

Summary

Black and minority ethnic groups account for 15% of the UK and 40% of the London population. African and Caribbean elders develop dementia more often and earlier than their white counterparts, but access dementia services later in the course of their illness and often in response to crisis. Their involvement in research and treatment uptake for dementia also seem to differ from the majority population. Timely help-seeking for dementia is recommended around the globe because receiving a diagnosis allows access to therapeutic treatments and interventions which are known to be more effective in the early stages of the condition. Timely diagnosis of dementia also facilitates access to health and social care, prolongs independent living, and allows patients and carers to maintain good quality of life for longer while reducing crises and costs associated with delayed help-seeking behaviours.

We know that cultural factors about health and ageing influence how people respond to dementia and whether or not they access services. This CLAHRC funded project conducted by UCL in collaboration with Camden and Islington NHS Trust set out to understand how black families respond to memory problems, a possible sign of dementia and what prevent them from seeking help from healthcare professionals when they first notice symptoms indicative of dementia. We carried out multiples qualitative interviews with 50 black adults with various socio-demographic characteristics and from different backgrounds to identify the barriers and facilitators to seeking help for dementia.

We used people's responses to develop an intervention specifically tailored to a black audience. We then refined it by incorporating feedbacks and comments from dementia patients, carers, volunteers from the public, clinicians and experts in the treatment and research of dementia. The intervention which consisted of a letter and a leaflet highlighting the symptoms of dementia, the importance of talking to a GP about these symptoms, the benefits of overcoming barriers to help-seeking early, and listed contact details for help and more information.

We trialled the intervention with GP registered patients and they liked it. Our findings also indicated that a larger efficacy trial would be feasible (See links below for our published results).

We have made the leaflet, which is entitled "[Getting help for forgetfulness](#)" available to the

public throughout the UK through NHS, Community, voluntary and charitable organisations.

Find an online version

here: http://clahrc-norththames.nihr.ac.uk/wp-content/uploads/2018/07/RocheDL_3spreadNew_Web_030718.pdf

Findings of our qualitative study and feasibility trial can be found below:

<https://onlinelibrary.wiley.com/doi/full/10.1002/gps.4891>

http://clahrc-norththames.nihr.ac.uk/wp-content/uploads/2017/07/Berwald-et-al-We-dont-do-dementia_Plos-one_April-2016.pdf

Principal investigator: Professor Gill Livingston, UCL

Other project team members: Moïse Roche and Peter McCarthy, UCL

Start date and duration: April 2014, three years

Partners and collaborators involved: UCL, Camden and Islington NHS Foundation Trust