

CLAHRCBITE

Brokering Innovation Through Evidence

How can we improve dementia care in UK black elders?



Black elders dismiss the warning signs of dementia until the condition becomes too severe to ignore or a crisis strikes. They are also less likely to receive a diagnosis of their condition, resulting in delayed treatment and less time to plan for the future.

This is of great concern for black families whose older relatives are more likely to develop dementia than their white counterparts, and for health professionals who strive to improve the care of their black patients.

By working together with patients and the public we aim to promote early help-seeking for dementia in black African and Caribbean families.

What was the aim of the project?

Because we know that a group culture guides its members' understanding of and behaviour towards health and ageing, we first set out to understand the cultural factors influencing how black adults respond to the warning signs of dementia.

We then devised an instrument rooted in what members of the black community told us that promotes early help-seeking for dementia. To finish, we compared black elders' evaluations of the instrument against another that was not specifically designed for a black audience.

What did we do?

The full project comprised 3 phases:

In phase 1, we held multiple qualitative interviews and focus groups with 50 African and Caribbean adults with diverse socio-demographic characteristic and from different background in an attempt to identify barriers and facilitators to seeking help for dementia.

In phase 2, we used interviewee's responses to tailor an intervention targeted at a black audience, which we later refined by incorporating feedbacks and comments from dementia patients and their carers, volunteers from the public, clinicians and experts in the treatment and research of dementia.

In phase 3, the intervention, which consisted of letter and a leaflet, was trialled with GP registered patients, who were asked to rate it and evaluate its effect on their intention to seek help from their doctor.

What we found

We found that it is feasible to devise an acceptable and inexpensive public health resource to encourage timely help-seeking for dementia specifically designed for black elders. The leaflet included in the intervention is entitled “Getting help for forgetfulness”, and is available to people and organisations – NHS and community – interested in improving dementia care in black populations.

The reasons why black elders dismiss warning signs of dementia are complex and diverse and include:

- The belief that memory problems is a normal part of ageing and not important enough to warrant a call to their GP.
- The belief that dementia is a “white people” illness and does not affect black people.
- Feeling uncomfortable talking about memory problems to anyone outside their immediate social network, even to a healthcare professional.
- Difficult experiences and mistrust in healthcare professionals.
- Worries about being over medicated and the fear of lifestyle changes.
- Concerns about confidentiality, privacy, and legal consequences of information disclosure.

Nonetheless, we also found that black families are willing to accept information about dementia and welcome resources that are culturally informed and representative. Black elders also seem willing to seek help for dementia from their GP, which provides insight into the counterintuitive trend that black people do not seek help for early signs of dementia, whilst raising the alarm about possible failings in healthcare service provision.

What next?

Our feasibility trial indicates that a full scale trial is feasible and the intervention was acceptable to people.

We have developed and extended the topic into a 3-year PhD programme, which was awarded funding by the Alzheimer’s Society.

The IDEMCare Study—Improving Dementia Care in Black African and Caribbean Groups: A feasibility cluster randomised controlled trial.

Roche M, Mukadam N, Adelman S, Livingston G.

Int J Geriatr Psychiatry. 2018;33:1048–1056. <https://doi.org/10.1002/gps.4891>

Find out More

Improving the care of Black African and Caribbean people with memory problems:

https://clahrc-norththames.nihr.ac.uk/mental_health_theme/improving-care-of-people-with-memory-problems-in-black-african-and-caribbean-groups/

For the feasibility trial of the intervention, visit: <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.4891>

Berwald S, Roche M, Adelman S, Mukadam N, Livingston G (2016) *Black African and Caribbean British Communities’ Perceptions of Memory Problems: “We Don’t Do Dementia.”* PLoS ONE 11(4): e0151878. doi:10.1371/journal.pone.0151878