

MICRA Seed-corn Research Project

African Caribbean families' perspectives on aging, dementia and dementia care: An inter-disciplinary pilot study

Applicants

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Background

There is evidence that ethnic health inequalities persist into old age¹. For example, African Caribbeans have earlier onset and significantly higher prevalence of dementia (28% versus 8.7%) than white British people but access services later and with more advanced symptoms². This may be lack of dementia awareness in among African Caribbeans cause family members to label sufferers 'difficult' and blame them for symptoms³. Coupled with shame, stigma, mistrust of mental health services, and strongly-held beliefs about familial duty of care; this militates against formal help-seeking⁴. Low uptake of specialist dementia services by Black and minority ethnic (BME) groups has prompted Manchester Supporting Health Programme (MSHP) dementia project to target those at increased risk of dementia such as African Caribbeans who experience high rates of vascular, metabolic and deprivation-related risks². However, whilst the Manchester Dementia Strategy⁵ acknowledges a link between dementia and deprivation, there is little about BME-specific needs in the Joint Strategic Needs Assessment (2008–2013) <http://www.manchester.gov.uk>. This is important because more than one third of African Caribbeans in Manchester is of retirement age. As this is the first generation of African Caribbean migrants to grow old in the UK, little is known about how they conceptualise dementia, their patterns of help-seeking or views on what constitutes acceptable dementia care.

Outline

The proposed study aims to understand the reasons for low uptake of formal dementia services by African Caribbeans by exploring the relationship between their beliefs about dementia and help-seeking behaviours. Previous research by the PI has shown that African Caribbeans with depression are more likely and rely upon informal care networks (especially faith-based associations) than formal service provision⁶ but we do not know if this is the case for dementia. This study will therefore focus upon help-seeking/giving for dementia within this ethnic group; seeking to understand patterns of association within social networks and their interface with formal services. Engaging with whole families (versus solely main carers) will also facilitate understanding of trans-generational perspectives on dementia thus highlighting potential age/cohort-specific differences. In partnership with MSHP, this approach could be an important first step in developing more culturally-appropriate and accessible care both for current elders and for strategic service planning and delivery. This exploratory, pilot study will use qualitative methods with families of people with dementia (PWD). Findings from this study will inform a larger scale study in which PWD will be active participants.

Study Aim

The overarching aim of this study is to pilot methodologies for gaining insight into African Caribbeans' low uptake of specialist dementia services thus facilitating service response to apparent inequalities in access to appropriate dementia care.

Objectives

- i) To assess the feasibility of undertaking qualitative research into dementia with African Caribbean families in the context of known stigma and reluctance to disclose mental health problems in this community⁷

- ii) To explore trans-generational perspectives on dementia care and help-seeking with particular focus on the barriers and facilitators and participants' 'ideal model' of care
- iii) to explore the feasibility of including PWD in a larger study
- iv) to develop topic guides and other research tools to support a larger scale study.

Sampling and recruitment

We will recruit 6 families of African Caribbean PWD. As uptake of statutory services is low, we will recruit via: voluntary sector (such as Afro-Caribbean Care Group), local media, and community groups – focusing particularly on faith-based organisations. A recent 'Faith & Dementia' conference organised by the PI in a 'Black Majority' church (BMC) was attended by over 300 community delegates from a range of faiths and people with no religious affiliation; confirming previous reports of BMCs as 'community mental health resources' with which non-members will engage⁸.

Outline of Methods

In line with the MRC framework for developing complex interventions⁹, we will undertake preliminary, theory-building, qualitative research to generate evidence to underpin development of future funding proposals. Specifically, we will explore participants' beliefs about dementia, dementia care and help-seeking – for example, beliefs about the causes of dementia and appropriate response.

1. Using a topic guide based on existing literature and analysis of feedback from our recent 'Faith & Dementia' conference, we will interview families of PWD who volunteer to participate.
2. To test the feasibility of our methods, we will undertake both focus group and individual interviews.
3. First, we will attempt to collect data in 6 trans-generational family focus groups (4-6/family; n=24-36 participants in total).
4. However, we are aware that although they are effective means of data collection, dynamics within focus groups can hinder open discussion – particularly where subjects are emotive, carry risk of stigma and/or participants' relationships extend beyond the group. We will therefore also undertake individual interviews with family members – we anticipate this to be main carers plus one second generation and one third generation family member (n=18) depending on family configuration.
5. Finally, we will invite a purposely selected group of participants to a final focus group (n=6) in which we will i) share preliminary findings as a form of data verification ii) elicit any additional insights iii) agree and invite participation in disseminating our findings.
6. All interviews will be digitally recorded and transcribed. Data will be analysed using thematic content analysis within a qualitative methodological framework¹⁰. NVivo¹¹ will support data management and analysis.

Intended Outputs

- 1) Development of a community presentation, placing participants' 'stories' in historical and biographical context using documented and oral histories of African Caribbeans in Manchester
- 2) Production of a briefing paper for relevant community, third sector and public health organisations
- 3) Development of supporting research tools
- 4) Complete application for external funding
- 5) Publish our findings in appropriate peer-reviewed publications

Reference

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