People from minority ethnic groups may have a need to use social care services, but have had difficulty finding out about services due to language barriers and cultural differences.

Many people struggled to find out how to access social care services in the first place.

There were both differences (e.g. language issues) and similarities (e.g. the importance of care staff having a kind manner) between South Asian and White British service users and family carers.

People with a good understanding of the social care system were more in control of their care.

People with a poor understanding were uncertain about how to access further care, or why a service had been refused or withdrawn.

More White British than South Asian people had a good understanding of the social care system.

Main recommendations include: thorough assessments, language needs being met, accessible named social care staff and better communication to service users and family carers throughout the whole social care process.

This study aimed to meet with people from South Asian groups and conduct in-depth interviews to explore their experiences with social care services. A White British comparison group was also interviewed to see how similar or different their experiences were to those of the South Asian participants.

The project aimed to suggest improvements for the benefit of both groups.

The study took place in Hampshire, Southampton and Portsmouth, where there is a sizeable population of South Asian people.

METHODS

Individual in-depth interviews were carried out with 121 participants, comprising 46 service users, 36 family carers, and 39 social care practitioners. Within the service user and family carer groups 39 people from South Asian backgrounds and 43 people from White British backgrounds were interviewed. The practitioners were from a range of ethnicities.

The interviews explored participants’ experiences with social care services and
their opinions for the future improvement of services.

SEEKING HELP

Participants were asked how they had come into contact with social care services. Four types of help seekers were identified: medically-focused, word-of-mouth, enablers and informed. Participants from both the South Asian and White British groups were found in all categories.

The medically-focused participants believed that the general practitioner (GP) or hospital was the appropriate place to find out about social care services. However, some reported that they had not been able to find the information they sought from these health services.

The word-of-mouth participants had not known how to get in touch with social care services in the first place, and had only found out through conversations with friends or relatives who already knew about them.

The enablers helped other people to access services by passing on information.

The informed participants were more aware of how to find out about services and some used the internet to look for quality ratings.

The most common strategies were word-of-mouth, which is dependent on knowing the right people, and medically-focused, which was not always successful. A key finding was that many participants did not know how to ask for help from social care services. Furthermore, even though participants had accessed one type of service, many were unsure what else was available.

DIFFERENCES BETWEEN SOUTH ASIAN AND WHITE BRITISH PARTICIPANTS

Differences between the experiences of South Asian and White British participants fall into two main aspects: (i) aspects specific to being part of a religious, linguistic, ethnic, and/or cultural minority, and (ii) aspects related to understanding the social care system.

Specific issues – South Asian participants

- South Asian participants emphasised that language needs should be met within social care services, but these needs were not usually met within mainstream services. For example, one family carer reported that his Punjabi speaking mother was unable to tell the English speaking domiciliary carers that she needed a painkiller. Culturally specific services or language-matched practitioners were preferable. Another family carer chose a respite service where Punjabi speaking staff worked in order to ensure his father would feel more comfortable.

- A wish for appropriate food was expressed strongly. The definition of ‘appropriate’ food varied considerably depending on the religious background of the participants. Many Hindu and Sikh participants preferred vegetarian food, Muslim participants required halal meat, while members of Jainism and the Swaminarayan Dharma sect could not eat onions or garlic. Appropriate food was obtained at culturally specific services, such as an Asian carers’ group or lunch club. There were examples of meals-on-wheels providing Indian food.

The way food was served was also important – if the correct rules were not followed then service users felt unable to consume it. One carer was concerned about his father with dementia accidentally eating the wrong food, and thought that meat and vegetarian food should be served in separate areas. Another spoke about “jhoosha” (a concept of avoiding contamination between food and mouth, usually through unwashed hands or cutlery), reporting that a staff member had not washed their hands in between drinking a cup of coffee and serving food, so the food could not be eaten.

- Unfortunately, the research team did find some examples of experiences of racism and discrimination within social care services. They also found people feeling they had been treated unfairly compared to others, but not linked to racism.

- Many within the South Asian sample preferred that people’s care needs were met within the family, where possible, but a few considered that this viewpoint was becoming less common. Such expectations
may well influence people's evaluation of the quality of social care services. The expectation of family care was used negatively in one case, where a South Asian carer felt ashamed to ask for respite care because of services' assumption that he would not wish to use it. This finding shows the continued negative impact of the assumption that minority ethnic families prefer to ‘look after their own’. On the contrary, some of the Asian participants in the study reported that services were indeed desired once a certain level of need was reached. Therefore, the use of social care services was not incompatible with the view that family care is preferred.

**Understanding the system**

The second main aspect of differences between the South Asian and White British participants was their understanding of the social care system. More White British than South Asian participants had a good understanding of the system, including issues of structure such as funding, eligibility, and boundaries between local authorities. Participants with a good understanding had gained it through past experience as a service user or carer, or through working for social care services.

Participants with a good understanding of social care services were better able to work with the system in order to gain the services they needed. Participants with a poor understanding were unable to access what they needed, or were uncertain why a service had been refused, leading to frustration and lower satisfaction. Inaccurate expectations about what could be offered (such as expecting more hours of care) led to dissatisfaction.

Some participants reported that practitioners wanted to meet the needs of service users, but the way they expressed this was by asking service users what they needed. Without being aware of the range of help that social care services could provide, and perhaps more importantly what they could not do, service users were unable to answer this question. This led to unmet need.

Several of the White British participants also had a poor understanding of the services, reporting a lack of awareness of how to get help and a lack of information. The difficulties this group experienced ought not to be underestimated and shows that outreach is needed not only among BME groups. However, these issues are particularly problematic for the South Asian group, who had additional barriers to this knowledge including migrating relatively recently, language barriers and outreach not ‘reaching’ sufficiently.

**SHARED SOURCES OF SATISFACTION AND DISSATISFACTION**

The manner of individual social care staff was important to both White British and South Asian participants in this study, especially warmth, a caring attitude and being understanding.

Continuity of social care staff was also valued, although not often achieved, in our study. Participants pointed out how continuity of staff was important for building a sense of trust in people receiving intimate personal care, such as bathing. Service users also enjoyed building up a friendship with domiciliary care staff. Participants wanted to have a named social worker throughout their contact with services, rather than being removed from a caseload after the care plan had been arranged.

White British and, to a lesser extent, South Asian participants both reported being unhappy with the unreliability about the time domiciliary care workers would arrive. The length of time taken for a service to be provided was described as unreasonably long in several interviews.

Where continuity of domiciliary care workers was not possible, it was important that the worker had time to read the care plan before visiting. In several interviews researchers were told that the care worker had not read the plan, and the service users were either too embarrassed to ask for help (e.g. with bathing), or did not have the English language skills to explain what they needed.

A repeated discussion within interviews was the negative impact of no longer receiving a service that participants had greatly valued. Several services had been withdrawn due to budget cuts. These participants felt that the importance of the service to their lives had
been underestimated and they had not been offered anything adequate to replace it. Both White British and South Asian participants had been negatively affected by the closure of a valued service.

**RECOMMENDATIONS FOR SERVICES**

Better communication is needed throughout the entire social care process, from outreach to post-discharge, to ensure service users and family carers have accurate expectations and a better understanding of social care services. Social care services are keen to empower service users to make their own decisions about care, but service users need to understand what is available before making these decisions.

The project team’s experience of recruiting participants for this study showed that information stalls at places of worship were very effective ways of sharing information about the research. Similar approaches could be taken for outreach events to raise awareness about social care services.

Findings suggest that providing more information about social care services through GPs and hospitals will be particularly useful – this is where many people expect to find out about social care services. Since participants clearly expect their GP to know about social care services, GPs should be provided with training and information about social care services, and also to have the ability to refer patients to social care services directly. Some local authorities are already doing good work in this regard.

Trust between service user and care staff is developed over time, so having the same staff member as often as possible is recommended. Continuity of domiciliary care worker cannot always be guaranteed, so in these cases it is particularly important that the care worker has sufficient time to familiarise themselves with the care plan.

Language needs should be met at all stages, not only at first assessment. Although culturally specific services are clearly meeting these needs, there were reports of services being closed due to funding cuts. Alternative ways of meeting the language needs of clients could be considered. These include employing care staff with appropriate language skills, and equipping English-speaking staff with key vocabulary in Punjabi, for example.

Catering guidelines would benefit from the inclusion of the concept of jhootha (avoiding contamination between food and mouth through unwashed hands/cutlery), which was important to some Asian participants. Caterers could also be careful to clarify whether service users have specific dietary needs, especially if they have a cognitive impairment.

Few participants were entirely happy or entirely unhappy with their social care services experience, but these nuances were not captured by the social care satisfaction surveys. More opportunity for service users to convey their whole experience would be welcome, such as through face-to-face discussions.

**ABOUT THE STUDY**

This research was conducted from 2012–2014 by Dr Rosalind Willis (Principal Investigator), Dr Priya Khambhaita and Professor Maria Evandrou from the Centre for Research on Ageing at the University of Southampton, and Dr Pathik Pathak from the Department of Sociology, Social Policy and Criminology at the University of Southampton.

The project team would like to take this opportunity to thank all of the people who took part in this project.

The research findings have been submitted for publication in academic journals and full texts will be made freely available on the Centre for Research on Ageing’s website: http://goo.gl/dGqsL3

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