

Older BME carers of stroke survivors

Outline of a research project
funded by the NIHR School
for Social Care Research



Improving the evidence base for
adult social care practice

How do older BME carers of stroke survivors assess and report their satisfaction with social care services?

Service users' satisfaction with services is an important element of measuring service quality. However, there is evidence from health and social service satisfaction surveys that users from minority ethnic (BME) groups may describe themselves as less satisfied than users from majority White British groups. It is important to understand the reasons behind these findings in order to ensure equity of access and that the needs of all groups are met.

There are a number of possible, potentially overlapping, reasons suggested for the variation in satisfaction with social care services. These include differing experiences, expectations and interpretations of what satisfaction or dissatisfaction means.

Informal carers are an important relatively poorly investigated group here. In particular, a significant, growing demographic group are BME carers. Further research is required so that the needs of all of Britain's multi-ethnic population are met. This study will focus on older carers (aged 50+) supporting stroke survivors in their homes from Black African, Black Caribbean, Asian Indian, Asian Pakistani and White British groups.

This project

- seeks to improve understanding of expressed satisfaction with social care (including social services and third sector support) reported by BME stroke carers and White British stroke carers.

It aims to

- improve understanding of how stroke carers from different ethnic groups evaluate social care
- increase understanding of how factors such as language, terminology, cultural expectations, access to services and variations in experience influence satisfaction ratings
- determine the best ways to gauge satisfaction with services from a range of ethnic groups
- enhance carers' experiences of care services by disseminating findings back to practitioners in social services via reports and peer reviewed publications.

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WHAT IS THE CONTEXT?

Monitoring service user satisfaction with health and social care has been accepted as an important means of assessing service quality, as an outcome measure and as a basis for improving services. However, little is known about the impact of cultural factors on satisfaction with services.

Research has demonstrated that expressions of satisfaction vary with different demographic groups, but the findings are inconsistent. For example, some research has reported greater satisfaction with health services among some ethnic minority groups, but this can vary with specific disease groups.

These findings raise questions about the influence on respondents of survey language, perceptions of terminology and reporting, cultural expectations of services, access to services and support, and different experiences. Such factors are currently poorly researched in relation to the findings of satisfaction surveys. A better understanding could be obtained by asking participants to explain why they responded in the way they did to survey questions and to describe their experiences of services. This project will take such an approach.

In selecting a group to investigate, this study took several factors into account. Older people make up the largest group of social service users but, compared with investigations of satisfaction with health care, there is relatively little research about older people's experiences and satisfaction with social care including third sector services. An increasingly important sub-group of older service users are people from BME communities. They can be especially disadvantaged and are more likely to experience difficulties in accessing services. BME communities are known to be under-represented in mainstream services and often they may only come to the attention of services when they reach crisis point. The expectations and experiences of these groups are particularly under-researched.

Additionally, in England there are over 900,000 stroke survivors and approximately half of them are dependent on others for everyday activities.

Support comes primarily from spouses, families and friends. In long-term conditions such as stroke, where carers play such an important role, it is important to investigate carers' satisfaction with services. Despite this, there is little research here.

Compared with White British patients, stroke incidence and mortality is higher among Black groups so older BME carers of stroke survivors form an important sub-group. Research shows that Asian carers provide proportionally more care than White British carers putting them at even greater risk of the adverse effects of caring including poor physical health, social isolation and unemployment. Pakistani and Bangladeshi women provide significantly more care than other ethnic groups.

This project seeks to help address the evidence gap on the role of ethnicity in evaluations of carers' satisfaction with social care services. This will help social care systems understand how to be responsive to population diversity and to the needs of all individuals, regardless of background.

HOW WILL THE PROJECT WORK?

This study will carry out in-depth, focussed qualitative research on expressions of satisfaction and dissatisfaction with social care services by older BME stroke carers.

STAGE 1: Recruitment of participants

Older carers of stroke survivors who receive of care services will be recruited from several sources, including voluntary sector organisations and neuro-rehabilitation. Among these organisations will be Crossroads, Carers Support Merton, the Carers Trust, Stroke Association support groups and carers of patients discharged from inpatient neuro-rehabilitation after stroke.

STAGE 2: Focus groups

The main methods used will be focus groups and interviews. Initially there will be five focus groups with stroke carers, one for each ethnic

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group – Black African, Black Caribbean, Asian Indian, Asian Pakistani and White British – with four to eight participants per group. The main aim of the focus groups will be to inform the development of the topic guide for the semi-structured interviews.

STAGE 3: Interviews

Up to an estimated 80 stroke carers from the five ethnic groups will be interviewed. Participants will be matched for gender, age, whether they co-habit with the stroke survivor, and funding sources (whether self-funders or other).

Carers will be asked to complete two service satisfaction questionnaires, which will be translated if necessary. These questionnaires will be structured and contain closed questions (requiring only Yes/No responses or satisfaction ratings). One of these questionnaires is likely to be the eight item Client Satisfaction Questionnaire (CSQ) which is a very general satisfaction with services scale. It has been widely used and has well established validity and reliability. An additional suitable scale will be identified at a later date.

While completing these, participants will be asked to 'think aloud' – a style of interviewing referred to as cognitive interviewing where participants explain the reasons behind their responses. Cognitive interviewing uses both prepared and spontaneous probing, based on the interviewers' observations, plus the prepared topic guide about previously agreed items that need probing.

A retrospective probing technique will be used for each satisfaction item whereby participants are asked questions about satisfaction with services, and their answers recorded; the interviewer then returns to each question and asks the respondent how they understood and answered it. In this way this process will explore how the questions are understood by participants. The services of a translator will be offered to participants.

Participants will also be asked to describe positive and negative experiences of social care using the critical incident technique. This approach focuses on specific experiences that participants regard as good or poor and may make it easier for them to criticise services.

Together these methods will allow exploration of what stroke carers from minority ethnic groups mean by satisfaction or dissatisfaction with social care and the influence factors such as experience, language and differing expectations may have on satisfaction.

STAGE 4: Analysis

Researchers will use conventional content analysis and narrative analysis to maximize understanding of the carers' perspectives. Among the aims of the analysis will be to:

- compare BME and White British stroke carers' expressions of satisfaction and dissatisfaction with social care
- compare BME and White British stroke carers' experiences of social care
- identify aspects of social care that BME stroke carers find satisfactory and unsatisfactory.

Conclusions will be drawn on how stroke carers from different ethnic groups evaluate social care and the influence of language, terminology, cultural expectations, access to services and variations in experience on satisfaction.

Project publications

Findings will be disseminated through organisations such as Age UK, the Stroke Association, the Carers Trust and the Academic Health and Social Care Network. An executive summary of the main findings will be sent to participants, user groups, and other main stakeholders. Findings will also be published in peer-reviewed articles in academic and professional journals.

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HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

This project's qualitative in-depth investigation of factors influencing differing levels of service satisfaction among older BME carers of stroke survivors will improve understanding of client satisfaction and dissatisfaction among these carers.

A better understanding of carers' expectations, and the identification of what participants see as important when evaluating services, will provide guidelines for practitioners, and facilitate the development of culturally sensitive, responsive services. The findings will also be of interest to carer and stroke organisations.

As many experiences and expectations of services are likely to be common to all ethnic groups, this research has the potential to influence and improve services across all ethnic groups. Therefore the research will be valuable to a range of providers and commissioners and will have widespread relevance.

The Research Team

The research team has considerable research experience with older people and carers.

Dr Nan Greenwood, Senior Research Fellow at the Faculty of Health, Social Care and Education, St George's University of London and Kingston University, will lead the project and has previous research experience with carers of stroke survivors and with minority ethnic groups.

Ann Bowling, Professor of Health Sciences at the University of Southampton, will be actively engaged in advising on the research processes and will collaborate with the team on interpretation and outputs.

Gill Mein, Senior Research Fellow and Senior Lecturer at the Faculty, will be involved both in data collection and analysis.

Dr Geoff Cloud, a consultant stroke physician at St George's Hospital and Senior Lecturer at St George's University of London, will facilitate the development of the research and interpretation of the findings.

Project title:

A qualitative exploration of ethnic differences in satisfaction with social care amongst older carers of stroke survivors

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£272,877

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