

# Talking to carers of stroke survivors to understand ethnic differences in satisfaction with social care

**There are approximately 1.1 million stroke survivors living in the UK and more than half are dependent on others for everyday activities. We are comparing the experiences of stroke carers from different ethnic groups to understand different expressions of satisfaction with social care.**

When considering the carers of stroke survivors, it is clear that ethnicity is important. In the UK, for example, the incidence of stroke is estimated to be more than twice as high in some black and minority ethnic communities compared with their white counterparts. The reasons are various, possibly related to high blood pressure in some groups, with genetic factors probably also playing a role. There are many implications, not least that people from black and minority ethnic (BME) communities are more likely to have strokes and therefore also more likely to have the support of carers.

The increased use of clot-busting drugs for stroke survivors – reducing the likelihood of death and long-term disability – is having an impact. Nevertheless, the diversity of disability after stroke is greater than for any other condition and the numbers of people needing care remain large.

Stroke also can produce a very particular profile of caring. For example, with dementia, people tend to grow into caring as they look after someone with a condition that often has a gradual onset and decline. However, stroke is sudden and survivors' and carers' lives can change



dramatically. Overnight a person may find themselves taking on role that they may never have considered and in which they may have had little practice. Such stroke carers are very important, saving the economy an estimated £2.5bn a year.

The need for more insight into this field explains why a team from St George's University of London and Kingston University is studying older carers (50+ years) supporting stroke survivors in their homes from Black African, Black Caribbean, Asian Indian, Asian Pakistani and White British groups. They are

*'At lunch time, the care worker might come in and have a 20 minute slot to prepare a person's lunch. But if the person has to go to pray and she has also got to go and do her wudu (washing herself) and she needs a bit of help...'*

An Asian participant in focus group

looking for reasons why previous surveys have suggested that satisfaction with social care services is lower in general among these groups of carers than for their majority white British counterparts. This study is ground breaking because little research to date has been done about stroke carers from BME backgrounds, says Dr Nan Greenwood, who is leading the team.

She adds: 'A lot of the evidence I have found about general dissatisfaction among BME groups concerns issues that cut across all ethnic groups. For example users say: "I can't get hold of anyone, no-one answers the phone or I can't get there because it costs too much to get to the day centre or the day centre is not open at the right times". However, we also hope to identify specific issues for BME carers.

'We are using a cognitive interviewing technique called 'Talk Aloud'. You ask someone to fill in a questionnaire on satisfaction and, as they fill it in, they explain why they have said that they are, for example, "very satisfied", "satisfied" or "not satisfied". This helps us to understand the meaning of what they say. We will also ask a White British group for comparison. We are trying to understand what the term "satisfaction" means because it could be that different

satisfaction reflects different expectations. For example, someone from abroad might hear we have a great system and then they feel disappointed.'

The team is also using the 'critical incident technique', where participants are asked to provide an example of good care or some examples of a really poor service. Dr Greenwood explains: 'This gives people the opportunity to highlight what they like and don't like. It gives them licence to complain. Often people feel uncomfortable otherwise. They feel they are getting a free service so they shouldn't complain as they know a care worker may be under stress or they fear retribution because they have complained.

'I hope our study will unpick what works well and not works well. We will try to avoid the word "satisfaction" on its own which is problematic. We aim to give the perspective of carers rather than forcing a questionnaire on them which may not actually mean a lot to them. Then we can use what we find out and take it back to practitioners and sort out some solutions.' It is hoped the research will lead to the development of guidelines for practitioners, facilitate the development of culturally sensitive, responsive services and improve measures of service satisfaction.

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

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