016, Berdai Chaouni and De Donder 2018; Goudsmit et al. 2018) such as the Windrush generation[44] in the UK (BBC 2018). In some countries (e.g. Finland and Ireland), traveller communities have been largely excluded from healthcare and

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43 The authors make a very clear distinction between race and ethnicity but refer to them jointly in their article as 'race/ethnicity' in contrast to 'ancestry'.

44 Windrush was the name of the ship (MV Empire Windrush) which arrived at Tilbury Docks, Essex, in June 1948, bringing workers from Jamaica, Trinidad and Tobago and other islands, in response to post-war labour shortages in the UK. In 1971 immigration laws were introduced which ended this invitation to fill labour shortages.

schooling, often as a result of not having a fixed residence combined with structural discrimination such as difficulties registering with a general practitioner (GP) (KMPHO 2014, Jaakson 2018, Dementia Action Alliance 2018). The potentially vulnerable position of many people from minority ethnic groups threatens their right to be treated equally and this must be challenged in order to respect the moral principle of equity. In a report on the global impact of dementia, Prince et al. (2015, p. 75) point out:

> *"The basic principle is that all people affected by the condition should be acknowledged as having equal status and value, and should be accorded equal access to diagnosis, and evidence-based treatment, care and support, regardless of age, gender, socioeconomic status, ethnicity, or (at a global level) country of residence."*

Nationality and terms reflecting national origins

Often the name attributed to a particular minority ethnic group reflects the geographical origin of the members of that group who originally migrated to the country (e.g. Asian or Polish). Descendants of those people may sometimes be assumed to be members of that ethnic group based on knowledge that their relatives identify with that group or on their physical appearance. An emphasis on geographical origin of ancestors may lead to assumptions being made about similarities between groups bearing the same name (e.g. people from Pakistani or Chinese communities) in different parts of Europe.

In the United Kingdom, for example, the terms 'Black and Minority Ethnic' (BME) and 'Black, Asian and Minority Ethnic' (BAME) are quite commonly used, especially in the context of research and service development. However, terms such as 'Black' and 'Asian' are applied to very different groups of people, with quite different cultures. This may sometimes result in assumptions being made that people have things in common when this is not the case and overlooking significant differences such as different languages, religious beliefs, shared histories and traditions. As Regan (2014) points out, a person may define themselves culturally as 'Pakistani', but in terms of religion as Pakistani Muslim, Pakistani Sikh, Pakistani Hindu or as having no religious affiliation. Also, a person may identify with a particular minority ethnic group for various reasons without necessarily have any migratory or national link.

Some people who acquire citizenship in another country and live there for lengthy periods of time never feel a sense of identification with the culture of the host country. This may, in part, be linked to different degrees of acculturation[45]. In other cases, a person may, at some point, cease to identify themselves as a migrant and the country of their ancestors as relevant to their identity. They may, nevertheless, feel that they belong to a particular minority ethnic group. This might partly explain why some people in the UK, for example, identify themselves as being British Asian, a member of the BAME community, Asian or simply British (the latter perhaps also reflecting a statement about nationality).

Conflating assumed geographical origin with ethnicity is also problematic because the same categories are sometimes used differently by different researchers and policy makers. For example, the term Asian is often used by US and European researchers in one way and by researchers in the UK in another way (i.e. excluding or including people identifying with the Indian community). Sometimes the terms used reflect a broad cultural group, sometimes a specific group or sub-group. According to Mohammed (2017 and 2018), the term 'South Asian' covers people from Pakistani, Sikh and Gujarati communities and from other South Asian subgroups including people with a cultural heritage from Afghanistan, Bangladesh, Bhutan, India, Maldives, Myanmar (Burma), Pakistan, Nepal and Sri Lanka. This is problematic bearing in mind that minority ethnic groups are not homogenous in that there are also distinct differences between and within different ethnic communities (e.g. with regard to religion, gender, class and language). In Bristol alone, for example, over 100 languages are spoken (Baghirathan 2018). Rauf (2011) uses the term 'communities within communities' to explain these within-group differences

Within-group differences do not threaten or call into question the existence of a particular ethnic group. Each ethnic group defines the cultural features that are considered significant and these features set the boundaries, determining whether or not a person would consider themselves and be considered by others as belonging to that group. Other differences or similarities, which are not considered by the group as being significant, are ignored, played down or denied (Barth, 1998, p. 14). However, the intergroup differences are important to bear in mind when developing services which are not only culturally sensitive but also respond to the needs and wishes of individuals.

Religion

A shared religion sometimes becomes the defining feature of an ethnic group or a characteristic that people who are not members of that religion focus on. A minority ethnic group may, for example, be referred to as the Muslim

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[45] See also the sub-section on migrant carers in Section 6 on Issues and challenges encountered by professional and informal carers (p. 60).

or Jewish community or as people from the Buddhist, Hindu, Muslim or Sikh faiths. In some cases, however, references to religious groups have little to do with religion, as noted by the United States Holocaust Memorial Museum Organisation:

> *"The Nazis defined Jews as a 'race'. Regarding the Jewish religion as irrelevant, the Nazis attributed a wide variety of negative stereotypes about Jews and 'Jewish' behavior to an unchanging biologically determined heritage ..." (United States Holocaust Memorial Museum, undated).*

As with nationality, there may be significant differences between people within religious groups. Indeed, the same religion may be interpreted and practised very differently from one community to the next. In some cases, religion may cut across other aspects of people's cultural identity. For example, there may be people who would describe their ethnicity as being Asian, White or Black who all belong to the same church, mosque or temple and for whom religion is something that unites them. The sense of belonging and the different aspects of a person's cultural identity that they wish to emphasise may fluctuate over time and according to the situation.

Associated terminology

Many studies of relevance to minority ethnic groups use the terms 'migrant' and 'immigrant'. Some studies, especially from outside Europe (which we have not referred to in this report) also use the abbreviation 'CALD'. Several different terms are used to refer to majority ethnic groups. This section ends with a brief reflection on the use of these terms.

The majority ethnic group

In the United States, the majority ethnic group is often referred to as White with other possible groups being described as Black, Hispanic and Asian (although these terms are not fixed and have gradually evolved over time). It is not clear how the White versus Hispanic terminology would work in Spain though or how best to describe the Irish or Eastern European communities in the UK. Tilki et al. (2010) point out that Irish people in the UK are one of the largest minority ethnic groups but often ignored or aggregated within the White or White other category. In a few studies about dementia amongst different ethnic groups in Europe, terms such as native-Danish have been used instead of White (e.g. Sagbakken, Spilker and Ingebretsen 2018). This seems to reflect an implicit assumption about the migratory background of the minority ethnic groups (emphasising immigrant status despite some

members of the community having been born in the same country as the 'native' inhabitants) but helps avoid confusion between minority ethnic groups which might also be considered as White.

CALD (Cultural and linguistic diversity)

The concept of cultural and linguistic diversity (CALD for short) highlights the broad characteristics of culture and language as opposed to focusing on specific people and groups who find themselves in the minority. The expert working group decided not to use the CALD terminology in this report because if relatively unknown in many parts of Europe and it was felt that this might interfere with the effective dissemination of the findings of the project and in raising awareness about the database of good practices.

Migrant and immigrant

Another possible term, which could have been used instead of 'minority ethnic group', is 'migrant'. The concept of 'migrant' is quite unclear, often being associated with ethnic or religious minorities and with asylum seekers and refugees, and sometimes being used interchangeably with 'immigrant'. The term 'migrant' also has implications for residency rights and immigration control. The following extract provides a good example of the lack of clarity (in the UK) surrounding the term:

> *"Yet there is no consensus on a single definition of a 'migrant'. Migrants might be defined by foreign birth, by foreign citizenship, or by their movement into a new country to stay temporarily (sometimes for as little as a year) or to settle for the long-term. Some analyses of the impact of migration even include children who are UK-born or UK nationals, but whose parents are foreign-born or foreign-nationals, in the migrant population. None of these definitions are equivalent, and none fit precisely with 'migrant' defined as an individual who is subject to immigration controls. Moreover, in the UK 'immigrant' and 'migrant' (as well as 'foreigner') are commonly used interchangeably in public debate and even among research specialists, although dictionary definitions distinguish 'immigrants' – people who are or intend to be settled in their new country – from 'migrants' who are temporarily resident. Additionally, in some scholarly and everyday usage, people who move internally within national boundaries are called migrants" (Andersen and Blinder 2017).*

The EU Health Policy Platform paper on Migration and Health (PICUM and IRCT 2017) defines migrants on the basis of

having crossed an international border regardless of their length of stay but adds that many people can be migrants and members of ethnic minorities but that members of the latter are not necessarily migrants. Many people identifying with a minority ethnic group were born in the country to which their parents or grand-parents moved but nevertheless encounter similar difficulties to those experienced by the latter (e.g. linked to cultural and linguistic issues and social exclusion or discrimination). This might include some second or third generation descendants of migrants (e.g. from Portugal living in Luxembourg, from the Caribbean living in the UK or from Somali living in the Netherlands).

It was decided, already at the stage of drafting a proposal for funding for this project, not to limit the scope to migrant populations. The reason for this was that issues related to accessing or providing intercultural care and support for people with dementia were not considered as being necessarily limited to official status as a migrant or immigrant or to people having lived in different countries at some point in their lives. Nevertheless, it is clear from the literature that most minority ethnic groups have some link in the near or distant past to migration even though many people identifying with a particular group have no personal experience of migration.

11. Appendix 3 – Differences in performance between illiterate and literate cognitively healthy Turkish immigrants on a visuo-constructional test

The diagram overleaf is "Figure 1" from the article: T. Rune Nielsen & Kasper Jørgensen (2013). Visuoconstructional Abilities in Cognitively Healthy Illiterate Turkish Immigrants: A Quantitative and Qualitative Investigation. *The Clinical Neuropsychologist*, Vol 27:4, pp. 681-692. It has been reprinted with kind permission of the publishers "Taylor & Francis Ltd", http://www.tandfonline.com.
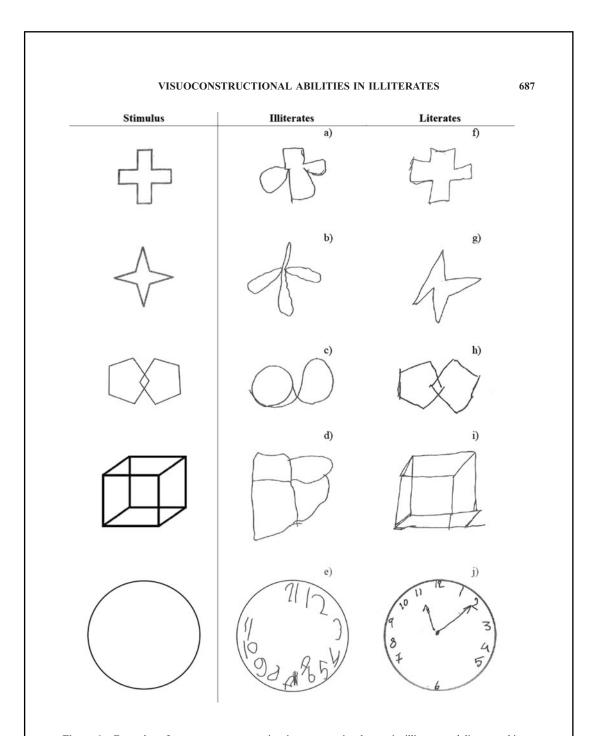
VISUOCONSTRUCTIONAL ABILITIES IN ILLITERATES 687

Figure 1. Examples of common error types in visuoconstructional tests in illiterate and literate subjects. Examples of common error types in illiterate subjects: (a) distorted angles in copying of a Greek cross (Strub and Black score of 2); (b) "flower design" in copying of a four-pointed star (Strub and Black score of 1); (c) "spectacles design" in copying of the intersecting pentagons (Bourke score of 3); (d) lacking three-dimensionality in copying of the Necker cube (Shimada score of 2); (e) failure to represent any hands of the clock, moderate spatial disorganization of the numbers and failure to get the sequence of the numbers correct in the Clock Drawing Test (Shulman score of 2). Varying elements of curved angles are found in (a–d). Examples of common error types in literate subjects: (f) different size of the arms in copying of a Greek cross (Strub and Black score of 2); (g) slightly distorted angles in copying a four-pointed star (Strub and Black score of 2); (h) minor omission in copying of intersecting pentagons making one of the pentagons a square (Bourke score of 5); and (i) disorganized placement of numbers in the Clock Drawing Test (Shulman score of 4).