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Understanding the influence of culture on caregiving process for people affected by dementia: an urgent call to end exclusion in mental health service delivery in the United Kingdom

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Commentary on “Equity in care and support provision for people affected by dementia: experiences of people from UK South Asian and White British background”. By James et al.

James *et al.* (2023) focused on equity in care and support for people affected by dementia in the United Kingdom, drawing on experiences of South Asian and White British ethnic groups who were people living with dementia, family carers, and clinicians from eight memory clinics across four United Kingdom (UK) National Health Service (NHS) Trusts. Findings showed that irrespective of ethnicity, care preferences with regards to who provides care varied across families with limited financial resources and English language literacy being a barrier to meeting identified needs. Authors also focused on difference between clinicians’ perceptions of South Asians’ care preferences and what people affected by dementia from this community want. With the increase in ageing population globally, the prevalence of dementia in the UK is projected to increase by 80% from around 885,000 in 2019 to around 1.6 million in 2040 (Wittenberg *et al.*, 2019), their findings raise questions around the sustainability of family caregiving as existing inequities make it important to reflect on the third goal of the Sustainability Development Goals (SDG) (United Nations, 2015). This SDG goal emphasised the need for everyone, irrespective of age, to have good health and

wellbeing. Moreso, issues relating to the health and wellbeing of minoritised ethnic communities have not been taken seriously by statutory health and social care providers in the UK for too long due to lack of appropriate healthcare treatment, discriminatory treatment by staff, and avoidance of services all together due to fear of being gaslighted and lack of trust (Kapadia *et al.*, 2022).

African Caribbean or Irish ethnic minoritised group are deterred from seeking support from formal services due to issues connected with stigma, fear, and mistrust (Shafiq *et al.*, 2021), which aggravates stressors and convolutes the process of caregiving. Similarly, James *et al.* (2023) found that family carers from both White British and South Asian background valued trust and that care preferences could be prioritised or hindered by paid carers' attributes such as language, gender, religion. Considering this, they further asserted that generalisation of caregiving needs for people affected by dementia based on ethnicity is unfounded. The assumption that family carers will take on caregiving responsibility is incomprehensive, without acknowledging that the socio-economic status of South Asian population in the study limited their access to formal services while the White British population were limited by their lack of transportation for instance. Concerning the availability and accessibility of culturally sensitive services, authors interestingly found that people affected by dementia rarely referred to English language being a barrier to accessing care, but clinicians identified this to be as a major barrier. As such, carers from minoritised ethnic communities had very limited options regarding culturally sensitive care as available psychosocial support is either too far "postcode lottery", or interventions were only delivered in English language. Authors concluded that despite both populations' inclination to receive post-diagnostic dementia care and support, the nature of support varied, and South Asian communities in the UK are much more disadvantaged due to factors ranging from sparse distribution of available culturally sensitive services to not having the financial means to access additional support.

Bearing in mind that clinicians in James and colleagues' study were aware that English language was a major barrier to seeking adequate support, the assumption amongst some clinicians that minoritised ethnic communities look after their own suggests epistemic injustice, where lack of knowledge and understanding of cultural nuances play a significant role in increasing health inequities gap (Mladenov and Dimitrova, 2022). There are strong indications that encounters between clinicians and people affected by dementia could be pervaded with bureaucratic tasks, constituting 'invisible' epistemic injustices. Supporting the

assertion, Bansal *et al.* (2022) found that statutory approaches to assessment and treatments within mental health services are experienced by minoritised ethnic communities to be a major barrier to accessing appropriate services. Therefore, one can infer that statutory care plans, for those who access services, are not necessarily collaborative and are exclusive of people in desperate need, especially when post-diagnostic support for people affected by dementia seem to not take issues relating to service availability, accessibility, and affordability of care services seriously. As such, James and colleagues concluded that people affected by dementia from South Asian communities “may experience the double disadvantage of having fewer options for care that meets their needs and fewer resources to seek care elsewhere”. This suggests that minoritised ethnic communities are left with very limited coping strategies, especially when they do not have fair access to anti-dementia medications compared to people from White ethnic background (Giebel *et al.*, 2020) and are often subjected to acute, chronic and vicarious stressors (Bifàrìn *et al.*, 2021). Addressing structural and interpersonal discriminations within health and social care systems would prove beneficial in supporting everyone irrespective of age or ethnic background by addressing issues with regards to accessing appropriate help in a timely manner. Considering lack of access to care or missed care as a breach of basic human rights and an opportunity to learn and improve public health and promote social well-being, mental health services across the world must move beyond comparing health and social care unmet needs between ethnic communities to deepening their values and commitments to the population they serve. To ascertain this, it is crucial to understand meanings individuals’ affected by dementia attribute to their experiences as epistemic injustice create huge barriers associated with delivering person centred care and are a major deterrent for social participation and emancipation (Mladenov and Dimitrova, 2022).

Considering that services for people affected by dementia from South Asian communities, specifically those who are practicing Muslims, are ill-prepared and sparse, it is equally important to understand that individuals practice their religion to varying degrees within any religion and this is no different for Muslims. There is, however, a strong sense of duty to take care of family members within South Asian Muslim communities with many finding strength and patience to fulfil their duties and responsibilities to family through practicing their faith (Kevern *et al.*, 2022). Hossain *et al.* (2020) found that for South Asians communities, residential care home settings are not a feasible option to support people affected by dementia due to concerns related to communication, availability of South Asian care staff, culturally

appropriate food, and respect for cultural and religious beliefs. Minoritised ethnic carers for people living with dementia often refused external input or undervalued formal services because maintaining parent's dignity is non-negotiable. This is understandable, especially when domiciliary care workers (external support) are not necessarily afforded time to reflect on their practices, resulting into desensitised and de-personalised approach to care (Kelleher *et al.*, 2022). As such, family carers from minoritised ethnic communities would feel obligated to fulfil the role as strong familial reciprocal obligations exist in many cultures (Ugargol and Bailey, 2020). Therefore, becoming a carer may imply willingness to do so, when the person may be providing care due to a sense of obligation or lack of alternatives (Price *et al.*, 2022). For instance, where Muslim South Asian families have no choice but to navigate culturally insensitive services and discrimination, feelings of guilt could arise for them with regards to accessing external support (Willis *et al.*, 2020). Out of desperation, affected individuals may therefore feel under pressure to demonstrate willingness to care for people living with dementia and suppress feelings of stress or struggle, which could adversely affect mental health of those whose motivation to care stems from reciprocity. Even in situations where care is obligatory, having a sense of choice and control about taking on caring responsibility has been found to be protective and strongly associated with carers' well-being (Al-Janabi *et al.*, 2018). It is understandable that quite a lot of attention has been placed on Black and Asian ethnic communities in comparison to White British people due to the threads of diagnosis in the UK (Pham *et al.*, 2018). It is however important to stress that communities such as the Chinese remain underrepresented within research and are arguably, subjected to even more health and social care inequities (Baghirathan *et al.* 2018).

To ensure that no one is left behind, existing mental health model of service delivery provision requires an overhauling, as much has not changed in the last twenty years (World Health Organization, 2022). One form of exclusion from care tends to be stem from lack of parity of esteems and "culture of senseless fragmentation" in mental health service delivery, which sometimes result in services operating on the basis of coercion (Beale, 2021). James and colleagues show that getting into secondary services such as memory clinics still does not guarantee post-diagnostic support, especially if you are from a minoritised community. Health inequities are not unavoidable and putting the problem on minoritised communities to solve is rather disingenuous. As such, health and social service providers as well as service commissioners ought to make conscious efforts to address processes impeding person centred care by recognising the wider implications of orders of epistemic control, characterised by

the nature of exchanges or interaction between clinicians, carers and people living with dementia. Hence, greater focus on sensitivity of clinical assessment and care pathways through education and training is paramount, as intergenerational racial trauma might explain why marginalised social groups receive late dementia diagnosis and not engage with research activities, resulting into disproportionate adverse repercussions.

Existing dementia training and education for health and social care staff appears to have limited impact on behavioural change (Parveen *et al.*, 2021). As such, staff must be trained and better supported in their roles to provide timely services irrespective of minoritised ethnic communities' English language proficiency, plan care holistically with people affected by dementia, provide services that are sensitive, prioritise care preferences and ensure that services are easy to get to. Considering this, setting research priorities with minoritised ethnic communities would aid the understanding of cultural nuance and improve recruitment to research studies. As much as insider perspectives are needed to advocate adequately for people who are often marginalised and generate rich data, it is equally important that they are given social power and actively supported to translate evidence to practice. Concerning health and social care service design and delivery, resolving issues of availability, accessibility, and affordability of care services would improve family carers' experience, especially as there is a relationship between 'being prepared' and 'being willing' to care (Parveen *et al.*, 2018). A concerted multidisciplinary approach is desperately needed to sustain initiatives such as the NHS England 'Core20plus5' strategy, to reducing health inequities.

The study by James and colleagues underscores the pervasive nature of injustice in mental health work. Given that health and social care environments can be complex, the culture within it predicts care outcomes. Future studies will need to move beyond understanding inviolable distinctions between ethnicities to paying close attention to intersections between culture of exclusion in mental health work, religion, ethnicity, and macro level of oppressive structures to move this field forward. Given that family structures across cultures are different, cultural competence of health and social care staff needs to be addressed to enable the success of a population approach to health, which organisations are aiming to adopt to tackle health inequalities. Further, understanding of epistemic dimension of experience and intrinsic means limiting care and support options for everyone would be crucial the ambition of NHS long term plan, which is geared towards "doing things differently".

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