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# **Towards inclusiveness in dementia services for Black and minoritised communities in the UK**

## **Abstract**

**Purpose:** The purpose of this paper is two-fold. To explore the existing evidence around dementia services and interrogate the over-arching UK policy development relating to service inclusion of Black and minoritised groups. The paper will go on to identify the implications for the Dementia wellness pathway and make recommendations regarding how services can be more inclusive.

**Approach:** This paper examines the policy/practice landscape around dementia care provision and observes if lessons can be learnt to improve health outcomes for people living with dementia from Black and minoritised communities.

**Findings:** A review of dementia policy demonstrates how opportunities to improve the awareness, diagnosis and post-diagnostic support for minoritised communities are being missed. The outcomes of this mean that individuals are denied vital treatment and support, which could enhance quality of life, and delay the progression of dementia.

**Practical implications:** The authors' premise is that not meeting the dementia support needs of less heard communities has negative financial as well as social and health related outcomes and has wider resonance and implications for all stages of the Dementia Wellness Pathway. Moreover, there is a legal responsibility for public services to provide culturally sensitive, responsive, appropriate and available care, to all people, without discrimination

**Keywords:** Black and minoritised communities, BAME, dementia, service provision, post-diagnostic.

## **Background**

It is estimated that around 50 million people worldwide are living with dementia, with around 10 million new cases every year (WHO, 2020). Dementia is one of the leading causes of disability and dependency in older people, often requiring intensive health and social care support in the later stages (WHO, 2020). In the UK there are around 850,000 people living with dementia, of which 25,000 are from Black and minoritised groups (Alzheimer's Society, 2020) By 2026, the number of people with dementia from these population groups is expected to double to 50,000 (Alzheimer's Society, 2020) and increase sevenfold by 2050 (APPG, 2013). These steep rises reflect the increased prevalence of risk factors in Black and minoritised groups (Moriarty et al, 2011; Finney et al, 2016) and the changing migration patterns in the UK (Ahmed et al, 2016).

Evidence shows that people from Black and minoritised communities are under-represented in their access of dementia services (Parveen, Peltier, and Oyebode, 2017) or present late to dementia services, often in crisis situations (Tuerk and Sauer,

2015). The reasons why this population group are not accessing dementia care are acknowledged to be complex and multi-dimensional yet remain unaddressed. Broadly speaking, one of the main factors is the general lack of awareness and understanding of dementia in Black and minoritised groups (Johl et al, 2016; Baghirathan et al, 2020; Hussain and Khan, 2020). Whilst, for those individuals migrating to the UK, there are practical barriers to accessing and navigating the complex administrative systems of the national health service (Moriarty et al, 2011) which are impeded by language and literacy barriers (Nielson et al, 2020) lack of knowledge of available services and having different help-seeking patterns, which are often at odds with western ideas and systems (Nielsen and Waldemar, 2016).

However, for many individuals from Minority ethnic groups, their past experiences of UK healthcare services have been poor, often exposed to racism and discrimination (Mukadam et al, 2015), or stereotyped (Dunning et al, 2020). Evidence also shows a lack of culturally appropriate services ( Baghirathan et al, 2020) where peoples cultural and religious needs are unmet (Hossain and Khan, 2020). Accessing dementia care is also enshrouded in stigma (Parveen et al, 2014) and compounded by cultural and religious values and beliefs such as familism, collectivism, and emotionalism which often dictate that care should be performed by family members (Nielson et al, 2020; Such family obligations may be compounded by the lack of culturally and religiously appropriate care, as was observed in a study by Hossain et al (2019) where family carers of Muslim patients were more likely to provide direct care as no appropriate care was available as an alternative.

In contrast, Hussain and Khan (2020) found that there was a lack of awareness from service providers of the need to engage with certain communities in their locality. Similarly, service providers are often observed to hold stereotypical views such as certain cultures prefer to 'look after their own' (Parveen and Oyebode, 2018). Such exclusionary practices compound health inequalities and promote the 'othering' of Black and minoritised groups (Darko, 2021). In a review of post-diagnostic dementia care by Frost et al (2020), it was found that very few Local Authorities provided tailored dementia services specifically for Black and minority ethnic populations.

### **Context of dementia care in the UK**

For over a decade UK central government policy has outlined the need to improve access to dementia services and improve dementia awareness for minority ethnic groups. However, as decentralisation devolves power to Local Authority control, the overarching dementia care frameworks and pathways often become diluted at grassroots level, in favour of local policy, producing fragmented services amid tight financial constraints. This paper will therefore review national dementia policy to allow an overview of the policy landscape within the context of the UK National Health Service (NHS).

The National Dementia strategy was launched in 2009 in the UK to improve the quality of care for individuals living with dementia, prioritising the need to raise dementia awareness and improve diagnostic rates, whilst highlighting the need for inclusivity and tailored approaches for minority groups (DoH, 2009). The strategy sought to provide guidance and support for commissioning bodies, strategic health authorities,

local authorities, acute, primary care and mental health Trusts (DoH, 2009). The responsibility for implementing the National Dementia strategy was given to the devolved administrations of Primary care Trusts (PCT's) across England, who largely set their own policies for dementia care (Powell and Baker, 2019) with clinical guidance being determined by the joint National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE).

Contextually these devolution measures have seen the passing of power from national to local bodies through a succession of policy initiatives designed to increase the level of local autonomy in health (such as the introduction of Foundation Trusts and Clinical Commissioning Groups (CCG's). CCG's were given the responsibility for the planning and commissioning of health care services for local areas. Alongside this the development of integrated care, saw parts of the NHS and health and social care being brought together to enable the NHS, Local Authorities (LAs) and other local partners to prioritise local needs and achieve more joined-up working and streamlined service provision. The impact of this decentralised approach allowed the potential for Local Authorities to respond more effectively to local need and engage local people to influence the local decision-making. However, it also created the possibility of inequalities developing between regions (Stubbs, 2015) and a fragmentation of services (Andre and Garcia, 2014). In terms of dementia care, the latter two consequences can be observed across England, particularly in relation to services targeting the needs of the Black and minoritised community (Frost et al, 2020).

### Dementia care pathways

National dementia policy which has followed the National dementia strategy, has given consistent reference to the increasing numbers of Black and minoritised older people developing dementia, and the need to increase early diagnosis. In 2016, the Government published '*Making a difference in dementia, nursing vision and strategy*' (DoH, 2016:7) cited one of their key aspirations was to increase the numbers of Black and minoritised people receiving a diagnosis of dementia, by making diagnostic tools that were *linguistically or culturally appropriate*. This aspiration was repeated in subsequent reports (DoH, 2016; DoHSC, 2019) and in associated guidance from the National Institute for Health and Clinical Excellence (NICE, 2010; NICE, 2015; NICE, 2019). The 'Dementia care pathway' published by the National Collaborating Centre for Mental Health (2018) saw the collaboration of NHS England and NICE to create a framework ensuring that people living with dementia have timely access to diagnosis and post-diagnostic support through to the end of life. The pathway was underpinned by the principles of living well with dementia, so that every individual has person centred care, tailored to their needs. NHS England's most recent guidance for practitioners and service providers highlights the use of the Dementia wellness pathway which encompasses five broad stages, designed to support service delivery and quality of care.

Table 1 Depicts the stages of the Dementia wellness pathway.

Stage	Description	Aims
1	<b>Preventing well</b>	To raise awareness of dementia and its associated risks.
2	<b>Diagnosing well</b>	Ensuring timely diagnosis Access to health and care services Person centred support to maintain independence
3	<b>Living well</b>	Health promotion to support the physical, mental and oral health of people living with dementia and their carers Tailored support to promote wellbeing
4	<b>Supporting well</b>	Person-centred care, treatment and planning Empowering people to be involved in research Considering the needs of carers and directing them to appropriate support.
5	<b>Dying well</b>	Opportunities to complete advanced care planning whilst people have the capacity to make long term decisions Access to palliative care and support facilitating people to die with dignity in a place of their own choice.

## Application of dementia care pathways in practice

### Preventing well

Having discussed the under-representation of Black and minoritised populations in dementia care it is therefore very troubling that this population group is at increased risk of developing dementia. Risks are thought to be increased in Black and minoritized individuals due to a range of factors including the prevalence of genetic variants such as ApoE-ε4 genotype which is linked to dementia (Mayeda et al, 2017); increased cardiometabolic risk factors, such as diabetes and obesity (APPG, 2013); poor socio-economic factors such as low income, poor education, poor working conditions and social isolation (Pham et al, 2018 ) and diet and exercise patterns which may be socially and culturally determined (Gordon-Larsen and Popkin, 2011). Compounding these issues are the wide-reaching impacts of UK social policy which result in people from Black and minoritised groups being more likely to experience health inequalities across their life course (Finney et al, 2016) and live in deprived communities (Kingsfund, 2020).

The urgent need to target minority ethnic groups with pre-disposing conditions that put them at increased risk of dementia, has been the subject of UK dementia policy since 2009 (DoH, 2009) and reiterated in the Prime Minister's challenge (DoH, 2016). The Dementia Care Pathway (National Collaborating Centre for Mental Health, 2018) also addressed the need to reduce the risk of early-onset dementia, in people from Black and minoritised backgrounds, stipulating that commissioners should address this in a Joint Strategic Needs Assessment and local Dementia Needs Assessment, which captures data and services within the local borough.

### **Diagnosing well**

Evidence underpins the fact that people from Black and minoritised communities are not accessing dementia services in a timely manner, instead presenting in crisis situations (Tuerk and Sauer, 2015). Pham et al (2018) observes that such inequity in care, denies people from Black and minoritised backgrounds the same benefits than the majority white population. Indeed, early diagnosis gives support, information and treatment options which generally improve a person's quality of life, but most importantly can prevent or delay the development of dementia by reducing exposure to common risk factors (Rasmussen and Langerman, 2019). Such treatment options may include accessing prescription medication (The Race Equality Foundation, 2016), or planning future care etc (Livingston et al, 2017) which are interventions which are time sensitive.

The literature shows that traditional, mainstream diagnostic approaches are difficult to apply in cross-cultural settings (Waheed et al, 2020) and can be affected by language difficulties (Bhattacharyya et al, 2012). Whilst validated assessment and screening are available in different language formats, these require a bilingual Health Care Practitioner to administer them or the presence of an experienced interpreter, which can be challenging in clinical settings (British Psychological Society, no date). It is unsurprising then, that many people from Black and minority backgrounds who have poor language and literacy skills have difficulty participating in mainstream cognitive testing to achieve a diagnosis, or access memory services which are culturally inappropriate (Giebel, 2020). A review by Johl, Patterson, & Pearson (2016) found that late diagnosis in minority populations may also be due to a lack of awareness of dementia, with symptoms such as memory loss being seen as part of the normal ageing process alongside limited knowledge of services and treatment options.

### **Living well**

The Prime Minister's Challenge on Dementia 2020 published in 2016 (DoH, 2016: Section 5.46) stated its goal to be that by 2020 it would have created a society: *'where every person with dementia, their families and carers – whatever their background, geographical location, age, gender, sexual orientation, ability or ethnicity – receive high quality, compassionate and culturally competent care'*. This objective was reflected in the Dementia Care Pathway (National Collaborating Centre for Mental Health, 2018: Section 1.4) stipulating that information and the design of services should be *appropriate and accessible, to meet the needs of diverse communities'* reiterating the need for services to be delivered by a culturally

competent workforce. The National Institute for Health and Care Excellence (NICE) (2018) recommend that individuals should receive a referral to specialist dementia diagnostic services and on diagnosis they should be assigned a named care-co-ordinator, receive access to interventions to promote cognition, independence and wellbeing, reduce stress and support carers (NICE, 2018). In England these services are supplied by public sector, third sector and private sector, as well as unpaid care, creating a 'postcode lottery', whereby services differ between area (Frost et al, 2020).

Using the narrative living well with dementia, there is an inference that all people should enjoy a good quality of life, yet evidence suggests that people from Black and minoritised communities continue to experience higher levels of health inequalities, compared to their white counterparts (Baghirathan et al, 2020). Koffman (2018) also makes the point that living well and life expectancy is also dependent upon when, and at what stage the disease is first diagnosed.

### **Supporting well**

The dementia wellness pathway advocates for person centred care and support for the person living with dementia and their carers. However, the literature suggests that people from Black and minoritised communities are under-represented in dementia services (Parveen, Peltier, and Oyebode, 2017) for a complexity of reasons which establishes a disparity between the narrative and the reality of care provision. This means that the human rights of people living with dementia from Black and minority communities are potentially being undermined. A rights-based argument, then contends that people living with dementia should have their human rights protected under the Human Rights Act (1998), the NHS Constitution for England (DoH, 2012) the Equality Act (2010) and the United Nations' Convention on the Rights of Persons with Disabilities (UN,2006).

Indeed, the values underpinning all human rights are the FREDDA principles of fairness, respect, equality, dignity, and autonomy, which are also the foundations of quality care (Curtice and Exworthy 2010). Whilst the NHS Constitution (DoH, 2012) states that the NHS 'has a duty to each and every individual that it serves and must respect their human rights'. Whilst the United Nations' Convention on the Rights of Persons with Disabilities (UN, 2006) establishes that persons living with disabilities should not experience discrimination or have their rights ignored. Although these legal arguments are applicable for every person with dementia, it is evident that those from Black and minoritised communities are being discriminated against and their legal right to receive high quality care, culturally appropriate care ignored.

The 'supporting well' part of the dementia wellness pathway highlights the need to empower individuals living with dementia and their carers to become involved in research. However, the literature suggests that Black and minoritised communities are absent from research in all areas of healthcare research (Farooqi et al,2022) which consequently means that their voices and experiences do not influence healthcare service design or future planning ((Rees, Wohland and Norman 2013).

## **Dying well**

The UK dementia strategy depicted in the dementia wellness pathway highlights the fact that individuals should be given the opportunity to prepare advanced care plans, and experience a dignified death, in the place of their choice. However, dementia is a progressive neuro-degenerative disease, which in the advanced stages will mean that individuals will have complex cognitive and physical needs which require specialist care in a care home environment (Rice, Howard, and Huntley (2019). For people from Black and minoritised communities there is reticence in accessing long term care homes (Giebel, et al 2015). The reasons for this may be in part due to cultural beliefs and values around care for family elders, as well as multi-generational living, but also the lack of culturally appropriate care home provision in the UK (Rice et al, 2019). However, managing symptoms in the advanced stages of dementia is challenging, and often distressing (Husebo et al., 2011) with commonly reported symptoms being pain, dyspnoea, anxiety, and hallucinations which benefit from specialist palliative care interventions (Etkind et al., 2017). A report by Calazani et al, (2013) examined 45 literature reviews on unmet need and disparity in palliative and end-of-life care for BAME groups, highlighting the poor care and treatment which people had received. Crawley and Koffman, (2015) observe that the inequalities experienced by Black and minoritised populations in life, are also apparent in dying and death.

## **Discussion**

From an appraisal of Government policies, the provision of dementia services targeted to individuals from Black and minoritised backgrounds are supposed to be driven by the needs of the local community and commissioned by Local Authorities and/or integrated organisations. Often third sector organisations are at the forefront of service development, designing services around the needs of their own local communities (Jeraj and Butt, 2018). Indeed, even in areas which have high levels of diversity the experiences of marginalised communities are still poor (Ahmed et al, 2016) Research on the mapping of post-diagnostic services has observed as being problematic, with surveys generally focusing on specific provision, such as memory services (Chrysanthaki et al., 2017), dementia adviser services (Ipsos Mori, 2016), or regional service provision (Robens et al., 2015). Frost et al (2020) completed a national e-survey of commissioning bodies across England but only achieved responses from 50 CCGs and 26 LA's. The work by Frost et al (2020) found fragmented service provision by multiple providers, with limited commissioning of dementia services targeting Black and minoritised groups.

Whilst challenges to integrated commissioning services are evident, there is a rights-based argument for local and central government to consider. This is the right to receive care, which is culturally sensitive, responsive, appropriate and available. These rights are enshrined within the Equality Act (2010). Under this legislation, public services in England, Scotland and Wales have a duty to reduce the inequalities of outcome which result from socio-economic disadvantage [Section 1] and provide



services without discrimination [Section 13]. Indeed, the Human Rights legislation also protects people with dementia, and advocates for person centred care, by using the articles of the Human Rights Act in a practical way to impact people's daily lives (Nyamu-Musembi and Cornwall, 2004). This area of the law is especially significant when we consider the increased risks being experienced by people from Black and minoritised backgrounds, who are receiving inequitable services compared to their white counterparts.

### Conclusion

The evidence base offers compelling evidence that people living with dementia from Black and minoritised backgrounds are being failed by UK service provision throughout their dementia journey. The policy review shows what can now be entitled as empty rhetoric, where guidance on how to serve minority communities does not translate into service provision. Moving forward, it is imperative that Integrated Commissioning bodies in the UK take notice of statutory legislation to provide public services which are appropriate in meeting the needs of individuals from Black and minoritised groups and take steps to reduce inequalities of outcome (Equality Act, 2010). There is a need to eliminate the disparity in services between areas/regions which result in a 'post-code lottery' of service provision for people living with dementia (Frost et al, 2020). Collaborative working between primary care and specialist dementia services (Sheiban et al, 2018) and the third sector (NHS England, 2019) would facilitate more efficient care delivery.

### Recommendations

1. There is currently no evidence base showing how post-diagnostic dementia services are commissioned (Kane and Terry, 2015), with data held locally, not nationally. Future research needs to centre on a review of each Local Authority Joint Strategic Needs Assessments to gauge an accurate picture of dementia services nationwide, which are tailored to people from Black and minoritised backgrounds.
2. evidence shows that people living with dementia from Black and minoritised backgrounds are absent from dementia research, and as a consequence do not have the ability to influence future service design.
3. Central and local Government in the UK have a legal responsibility to protect the needs of all citizens and deliver culturally appropriate dementia services. This will decrease the disparity in outcomes and financially reduce the cost of long-term care for people living with dementia from Black and minoritised communities.

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