

BETTER HEALTH BRIEFING 45

Dementia and end of life care for black, Asian and minority ethnic communities

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A Race Equality Foundation Briefing Paper
June 2018
www.better-health.org.uk



Key Messages

- 1** Dementia is recognised as a worldwide health priority. Our ageing population means that it will affect an increasing number of people over the coming decades. Many people who live with dementia die from dementia. According to the WHO, palliative care has two main aims: (i) to improve quality of life of patients and families and (ii) to prevent and relieve suffering. This is irrespective of disease group. Given that dementia is a progressive neurodegenerative, life-limiting disease, palliative care is highly appropriate for those who live with it, die with it, and their families.
- 2** The United Kingdom is now home to many people who categorise themselves as being from black, Asian and minority ethnic (BAME) groups. They represent one fifth of the total population. There are great variations in the concentrations of those from BAME groups in different geographical locations, the highest being in London.
- 3** Demographic ageing means increasing numbers of people from BAME communities are getting older. Predictions estimate that by 2026 In England and Wales there will be over 1.3 million people from BAME groups aged 65+, compared to over half a million in 2001; in 2026 almost half a million will be aged 70+ years.
- 4** Little is known about the relative prevalence of dementia among BAME groups, although there is a growing body of evidence that the Black African-Caribbean community in the UK has a higher prevalence of vascular dementia than other communities.
- 5** Beyond evidence from United States, principally among African-Americans and Asian groups, little research has examined the palliative care needs of people of BAME groups who are dying with dementia, and their families. This research has identified that when compared to white patients, artificial nutrition and other life-sustaining treatments were more frequently requested by African American and Asian groups, whereas decisions to withhold treatment were less common.

- 6 This absence of UK-based research cannot continue. An epidemiological needs assessment must take place to quantify current and future needs of BAME groups with dementia at the end of life. Moreover, research must examine person-centered needs for palliative and end of life care among BAME communities, their knowledge and awareness of palliative care and its benefits, the training of health care professionals in cultural competence and skilled communication when working with people living with, and dying from dementia within different cultural groups, and the evaluation of services to identify good practice.

Introduction

Dementia is a growing issue and concern for societies across the world. The number of people living with dementia worldwide currently stands at 35.6 million, and is expected to double by 2030, and triple by 2050. Our ageing population means that dementia will affect an increasing number of people over the coming decades and represents one of the major health and social care challenges facing the United Kingdom. Dementia is a progressive life limiting condition; many people who live with dementia, will die from dementia. Given that dementia is associated with many distressing symptoms that impact on patients and their families, palliative care lends itself to caring them.

The UK is now home to an increasing number of people from black, Asian and minority ethnic communities. Indeed those from BAME groups now represent one fifth of the total population of the UK. Many members of these communities are now reaching a point in their lives where dementia is becoming more common. This is expected to increase dramatically over the next few decades as younger members of these communities become older. This document critically examines issues relevant end of life care of dementia among BAME communities and suggests solutions.

Dementia

The term 'dementia' is used to describe a syndrome that may be caused by a number of illnesses in which involve progressive decline in multiple areas of function, including declining memory, reasoning, communication skills and the ability to carry

out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms, including depression, psychosis, aggravation and wondering, these are problems in themselves, which are complicated and can occur at any stage of the illness (Knapp et al., November 2014).

Dementia does not have a single cause. Rather is caused by a range of underlying conditions that include Alzheimer's, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Whilst there are some treatments to alleviate the symptoms associated with dementia there are currently no known cures and it is a terminal illness. Dementia is typically a disease of older people; the vast majority of those living with dementia are aged over 65 years of age (Alzheimer's Society, 2017)

Providing exact figures for the number of people with dementia is problematic because diagnosis is difficult, particularly in the early stages. Estimates, nevertheless, suggest that there are approximately 850,000 people living with dementia in the United Kingdom (Alzheimer's Society, 2018). Specifically, latest figures from the Alzheimer's Society identify that in England there are approximately 714,000 people living with dementia. It is important to note however that estimates from the Alzheimer's Society suggests that there are just over 42,000 people under the age of 65 who have dementia (Alzheimer's Society, 2013). This is referred to as early onset dementia. More women than men are diagnosed with dementia.

Many people living with dementia die of dementia

The latest data suggests that for the first time dementia, or Alzheimer's, is now the biggest single cause of death amongst women in England and Wales, having overtaken forms of cancer for the first time (Alzheimer's Society & Marie Curie Cancer Care, 2014) (Office for National Statistics, 2016). However, just as it is difficult to estimate the exact number of people with dementia it is similarly difficult to estimate dying as a result of dementia. This is because many deaths are not directly attributed to a dementia, but rather to be a precursor to death, such as through an infection or another coexisting condition that are very common amongst older people (Sachs et al., 2004) (Sleeman et al., 2014). In England and Wales in 2013, 31,850 women and 15,262 men had their death attributed to dementia or Alzheimer's disease (Office for National Statistics, 2013).

Palliative and end-of-life care for people living with and dying from dementia

Palliative care has been defined by the World Health Organisation (WHO) as:

... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (World Health Organisation, 2011)

Palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death. Palliative care integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death. It also offers a support system to help the family cope during the patient's illness and during bereavement. The WHO's definition of palliative care specifies two main goals: (i) to improve quality of life of patients and families and (ii) to prevent and relieve suffering. Over the last several decades the experience of advanced disease, dying and bereavement have all significantly benefited from palliative care. Given that dementia is a progressive neurodegenerative, life-limiting disease, palliative care is highly appropriate for those who live with it, die with it, and their families

Many people living with dementia typically experience multiple symptoms at all stages of the disease, many of which become more severe over time. Specifically symptoms associated with dementia include the following, all of which have potential to cause profound distress, and may benefit from palliative care interventions (Etkind et al., 2017); pain: (12–76%) (van der Steen, 2010); breathlessness (8–80%) (van der Steen, 2010); depression (9–32%) (Mitchell et al., 2009); anxiety (3–22%) (McCarthy et al., 1997), hallucinations (2–11%) (Lyketsos et al., 2002b) (Mitchell et al., 2009); and delusions (18%) (Lyketsos et al., 2002a). However, it is widely acknowledged that assessment and subsequent management of these of these symptoms is challenging with patients' declining verbal communication and cognition and absence of biological markers (Ellis-Smith et al., 2016). Untreated, these symptoms often lead to considerable distress and behavioural complications, and compromise quality of life, resulting in challenges to clinical management (Husebo et al., 2011)

The length of time a person can expect to live with dementia also depends on the stage that the disease is at when they are diagnosed. Dementia's relatively long and unpredictable disease trajectory makes it difficult for healthcare professionals to provide an end of life prognosis (Lunney et al., 2003) (Etkind et al., 2017) - and perhaps makes them unwilling to do so.

Many people with dementia will find themselves living and dying in care homes rather than at home or in hospice (Ellis-Smith et al., 2016) (Sleeman et al., 2014). A study of nursing home deaths found that most people with dementia were given a prognosis of more than six months, but 71% of these people died within the six-month period (Bayer, 2006). The period for which a person with dementia might require care is long compared with a number of other terminal illnesses for example, cancer. Since the disease trajectory of dementia is both prolonged and unpredictable, specialist palliative care services may need to care for individual patients for longer periods of time and potentially provide support for patients at several time points. People with dementia also often struggle with daily living and taking care of themselves at an earlier stage than those with some other conditions due to the nature of the symptoms.

Diversity in the United Kingdom

According to the 2001 and 2011 UK Censuses, in the past 20 years the entire UK has become more ethnically diverse. This was especially true in England where both the numbers and proportions of people from BAME groups (all ethnic groups other than White British) have increased; in 2011 they represented a fifth of the population (Office for National Statistics, 2012b). In England, Other White (4.6%), Indian (2.6%) and Pakistani (2.1%) were the largest BAME groups in 2011.

Census data identifies that ethnic groups are not equally distributed across England. For example, while in London less than half of the population is White British, in the North East they represent over 90% of the population (Office for National Statistics, 2012a). It is also important to note that diversity can also be understood in relation to other social metrics, for example religion and language. In the case of the former, the numbers and proportions of people who described themselves as Christian in England have decreased from 2001 to 2011 (from 71.7% or over 35 million to 59.4% or over 31 million) (Office for National Statistics, 2013a). While numbers and

proportions of people from religions other than Christian have increased, with Muslims being the second largest religious group (Office for National Statistics, 2013a). When it comes to language, over 90% of people have English as their first language, but one out of five people who do not have it as a principal language either cannot speak English well or cannot speak it at all (over 800,000 people), which could indicate a demand for translation services when in receipt of care (Office for National Statistics, 2013b).

The rise in the number of people from black, Asian and minority ethnic communities has been driven by population growth and immigration. This has indicated a relatively younger profile of BAME people compared to the wider population. However this is, and will continue to change as those who originally came to the UK get older.

Three recent population projections describe the possible changes in ageing of BAME groups in the UK (Coleman, 2010) (Wohland et al., 2010) (Lievesley, 2010). All of them predict an upward trend in the numbers and proportions of older people from BAME groups in the future (with variations across groups according to different projections). Lievesley's projections show that although BAME groups have a younger age structure than the majority White British population, the numbers of older people will substantially increase in the upcoming decades. In England and Wales it is predicted that by 2026 there will be over 1.3 million people from BAME groups aged 65+, compared to over half a million in 2001; in 2026 almost half a million will be aged 70+ years. Amongst BAME groups, the White Irish is expected to have the highest proportion of people aged 65+ (35.9% of its population expected to be in this age group), followed by the Black Caribbean (13.4%), Other White (10.7%), Indian (10.6%) and Other Asian (9.6%) (Lievesley, 2010).

Black, Asian and minority ethnic groups, dementia, and end of life care

Having outlined the future growth and ageing of people from BAME communities we now turn to the issue of dementia prevalence. Anyone, regardless of gender, sexuality, ethnicity, ability, or socio-economic background can develop dementia (Bingham et al., 2016). However, beyond several small-scale studies there has been very little research done on the presence, and experience, of dementia amongst

black, Asian and minority ethnic communities living in the United Kingdom (Milne and Chryssanthopoulou, 2005) (Johl et al., 2016). In the absence of clear indications to the contrary, it has been assumed that the prevalence was the same as for the UK population as a whole, even though most communities are younger overall than white British population (Truswell, 2014).

However, a study from North London suggests a somewhat higher prevalence of dementia among people of African-Caribbean country of birth than among white UK-born people (Adelman et al., 2011). In this study, the prevalence of dementia was found to be significantly higher in the African-Caribbean (9.6%) than the White British group (6.9%) after adjustment for the confounders, age and socio-economic status (odds ratio (OR) = 3.1, 95%CI 1.3–7.3, P = 0.012). These findings are consistent with non-statistically significant trends reported in two other studies (McCracken et al., 1997) (Richards et al., 2000), and may be related to vascular risk factors and diabetes, more common in several black, Asian and minority ethnic groups, that lead to increases in the rates of Alzheimer's disease and vascular dementia (Adelman et al., 2009) (Skoog, 2008). Nevertheless, more epidemiological research is required to clarify the prevalence of dementia among other ethnic groups and in order to understand the expected growth.

In the absence of larger scale studies, the Centre for Policy on Ageing and the Runnymede Trust recently applied well-established dementia prevalence rates to census data and projections based on census data. They estimate nearly 25,000 people with dementia from BAME communities in England and Wales. To accompany projected growth in the numbers of older people from BAME communities there is an expected growth in the number of people with dementia to nearly 50,000 by 2026 and over 172,000 people by 2051 (Alzheimer's Society and the House of Commons All-Party Parliamentary Group (APPG) on Dementia, 2013).

For the purposes of this briefing we applied the Alzheimer's Society's Expert Delphi Consensus findings of the prevalence of dementia in the UK to different ethnic groups. In some instances groups have been combined due to small numbers i.e. those who are Chinese (figure 1). The figure reveals the relatively high numbers of dementia expected to exist among the White Irish communities who have an established history of living in the UK. Among those who are not white, the Asian or Asian British: Indian groups have the highest expected numbers and this again

reflects a longer history of having been resident in the UK. Critically, the numbers of people likely to experience dementia across all groups will increase as they become subject demographic ageing.

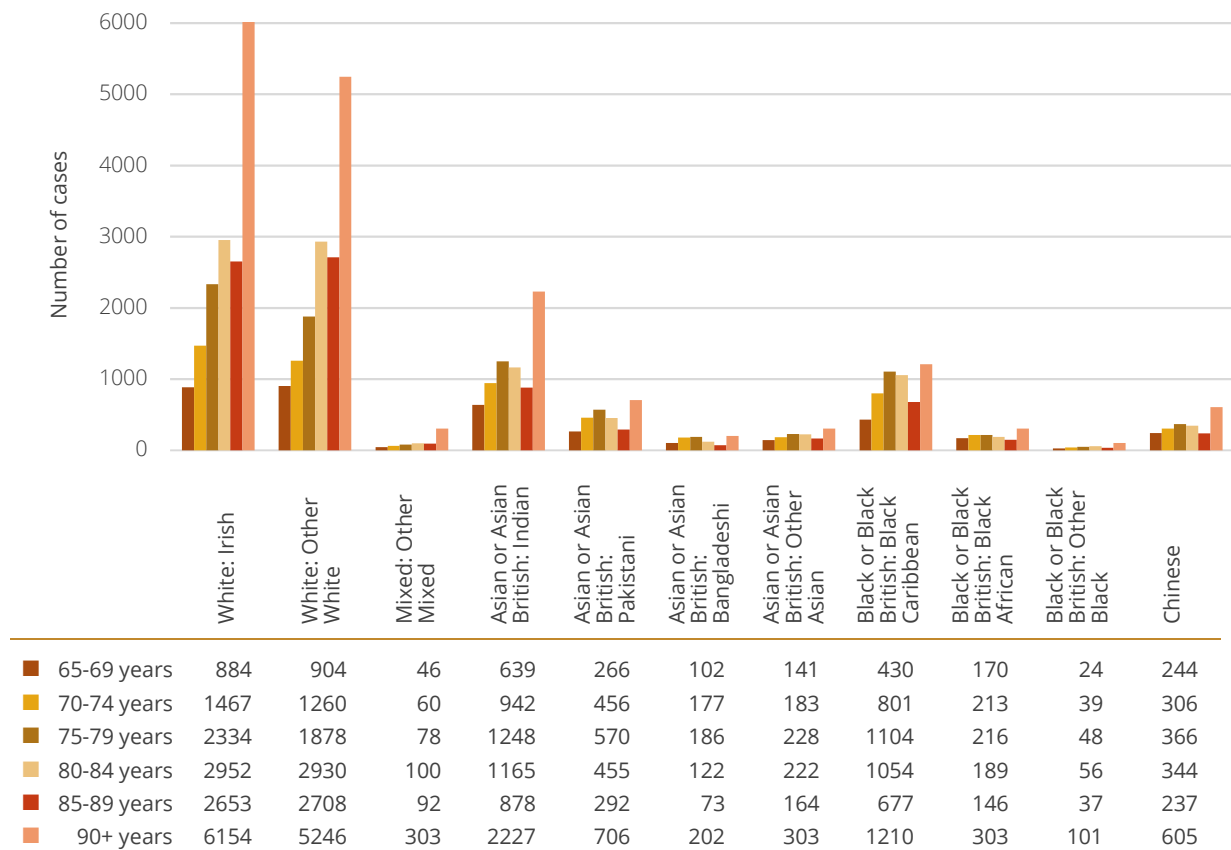


Figure 1. Number of cases of people with late-onset dementia by ethnic-group and age based on consensus estimates of population prevalence (source: Alzheimer’s Society)

Care for those from BAME groups living with, and dying from, dementia

The National Dementia Strategy has an overarching aim of improving end of life, with specific focus on hard-to-reach groups, including those from black, Asian and minority ethnic community and religious groups. However, this call to improve end-of-life for people living with and dying from dementia, irrespective of their population group, is tempered by evidence that we are neither all equal in life or in death and dying (Crawley and Koffman, 2015). Recently, Calazani, Koffman & Higginson (Calazani et al., 2013) reported on 45 studies that examined disparities in palliative and end-

of-life care provision highlighting inadequate assessment and communication, involvement of patients and families in critical decisions, poor uptake of specialist services, and sub-optimal management of symptoms associated with advanced disease.

Whilst some studies have identified ethnicity as being one factor among many others associated with specific outcomes of care among those with dementia in their last year of life [example emergency department attendance (Sleeman et al., 2017)], very few studies have focused specifically on the needs and experiences of people with dementia from BAME communities living in the UK. Broad areas of concern specific to those with dementia from BAME groups are examined below.

Access to services

A common theme running through studies of BAME groups and palliative and end-of-life care is the low uptake of palliative care services that may be of benefit (Ahmed et al., 2004) (Koffman et al., 2007). A number of explanations have been suggested to account for this including low referral rates from health professionals, gatekeeping, poor knowledge of services and specifically services related to palliative care, as well as religious and family traditions that may run counter to palliative and hospice care philosophies (Koffman et al., 2007). Although there is evidence that those from BAME populations are less likely to access specialist palliative care and hospice care with respect to cancer, research from United States does not wholly support this concern among those with dementia. Instead the authors of a recent systematic review of 20 studies suggest that in some instances African American and Hispanic patient populations may be in receipt of equal, or in some circumstances receive more care than their white peers (Connolly et al., 2012). However, caution must be expressed as the majority of studies in this review were from North America and may not be representative of the situation in the United Kingdom, Connolly and colleagues conclude that whilst there are instances of equal receipt of care, disparities in end-of-life care for people with dementia from minority groups exist. They suggest that these may be due to the double disadvantage of having dementia and minority ethnic status.

The importance of impeccable assessment and communication with diverse communities

Critical to assessing and monitoring palliative care needs is the ability to communicate clearly and effectively. The inability to do so not only affects access to palliative care services but has been shown to be a source of serious problems in clinical consultations and the cause of misunderstandings amongst patients, family members and healthcare providers (Koffman and Higginson, 2001)

Important communication difficulties arise where there is an over-reliance on patient's relatives acting on their loved one or defendants' behalf (Frearson et al., 2013). Whilst this may well be easier than accessing an interpreter, it can potentially disadvantage both the doctor and the patient (Koffman and Crawley, 2008). The family interpreter may filter, abbreviate or omit vital information, or inform the doctor or the patient what he or she thinks the doctor and patient needs to know. Vital medical information may not be understood adequately or conveyed in full. Details about an illness may be very intimate and it places an unfair pressure on them, who, depending on their age may be less likely to understand adult conversations in English, or even their own language.

Guidance suggests the use of sensitive and appropriately translated materials and interpreters who have the correct language and dialect of the person with dementia is essential in order to avoid relying on family members to act as interpreters (Crawley and Koffman, 2015). Use of professional interpreters is essential to provide independence to the voice of the person with dementia, and reduce the extra burden stress placed on family members. Some studies report the communication can be further hampered when the cultural background of the healthcare staff providing social care differs from the person with dementia, and their family (Cox et al., 2006). This again may lead to heavy reliance on family members to translate or deliver more direct care than should be expected. However it should be acknowledged that little is known about the numbers of people from black, Asian and minority ethnic groups residents in care homes, or to the extent to which their end-of-life care needs are addressed in line with their specific requirements. If care staff fail to appreciate the cultural difference of the person in their care this can result in dissatisfaction, undue stress (Badger et al., 2009;) and less complaints about care (Health and Social Care

Information Centre, 2017) . Communication is not only an issue of spoken language. It also involves body language, cultural rules as to what is courteous (such as not looking the professionals - especially opposite gender - in the eye) and appropriate behaviours in an unequal gender and power relationships.

While there has been enormous progress in the field of pain in the recent years, the actual delivery of care to individuals in pain is still far from adequate. However, as we focus on pain and why it is too often ineffectively treated, there is evidence that certain minority populations are at higher risk of oligoanalgesia (the ineffective or sub-therapeutic treatment of pain) (Cleeland et al., 1997) (Bernabei et al., 1998). These disparities in treatment are evident across a number of types of health-care facilities and treatment settings, from the community hospital to the nursing homes. Various explanations might account for this but communication is a central concern. Data from a number of studies, principally cancer, suggests that the manner in which pain is communicated varies from one group to the next (Anderson et al., 2002) (Koffman et al., 2008a). Several important issues therefore warrant consideration. First, patients with serious medical conditions, such as cancer, may under-report their pain and its severity and this may be culturally determined. For example, Black Caribbean cancer patients have reported that stoicism and the belief that their pain is an inevitable part of their illness experience and must be accepted (Koffman et al., 2008a). Second, the most frequently studied factor that has been shown to influence pain assessment involves its actual severity. When pain severity is low, patients and health care professions report good agreement in rating of this symptom (Tait and Chibnall, 1997) (Grossman et al., 1991). However, when patients rate higher levels of pain there is evidence that health care professionals do not concur with their assessments (Chibnall et al., 1997). In addition, there is also evidence that patients reporting high pain severity also experience prejudiced stereotyping which may be amplified by racism. Research about the experience and management of pain among BAME patients living with dementia is urgently required.

End-of-life care decisions and interventions

In many parts of Europe, Australia, New Zealand and North America patient autonomy is the main focus of decision-making during life, specifically at the end of life (Kagawa-Singer and Blackhall, 2001). Patient autonomy emphasises the inalienable rights of patients to be informed about their condition, potential

treatments and their ability to opt for or refuse life-prolonging medical care. Advance care plans (ACPs) in the United Kingdom or directives (ACDs) in the United States, are meant to ensure that patients' wishes concerning end-of-life care are enforced, even when they are no longer able to speak up for themselves (Emanuel et al., 2000). This framework reflects core values of the dominant presiding culture that include independence, individual rights and sometimes fears of receiving too much care at the end of life (Kagawa-Singer and Blackhall, 2001). Whilst the presence of patient autonomy has clarified the legal status of patients who turn down therapy and increased the comfort of healthcare professionals to make these decisions, it is vital to acknowledge that patients (and their families) from different cultures may not share the same value base and concerns (Veatch, 2000). Advance care planning in dementia represents a little research field compared to the broader adult population (Harrison Dening et al., 2011). However, what evidence there is identifies that those from black, Asian and minority groups are less likely to be involved in advance care planning, to complete an advance directive, and to refuse treatment compared to their white peers (Harrison Dening et al., 2011). However, drawing from focus groups held with African-Americans and Caucasians, Modi and colleagues identified that there were more similarities than differences in how decisions were made and included elements such as following the wishes of the person with dementia, being true to their faith and religion, and concerns about decisions overriding these (Modi et al., 2010). Although this study is USA-based and may not represent the beliefs of those in the United Kingdom, it is imperative not to lose sight of the influence of religion and the principles of faith which provide valuable insights to support optimum end-of-life care of those with dementia, and their families (Koffman et al., 2008b).

A related area of concern is the use life-sustaining treatments for those with dementia. Braun and colleagues observed that there were significant differences in the intervention for life-sustaining across different ethnic groups; those from black, Asian and minority ethnic groups have a greater likelihood of receiving blood transfusions, resuscitation and mechanical ventilation than their white peers (Braun et al., 2005). No similar studies have taken place in the United Kingdom. This is an area that warrants further research. In interventions including artificial nutrition, Connelly and colleagues' systematic review identified differences in the rates of artificial nutrition and hydration across different ethnic groups; African-Americans had the highest rate when compared to Caucasians (Harrison Dening et al., 2011).

Taken as a whole there is evidence that decisions made on behalf of people with dementia from ethnic groups request more aggressive care at the end of life.

Religious and spiritual issues at the end of life and during bereavement

The experience of advanced disease, that includes dementia, can have a profound effect on patients and their family and friends. Indeed, during their illness many patients may raise questions that relate to their identity and self-worth as they seek to find the ultimate meaning in their life. Some patients and their family members may attempt to answer these questions by examining their religious or spiritual belief (Koffman et al., 2015). 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. Speck suggests this usually includes reference to a power other than self, often described as 'God', or 'forces of nature' (Speck, 1998). This power is generally seen to enable a person to transcend immediate experience and to re-establish their hope. The importance of religion and spirituality amongst patients with advanced disease and their families as a central component of physical and psychological well-being and is increasingly recognised by health and social care professionals (Selman et al., 2013).

To this end, acquiring core competencies in the assessment and management of spiritual and religious care for health and social care professionals working in end of life care, including with those caring for people dementia, is strongly recommended (Evans et al., 2012) (Speck, 2016). Most of the published literature on the role of religious faith at the end of life are descriptive and focus on 'fact-file/recipe guides' approaches to serve the experience of death and dying across different faiths (Neuberger, 2003) (Narayanasamy, 2001). However, this approach is not without criticism; it has a tendency to over-categorise religious and cultural groups and reify difference (Gunaratnam, 2003). There may be wide variation in the degrees of adherence to and the nature of that practice. Maybe considerable variations in attitudes within most religions is one person's approach to death and after death may be different, for example there will be significant and important differences between those who are Orthodox Jewish and those who are Reform or Liberal. There

may be important differences between each of the Christian denominations for example those who are Anglican Christian or Pentecostal. Skills in cultural competence and cultural assessment enable healthcare professionals to ask patients and their families what is important to them rather than over assuming.

Conclusions

The palliative care movement has taken a leading role in addressing the health and social care needs of patients and families facing the inevitability of death. This includes dementia. Only been recently has attention begun to focus on the importance of providing care for increasingly diverse societies, particularly as we are witnessing more members of BAME communities living and dying from dementia. This will become a demographic imperative in the next two decades.

Whilst there is now an established body of research that has focused on the experiences of those living with and dying from cancer and a number of other non-malignant conditions from BAME groups living in the UK, virtually no research has focused on those living with and dying from dementia. Research that has taken place has been limited to North America where disparities in end-of-life care for people with dementia from ethnic minority groups appear to exist and may be due to the double disadvantage of dementia and ethnic minority status. This research has identified those from some BAME groups as being less likely have requested do-not-resuscitate (DNR) and more likely to choose life-sustaining measures than their white counterparts. They also receive higher rates of intervention for example receiving receive blood transfusions, mechanical ventilation, and care in intensive treatment units (summarized in textbox 1).

Textbox 1. Summary of the current state of palliative and end of life care provision relevant to people with dementia from BAME group

Unmet needs/disparities in ACCESS to palliative end of life care relevant to dementia, and explanatory factors

- Low up-take of services compared to white/majority groups
- Lack of referrals
- Lack of knowledge about palliative care and what hospice care involves

Unmet needs/disparities in RECEIPT of palliative and end of life care relevant to dementia and, explanatory factors

Communication:

- Poor communication
- Lack of sensitivity to cultural and religious values
- Lack of translation of resources and

- Information not available in different languages
- Lack of cultural equivalents for palliative care or hospice
- Palliative care conflicting with religion
- Avoidance of disclosure due to religious and family values
- Mistrust by patients and their families
- Mis-assumptions from patients (care not accessible) and care providers (family will provide care)
- Social exclusion and social segregation
- Socio-economic factors (deprivation, education)
- Low prevalence/different prevalence of certain diseases

advocates

- Problems using family members or friends as translators
- End of life decisions
- Resources to train health care professionals
- Consequences of mis-treatment, unmet religious needs uncertainty and stress for health care professionals

End of life decisions and interventions:

- Less likely to complete advance care planning documents and more likely to desire life-sustaining or aggressive treatment
- Mistrust from patients and relatives
- Influence of religion
- Western values (autonomy/right to self determination in conflict with other culture)

Outcomes of care:

- Pain control:
 - ◆ Worse pain outcomes (mostly USA based)
 - ◆ Pain severity under-estimated (language and culture and potentially racism)
 - ◆ Lack of awareness that people from different cultures have different attitudes and responses to pain
- Less satisfied with care, lower care ratings

There is an urgent need to address the imbalance of research in United Kingdom. First an epidemiological needs assessment must take place to quantify the current and future palliative care needs of BAME groups living with dementia. Second, research must focus attention on how different migration histories and cultures influence the experience of end-stage dementia in relation to end-of-life care, decision-making and preferences. This research should also examine whether end-stage dementia is perceived as a terminal illness as this may affect uptake of palliative and end-of-life care services shown to be of benefit. Research should also be undertaken amongst informal family caregivers as social and cultural views may similarly influence their perceptions.

In the absence of research, guidance on improving care for those from BAME groups at the end of life can be drawn from existing resources, for example those recently developed by Calanzani, Koffman and Higginson (Calazani et al., 2013) that include:

- 1 Addressing social inequities in healthcare as a whole;
- 2 Involving BAME groups when developing new policies;
- 3 Training health care professionals in the importance of cultural competency and communication skills.
- 4 Rigorously evaluating if interventions that aim to improve care for BAME groups actually work/make a difference to patients and families. This must include patient and public involvement (PPI) to ensure research questions, conduct of studies, interpretation of data of study findings, and devising recommendations.

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Acknowledgement

I would like to extend my thanks to Dr Katherine Sleeman, NIHR Clinician Scientist, King's College London & Honorary Consultant Palliative Medicine, King's College NHS Foundation Trust, for her very constructive comments on the contents of this policy briefing.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk



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ISBN 9781873912314

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