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**Cultural Perspectives and Needs in Dementia Care: Dialogues
with African and African-Caribbean Communities in Nottingham**

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ABSTRACT

Introduction: Ethnic minority communities in the UK experience persistent inequities in dementia care, including underdiagnosis, lack of access to culturally appropriate services, and systemic exclusion from research. Initially conceived as a study on eHealth and intersectionality in dementia, this Niels Stensen Fellowship project evolved in response to community engagement, centring the voices and lived experiences of Black African and African-Caribbean communities in Nottingham. This study aimed to reflectively explore how these communities understand dementia, identify their priorities and challenges, and reconceptualize "needs" through participatory, community-based dialogue using the theoretical frameworks of Paulo Freire and Max-Neef.

Method: Two dialogue events were held in collaboration with a local African-Caribbean church and African community centre, involving 38 participants. Conversations focused on experiences with dementia, caregiving roles, stigma, cultural meaning, intergenerational dynamics, and the evolving needs of community members. Inductive thematic analysis of transcripts was followed by a short theoretical analysis applying Max-Neef's taxonomy of fundamental human needs.

Discussion: Participants voiced widespread mistrust of formal care systems, highlighted gendered expectations around caregiving, and articulated a strong desire for culturally embedded, relational models of dementia support. The experience of dementia was often shaped by cultural expectations and gender roles, and viewed through relational and intergenerational lenses. Needs were expressed not just as service gaps but as unmet existential and axiological needs for affection, protection, identity, participation, and freedom.

Conclusion: This study challenges the dominant biomedical and Eurocentric frameworks in dementia research. It underscores the importance of dialogical, community-driven approaches that value lived experience and cultural specificity. Public health practice must go beyond inclusion rhetoric to genuinely co-create knowledge and services with communities. Emancipatory dementia care demands trust-building, reflective listening, and recognition of evolving needs grounded in human dignity.

Key words

Dementia; Needs; Culture; Ethnicity



INTRODUCTION

Background

Dementia and ethnic minorities

Compared with the White indigenous population in the United Kingdom (UK), Black African and African-Caribbean communities people have a higher prevalence and earlier onset of dementia (1, 2). A systematic quantitative review has shown minority ethnic communities' presentation to dementia services is lower than in the indigenous population in the UK and other English-speaking countries (3). Potential explanations for this disparity include stigma around dementia, fears around bias and racism, historic discrimination in health services, cultural perspectives on cognitive ageing, and a lack of appropriate dementia services that meet diverse needs (4). Appropriate, culturally-informed, and co-designed community-based support services could help people with dementia and their carers from ethnic minority backgrounds by enhancing their social engagement, improving their wellbeing, and helping them live at home longer (5). While there has been some recent research exploring perspectives on dementia within these communities (6, 7), there has been limited focus on reframing and co-designing dementia services to meet local, community needs. It is crucial to explore these needs, to design services that meet the identified needs from the ground up, rather than adapting existing services that were developed to meet needs identified in very different contexts (7).

Theoretical Grounding

Mainstream dementia service research often reflects biomedical and Eurocentric frameworks that frame needs in terms of service gaps and care burdens. But such frameworks are limited in their ability to capture the nuanced, culturally-specific ways in which dementia is experienced and discussed in Black African and Caribbean communities. Brazilian educator and philosopher Paolo Freire's pedagogy (8) emphasizes that knowledge is co-created through dialogue and critical reflection, especially among marginalized groups whose voices are often excluded from formal knowledge systems. He argued that only through conscientization - becoming aware of one's social, political, and cultural reality - can people begin to transform it. Complementing Freire, Max-Neef's Human Scale Development model (9) helps us understand these realities. It shifts the concept of 'needs' away from material deficits toward a system of interrelated existential and axiological needs. Existential needs reflect ways of being: subsistence, protection, affection, understanding, participation, idleness, creation, identity, and freedom. Axiological needs refer to ways of expressing those: being, having, doing, and interacting. This model became a useful interpretive lens for the rich data generated through our dialogue events.



Aims

This study aimed to reflectively explore how these communities understand dementia, identify their priorities and challenges, and reconceptualize "needs" through participatory, community-based dialogue using the theoretical frameworks of Paulo Freire and Max-Neef.

METHOD

Study design

Two dialogue events were held in April and May 2023 in Nottingham, one with members of a Black African-Caribbean church (n=13), and the other with members of an African community centre (n=25). Participants ranged in their experiences. Topics included awareness and understanding of dementia, caregiving roles, access to services, cultural beliefs, intergenerational relationships, and technology. No demographic data was collected, in line with the trust-building aims of the research.

Recruitment

Participants for the dialogue event with the African-Caribbean community were recruited through flyers disseminated via a local (largely African-Caribbean) church and local (largely African) community organization. Inclusion criteria were: (i) being a member of the local Black African and Caribbean community, and (ii) be willing to share your experience (first or second hand) on dementia and healthy ageing. People with dementia were not included in these community dialogue events, as they focused on perspectives of the community for dementia support.

Informed consent

Ethical approval for the study was granted by Nottingham Trent University. After several introductory visits to the community centres, to build trust and familiarize ourselves with the population and their activities and interests, all participants were provided with study information and signed an informed consent form prior to data collection through the dialogue events.

Study population

There were two dialogue events. One was with the African-Caribbean community (n=13). One was with the African community (n=25). Given the nature of this research project and its integration into existing community events, no additional demographic data was collected on the participants, to aid in fostering trust and reducing barriers to participation. In both groups, some participants had experience of caring for a loved one with dementia, while some did not (though could provide their own perspectives on community needs for dementia care).



Data collection

The dialogue events were audio recorded and transcribed verbatim. The dialogue event with the African-Caribbean community was 1 hour and 46 minutes long and took place in English. The dialogue event with African community was 52 minutes long and took place in English and in Portuguese, while a translator simultaneously translated all contributions in Portuguese to English.

Topics

Appendix 1 contains the topic list for the dialogue events.

Data analysis

Authors HC and ER independently coded the transcripts using inductive thematic analysis (10) in NVivo. Both coders independently coded the dialogue event transcripts and inductively structured these codes into larger subthemes and themes. Any differences in coding or interpretation were resolved in a consensus meeting with co-author PS.

RESULTS

Themes

The inductive analysis of the dialogue events resulted in three themes, subdivided into categories (Table 1) and illustrated by quotes from the participants (Ps).

Inductive themes	Categories
Needs in the community	Staying active and connected
	Awareness of dementia
Needs in informal care	Access to care and support
	Unequal impact
Needs in formal care	Personalized care
	Distrust in care homes
	Culturally specific care
	Evolving dementia care

Table 1. Inductive interview themes

Theme 1: Needs in the community

Awareness

In both events, participants talked about how they felt there was a lack of awareness in their communities on what dementia is, and how it might be different from normal ageing. Participants made clear that there is much variation in views on dementia and the extent of dementia care services within the African continent.

"We didn't know how long it was; we didn't know how long it was going to last for, and why he was having it. It was really scary. A lot of people think it's an old age thing. So, we automatically believe anybody ageing should have it. But my great grandmother, she didn't have it, she could remember things you know, so it was really scary." – P2.4, African community

One participant, who was from the Southern part of Africa, said that there is not much institutionalised care. As a result, culturally, the responsibility to care for and protect his elderly relatives was individual and fell only to him, not the state.

Finally, in both events (without being prompted), participants stressed the potential of the built environment to foster or inhibit connection with people with dementia in the community. The built environment (e.g. how buildings and communities are designed) does often not fit the needs of older people to go outside, interact with other people and retain independence. In the Caribbean the built environment is often more conducive to fostering connection:

"It wasn't a close one but it was still a family member who came and did that, who needed the money - paid. And they did get them up in the morning, wash them and they will go and sit on the veranda. They will sit on the veranda all day till sundown. So, if you lived in that house, you could still live. But now we're in these little square boxes. And looking at it I thought, nothing is actually constructed for older age or for extended families that want to care for each other. It is making everything more difficult." – P1.3, African-Caribbean community

Staying active and connected

Participants in both dialogue events described the importance of staying active as a way to age well within the community. In the African dialogue event, participants explained that stopping your work routine after 40 years is very challenging and it's hard to stay mentally stimulated. Participants said that they felt that spending time together could help with dementia symptoms, by activating memories and playing games the person with dementia used to play. The types of games that work for this are very culturally-specific. This is also

true for art and movies. For the Angolan community, it was important that these activities are available in Portuguese.

"Activating past memories, whether it be games that they used to play, everyone will have different ones. So, she went to a group where it was mainly for English speaking. But if you have family support and you like this art or if you like this movie when you were younger, they can help activate those memories." – P2.2 (via translator), African community

These participants also said they found it important to have a sense of purpose. After retirement, this can be grandchildren or traveling. Technology is used often by this group to combat loneliness and stay engaged, as family is often not in one place anymore, especially in these communities. Examples of these types of technology include social media (such as Facebook) and group chats (such as WhatsApp), which can be used to chat with loved ones.

"The others spoke about artificial intelligence. Having the ability to speak to technology and it responding back has been very helpful. So, it seems that this age group may or may not be associated with like shopping lists on the internet, but this is what is keeping them engaged. Those times where loneliness kicked in." -P2.1, P2.3 (via translator), African community

Theme 2: Needs in informal care

Access to care and support

First, participants in the African-Caribbean event told us that they did not identify with the term 'carer', as they see themselves first as someone who loves someone with dementia.

"I actually wouldn't even refer to myself as a carer. It's just a term I've got to use because other people seem to have an understanding" – P1.3, African-Caribbean community

When it came to accessing care and obtaining a dementia diagnosis, both groups reported significant barriers.

"Even when my mum got diagnosed, doctors still didn't take you seriously, because Mum was very composs mentis. If you sat here and said, what did you do today, and she could tell you and then if you ask five minutes later, she couldn't tell you. And because when I asked them for care for my mum, because I was doing it, they were happy to leave me to do it and let me burn myself out." – P1.1, African-Caribbean community



Unequal impact

Participants stressed how usually daughters would take on the majority of the burden of care, and it is assumed they will do so. This intersection surrounding the gendered division of care work was prominent in both communities.

"In our culture if you are the oldest and you're a girl then that's it. Even though I was married with kids and that, that didn't seem to matter. I don't think my mum meant to do that. But it's their expectation, cultural expectation, and it was made clear." – P1.4, African-Caribbean community

Participants described the relational impact of being the primary carer of someone with dementia in their communities, further illustrating the gendered vision of caring labour and the unbalanced sacrifices made by women to provide dementia care, in this cultural context.

"I've got two grandkids that I never saw for about five years. My life was dedicated to my mum, and I even said to my partner at the time, I can't give you none of my time. Because my time is for my mum. She's on limited time now. And I want to spend 100% of my time with my mum." – P1.1, African-Caribbean community

Technology to support informal care

Participants also described technologies as ways to get personalised support. They explained that they were already using different forms of technology such as cameras for monitoring their loved ones remotely and keeping in touch via speakers. They also described attending online courses and seminars to learn how to deal with dementia in their specific situations, YouTube, audiobooks. However, there was a concern around the quality of dementia information on the internet. It was clear that it is hard for participants in these communities to know what information to trust. There were also worries about issues with safety and security and having to create and remember many passwords.

Theme 3: Needs in formal care

Distrust in formal care services

In addition to the described challenges around trusting information accessed through technology, this topic of distrust also extended into distrust of formal care services. Particularly in the African-Caribbean community dialogue event, participants expressed that they could not trust care homes to look after their loved ones.

"It's not a natural thing within the Black culture" – P1.8, African-Caribbean community

Several participants described instances of relatives with dementia being neglected and their safety not fully secure.

"I booked her in on the Monday and this was the Thursday morning she hadn't had a shower, she hadn't cleaned her teeth, she hadn't changed her clothes and they said to me how do you know and I took pictures the toothpaste is still got that little seal on, the flannel still have the price tag on it. Mum's armpits smelt like I don't know what. - P1.1, African-Caribbean community

Also, participants described the financial aspect of formal dementia care and the mistrust they felt at how their relatives were approached after diagnosis.

Participants from Western and Southern Africa repeated that looking after older family members is the individual's and the family's responsibility.

"You will be viewed or seen as an uncaring child, ungrateful child if you keep your parents in a care home, despite all the sacrifices they put on you while you're growing, so we don't really do that. And now that is kind of putting a strain on people, because, like somebody said, the times are changing. It's no longer those days when people go to farm or people just you know just communal, now people are going to work, people stay longer at work in traffic."
– P2.5, African Community

However, nowadays, family care is hard to combine with work responsibilities, so sometimes there is no care available for them. Moreover, the life expectancy is around 65 in certain parts of the African continent, so it is rarer to see very old people. In that sense, dementia is a new thing in many African cultures. They expected that this will change, as more medications and technologies are becoming available.

Personalised care

Participants expressed a need for personalised support, which can only be achieved by building a relationship with the formal dementia care services:

"I think improved carer support services, where there is more consistency in the people who come, so you can develop a better relationship and where there is a shared culture, so there is more of a dynamic really between my mom and the carer and it's not just them coming for 25- 35 minutes carrying out actions. I mean, ideally it would be nice if we could pay for one or two people, the same people." – Participant 1.3, African-Caribbean community

Culturally-specific care

Participants also expressed a need for culturally-specific care. Participants felt that care professionals seemed to find it difficult to talk about culturally-specific

aspects of dementia care, so they often avoid the topic entirely. Participants said that they would like it if care professionals were able to have culturally-informed conversations with those caring for people with dementia. They provided specific examples, such as knowing how to show respect, like taking shoes off at the door and avoiding taboos, not sitting inappropriately on a bed with outside clothes on, treating people with dementia as extended members of family e.g., calling elderly patient's 'Mummy'. Participants stressed that these behaviours are crucial for care professionals to build trust with people with dementia, carers, and their loved ones

"I know, because I used to be a social worker and that was part of my course, to be aware. Yes I was aware of my culture, I was aware of Asians, I was also aware of Bosnians, Europeans etc and that helped with relating with my clients. I worked with young offenders but also with their parents and to order in how you actually speak to an individual and how you sit etc." - P1.12, African community

Participants expressed a desire for culturally-appropriate services for the Black African-Caribbean community (such as respite services), professionals who really listen, better housing, and improved culture awareness training for professionals. There is a need for places that provide African and African-Caribbean food and haircare.

Evolving dementia care

Finally, it is important to emphasize that needs and perspectives on care are always changing. Traditionally, dementia and elderly care would often take place within the home. Participants expressed that things might change and this might not be possible in modern times, but it is still their preference. However, some people are now informing their children that they understand the situation is different now. Participants also expressed concern about anticipating the needs and wishes for future care of members of the community (including themselves), who may not have large families close by.

"Can I say, in 10-15 years' time, those of us born in the 50s and 60s will be looking for support, we do not have families of six, seven or eight children. Our parents have managed to get support because they could choose out of six, seven or eight, so this is a quite crucial thing in the next five or ten years." - P1.3, African-Caribbean community

Theoretical analysis

Applying Max-Neef's framework allowed us to analyze these needs not as hierarchical (as in Maslow's model (11)), but as interrelated and contextual. For example, lack of culturally-appropriate care homes is not only a material problem

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(subsistence) but affects emotional well-being (affection), autonomy (freedom), and cultural continuity (identity) (12). Similarly, Freire's focus on dialogue helped us uncover how communities interpret and respond to dementia in ways that differ significantly from mainstream narratives. "Needs" in this context are not fixed but evolve alongside social and cultural change.

DISCUSSION

Main findings

This project offers critical insights into how dementia is experienced in communities that public health systems often overlook. Needs are not simply service gaps but expressions of cultural identity, emotional connection, and systemic trust or mistrust. An important finding of this study was that communities feel that there is an urgent imperative to anticipate their own future care needs, in light of changing demographics and their own evolving cultural perspectives.

Developing tools to satisfy the identified needs

It is important to consider how the identified needs might be satisfied. In his theory, Max-Neef discusses 'tools' which can be used to achieve satisfaction of certain needs. A first tool that could be used achieve satisfaction, concerns the expressed need for more *awareness* of dementia (axiological needs understanding and affection). This is in line with previous research on Black African and African-Caribbean communities' perspectives on dementia (13). Future dementia services research should focus on developing new, culturally sensitive training resources for dementia care professionals (such as case managers), to empower them to have conversations about dementia with their clients. This is in line with previous recommendations on culturally competent mental health and dementia care (14). Person-centred support for care professionals will in turn facilitate person-centred care and improve dementia services (15, 16). In developing these training resources, it is important to prioritize an inductive, community-based, and emancipatory approach, rather than a traditional public health where one group is "educated".

A second tool to achieve the satisfaction as identified in the secondary analysis, could include addressing participants' need to achieve better *signposting* of culturally specific dementia care services (axiological needs subsistence and protection), also in line with previous research with the UK's largest minority ethnic communities (17). Building on this need, future research should develop maps of culturally-specific dementia care services, to identify gaps and help care professionals to signpost relevant services. Participants recommended that specific services could include the respite services and the development of better built environment projects for dementia.



Finally, in order to satisfy the identified needs around *evolving* dementia care needs, it is essential to develop tools that avoid reducing communities to one set of recommendations or preferences, and keep involving and interacting with communities as time goes on. Participants indicated that norms change from generation to generation. This is especially true in the context of immigration and assimilation to a new culture (18, 19). In this sense, this small research study is just a 'snapshot in time'. Continuing application of community-based participatory research principles (20) can help researchers develop tools to satisfy evolving needs.

Implications for Public Health in Practice

Based on these findings and our reflections, we have formulated several implications for co-designing future community-led, participatory dementia care services with Black African and African-Caribbean communities:

1. Move beyond culture as a variable: Culture should not be treated as a demographic factor to be addressed by add-on services. It is a lived, evolving practice that shapes how people interpret, respond to, and cope with dementia.
2. Invest in relational research: Community-based, participatory, and dialogical approaches are essential. These allow for deeper insights that challenge dominant frameworks and centre the voices of marginalised groups.
3. Design culturally embedded services: This includes food, language, music, and spaces that reflect communal ways of living. It also means training professionals to understand and respect these dimensions.
4. Plan for evolving needs: Services must be responsive to generational changes within communities, recognizing that future elders may have different needs than their parents.
5. Build trust through presence: Familiarisation phases and long-term relationships, rather than extractive research practices, build trust. This is essential for both research and service design.

Strengths and limitations

As this was an exploratory study with two interested community organizations, it is possible that data saturation was not reached and more than two dialogue events are necessary to fully capture community needs for dementia support. Moreover, as we collaborated with local organisations who have a very varied membership, our sample is also very heterogeneous. Even within the African-Caribbean community or within the African community, there are many cultural, demographic, and societal differences within these groups, which we not fully able to do justice to in this limited study. We did not collect any demographic



data (e.g. age, occupation, years of experience in dementia care). This approach was chosen as it afforded complete anonymity and aided the building of trust. Having this data may have allowed us to discuss more from an intersectional perspective. Nonetheless, we noticed several overlapping themes between the populations present at the dialogue events.

CONCLUSIONS

This study emphasizes the critical importance of adopting community-based approaches to effectively address the diverse needs of Black African and African-Caribbean communities in dementia care. Through the combined lens of Freire and Max-Neef, we were able to frame the dementia service needs of Black African and African-Caribbean communities as human, contextual, and culturally embedded. These included an urgent imperative to anticipate their own future care needs, in light of changing demographics and their own evolving cultural perspectives. Future dementia care initiatives should prioritize the development of tailored services for these communities, including evolving, culturally specific training for dementia care and adequate signposting of these services to accommodate cultural needs.

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HC, CF, and PS designed the study, with input from ER. HC, ER, CF, and PS collected the data together. HC and ER performed the analyses. HC and ER prepared the initial manuscript for publication, under guidance from PS. All co-authors reviewed and approved this manuscript.

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