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# “You don’t know what you are saying ‘Yes’ and what you are saying ‘No’ to”: hospital experiences of older people from minority ethnic communities

JO ELLINS\* and JON GLASBY†

## ABSTRACT

Improving responsiveness to the needs of older people from minority ethnic communities has been emphasised as a goal in England since the publication of the National Service Framework for Older People in 2001. Despite this, people from minority ethnic groups consistently give poorer ratings of their health services than ‘majority’ populations, both in England and across many other health-care systems. Language barriers have been shown to play a particularly important role, and appear to be a stronger predictor of perceived quality of care than ethnic origin *per se*. This paper reports findings from a larger study exploring older people’s experiences of care transitions, focusing on the findings from one case study area which explored the hospital and discharge experiences of older people from minority ethnic communities. A participatory approach was adopted, with older people from the local area collaborating in the design, delivery and analysis of the research as ‘co-researchers’. Twenty-four in-depth narrative interviews were carried out with people who had experienced a recent hospital stay as a patient or a family member providing care and support. Our findings show that many aspects of the hospital experience, including the desire for personalised and humanistic approaches to care, are important to older people irrespective of ethnic background. However, older people from minority ethnic communities can also face language and cultural barriers which negatively affect the quality and experience of care. People who had limited English proficiency struggled to understand, communicate and participate in their care. Where professional services were not available or requested, interpreting was provided informally by other patients, family members, hospital staff in clinical and domestic roles, or not at all. We conclude that targeted strategies are required to ensure appropriate and effective hospital services for a multicultural population.

**KEY WORDS**—health care, minority ethnic older people, hospital care, experiences, language barriers, participatory research, person-centred care, culturally appropriate services.

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## Introduction

Patient surveys have consistently found that people from minority ethnic communities evaluate their health care more negatively than white patients (Campbell, Ramsay and Green 2001; Harmsen *et al.* 2008; Murray-Garcia *et al.* 2000; Raleigh *et al.* 2007; Schnitker and Bhatt 2008; Taira *et al.* 2001). This finding has been replicated across a number of different health systems and types of services, including acute, primary and mental health care. Variation *between* ethnic minority groups in their assessments of health services has also been demonstrated. In England and the United States of America (USA), patients from a range of South Asian communities generally provide the most negative reports of their health care compared to other minority groups (Department of Health 2009; Lurie *et al.* 2003).

Language has been shown to play a particularly important role, and appears to be a stronger predictor of perceived quality of care than ethnic origin *per se*. In a large-scale survey of patients using Medicaid-managed care facilities in the USA, non-English speakers rated their care significantly lower on a number of dimensions of quality compared to English-speaking respondents from the same ethnic or racial background (Weech-Maldonado *et al.* 2003). Linguistic minorities have also reported the poorest care in terms of courtesy and respect, provider skills (*e.g.* listening, giving explanations), involvement and specialist referrals (Carrasquillo *et al.* 1999; Harmsen *et al.* 2008).

Several factors complicate the interpretation of these quantitative findings. The appropriateness of standardised survey instruments for cultural and linguistic minorities has been questioned, opening up the possibility that results may be measurement artefacts (Weech-Maldonado *et al.* 2003). Moreover, as Mead and Roland (2009) note, patient evaluations of health care are influenced by several factors other than the quality of care itself including health beliefs, previous experiences, values and expectations. Therefore, it cannot be assumed that survey results accurately reflect differences in the quality and standards of care provided to different ethnic groups. They conclude that detailed qualitative research is needed to understand more fully whether and why patients from ethnic minorities report poorer experiences of care.

To date, few qualitative studies have addressed this topic. For example, a systematic review of qualitative research on older patients' and relatives' experiences in acute care settings published in 2010 identified 42 studies, only one of which focused on minority ethnic groups (Bridges, Flatley and Meyer 2010). This particular study, and another involving recently discharged patients from South Asian backgrounds (of all adult ages),

found that cultural background directly shaped the lived experience of hospital services (Policy Research Institute on Ageing and Ethnicity (PRIAE) and Help the Aged 2001; Vydelingum 2000). Key themes from participants' accounts included a lack of sensitivity to cultural and religious needs, and the negative effect of language barriers on the delivery of care processes and development of therapeutic relationships. There was a widespread perception among those interviewed in one study that command of the English language predicted the quality of service provided (PRIAE and Help the Aged 2001).

This paper reports qualitative data from a larger study exploring older people's experiences of transitions in care. One of the study sites focused on the journeys that older people from minority ethnic communities took through the acute health-care system. The findings concerning the time people spent in hospital are reported here, and the analysis provides an opportunity to explore further the contribution of culture and language to the health-care experience.

## **Methods**

### *The wider study*

This paper is based on results from a national study exploring older people's experiences of moving across service boundaries (Ellins *et al.* 2012). While the health and social care literature often focuses on the problematic nature of the divide between health/social care and between hospital/community, it tends to approach these issues from a service perspective. In contrast, our study sought to understand the lived experiences of people undergoing such transitions, utilising an in-depth narrative approach and adopting a participatory action research method (*see below for further discussion*). The overall research was based on four in-depth case study sites, each choosing a different transition as a local focus for the health and social care system to work on together with the research team. An explicit aim of the study was to facilitate translation of the research findings into practice to promote service improvement. To this end, we worked collaboratively with a local statutory and voluntary-sector partner organisation in each area, with whom we co-designed the study and supported to implement the findings within their services.

In this paper, we report findings from one case study site, a City Council and a wider Shire County, which chose to focus on the issue of discharge from hospital. Each of the four case studies were chosen to reflect a different set of local circumstances (with one focusing on the experience of older

people in rural areas, one focusing on people with dementia and one focusing on a city with a very young population). The case study reported here was selected because of the ethnic make-up of the local population, and the resultant focus was on the experience of older people from minority ethnic communities (for more detail on the overall study, see Ellins *et al.* 2012).

### *Co-research methodology*

As suggested above, a key feature of the study was the use of participatory methods and the active involvement of older people as co-researchers. Whereas traditional research methods typically involve participants as passive suppliers of information, participatory research calls for a collaborative approach in which participants can shape the research agenda and co-produce its outcomes (Cornwall and Jewkes 1995). Given the commitment to empowerment and a concern to break down traditional boundaries between ‘the researcher’ and ‘the researched’, participatory methods are particularly well suited for research with disenfranchised and seldom-heard groups (Heron 1996; McLaughlin 2009).

Studies that have recruited older people as co-researchers identify the ability to communicate and empathise with the interviewees on the basis of shared experiences as beneficial to the research process (Clough *et al.* 2006; Miller *et al.* 2006; Warren and Cook 2005). It is also reported that older people are likely to feel more relaxed and at ease with a peer interviewer, thus eliciting richer and more nuanced insights (Leamy and Clough 2006; Repper *et al.* 2007). However, the complex nature of identity construction and identification militates against any straightforward assumption that empathy will be established or enhanced on the basis of a particular demographic characteristic such as age, gender or ethnicity. As Ray (2007: 80) notes on this issue, ‘Given the diversity of ageing, it is erroneous to assume a shared perspective.’

Eight older people from minority ethnic communities in the study area were recruited as co-researchers through a local voluntary-sector organisation, and received training over five sessions on different aspects of the research process. Co-researchers contributed to every aspect of the study including designing the interview tools, participant recruitment, carrying out interviews, and data analysis and presentation of findings. Participants were told in advance about the involvement of co-researchers and given the option of being interviewed with a co-researcher present, or by the author alone. In all but two cases, participants agreed to a co-researcher being present.

### *Research ethics*

Ethical approval for the overall study was granted by Nottingham Research Ethics Committee 1. It is increasingly recognised that the marginalisation and vulnerability of some groups of older people is reinforced by their exclusion from fields of research (Amado and Ambrose 2001; Dewing 2002). In this study, older people were invited to share and define their own experiences as participants and co-produce the study outcomes as research collaborators. These roles nonetheless raise important ethical considerations, particularly for older people with dementia who may have deteriorating mental capacity. With this in mind, the study design included the following features:

- A single academic researcher was assigned to each case study site, thereby ensuring a continuous point of contact for co-researchers and participants for the duration of the study.
- Plain language and large print information and consent sheets were designed that minimised the volume of text while ensuring all salient information was provided.
- Participants were invited to have a friend or family member present during the consent process and/or interview for support.
- The co-researcher training programme included a session on gaining consent and maintaining confidentiality, with opportunities to give and gain consent in a practice situation before the first interview.
- For co-researchers, the study used a model of 'ongoing consent' involving regular discussion and reflection on the research process; central to this process was a debrief between the academic researcher and co-researcher after every interview.
- Representatives from the local voluntary-sector partner acted as an alternative source of advice, guidance and support for co-researchers which was independent of the study and research lead.

In this specific case study site, the issue of translating information and consent materials was discussed with our co-researchers and voluntary-sector partner. They advised that written translations would be less effective than having people available who could verbally translate information and respond to questions as and when required. This role was fulfilled by the co-researchers, who were centrally involved in identifying and approaching potential participants, and who spoke eight languages between them.

In line with the Mental Capacity Act 2005 Code of Practice, provision was made for the appointment of consultees in situations where potential participants lacked the capacity to consent to participation in the

project – although this was particularly relevant to the case study focused on dementia and no consultees took part in the element of the research reported here.

### *Sampling and recruitment*

A purposive sampling strategy was used to recruit 24 participants from minority ethnic communities who were either: (a) aged 60 or above with recent experience of a hospital stay or (b) a family carer of a relative aged 60 or above with recent experience of a hospital stay (Table 1). ‘Recent’ was defined as the previous six months, although we aimed to identify participants as soon after discharge from hospital as possible to maximise recall. This recent hospital stay had been experienced by 20 participants as patients, and by four as carers. But many of the ‘patient’ participants indicated that, at other times, they also provided care and support to another person in their family (in most cases, this was a spouse). This reflects the dual role that older people often have, as both ‘carer’ and ‘cared for’ (Molyneaux *et al.* 2011).

Participants were recruited through local voluntary and community organisations, support groups and co-researchers’ personal and community networks. Additionally, the author was directly approached by a specialist nurse for travelling families based in the local area, which led to the recruitment of five women from the gypsy-traveller community. The large proportion of participants of Asian origin broadly reflects the ethnic mix of the case study area, where Asian residents comprise approximately four-fifths of the local ethnic minority population.

The decision to recruit a mixed ethnic sample was taken with our collaborators in the case study area with whom we co-designed the study, and was mainly driven by a concern to foster wider engagement than would be possible if the study focused on a single ethnic group. The challenges of recruiting and retaining older people from culturally diverse communities have been highlighted by researchers, with Feldman *et al.* (2008: 482) noting that ‘the most successful recruitment strategies involved working with community partners and key informants’. While the final sample presented challenges for data interpretation, involving local collaborators in the research design helped to foster their ownership of the project and engagement with its findings. The sample size and sampling method precludes generalisability; nor are we suggesting that the diverse participants in the study can be treated as a homogeneous group – ‘ethnicity’, like any other social category, should not be assumed as the basis for shared experiences or cultural practices. Yet despite this diversity there was much commonality in the themes that emerged from the analysis.

TABLE 1. *Participant characteristics*

	N
Patients (aged 60–79)	20
Carers (aged 42–76)	4
Ethnicity:	
Asian or Asian British	18
Black or Black British	1
Gypsy-traveller	5
Gender:	
Women	15
Men	9

### *Data collection*

Interviews took a narrative approach, in which participants were initially invited to share what had happened to them and to tell the story of their transition across service boundaries. To structure interviews, we developed a framework – or ‘spine’ from the broader literature in order to reflect the entire pathway of care from first realising something was wrong right through to follow-up. The purpose of the spine was to trigger significant memories and thoughts, rather than to set out an agenda for the participant to follow (see Figure 1). Given the longitudinal nature of the study, the spine included both current and anticipated consequences of transition. For example, for the transition into and out of hospital, these consequences were defined as ‘life back at home’ (current) and ‘hopes and fears for the future’ (anticipated). Each stage was printed on to a small handheld card to be used if necessary during the interview. In addition, two further tools were developed to support the interviews: (a) a visual representation of the transition; and (b) a series of prompt questions that could be used to elicit further information.

Interviews started with a short preamble, explaining the purpose and format of the interview, after which the following opening question was asked: ‘We would like you to tell us about your recent experiences of going into and coming back from hospital. If it helps, please use this picture to remember what happened and share your story with us. Start wherever you like and please take as much time as you need.’ Interviewers could use the three tools (spine cards, visual representation and prompt questions) as and when necessary to suit the circumstances and participant, rather than following a one-size fits all approach. The spine enabled researchers and co-researchers to identify any gaps in the story as initially told, so that as full an account as possible was elicited. Given the

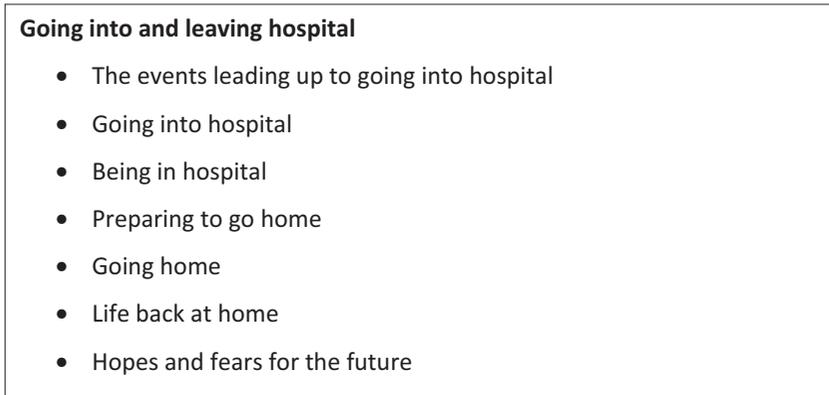


Figure 1. The interview spine.

emphasis within the study on influencing service change, interviews concluded with two specific questions asking participants for suggestions about how services for older people from minority ethnic communities could be improved. Interviews were audio recorded with participants' consent. Ten of the interviews were carried out by co-researchers in community languages, which were then translated into English by bi-lingual transcribers.

### *Data analysis*

Data analysis was carried out using NVIVO 8 software and guided by the principles of the framework approach (Ritchie and Spencer 1994), which combines inductive and deductive elements. This was achieved through the identification of *a priori* themes and categories derived from a conceptual framework developed for the study (details of which are available in the main study report: Ellins *et al.* 2012) to which novel themes and categories were later added as they emerged from familiarisation with the data. Themes were explored and relationships between them identified using axial coding techniques. Co-researchers were involved in the analysis of the data in two main ways. First, a debrief between the author and co-researcher was carried out after each interview during which initial reflections and thoughts about the experience shared were captured in the form of field notes. Second, at a data analysis workshop, the author and co-researchers read extended excerpts from interview transcripts and discussed issues, themes and meanings in the data, as well as identifying and exploring exceptional cases.

## Findings

Participants, or those being cared for by participants, were admitted into hospital for a variety of reasons. Two underwent a planned procedure; the remaining 22 were admitted as an emergency for ailments including heart attack, stroke, stomach pains, chest pains, severe diarrhoea and vomiting, fall and exacerbations of existing medical conditions. Length of stay in hospital varied from a single day to over three months; in all but one case, though, length of stay was under two weeks.

### *Being recognised and valued as a person*

People wanted to be seen as a person with needs, wants and feelings, rather than as a problem to be fixed. However, hospital care was sometimes experienced as cold, impersonal, even de-humanising:

When you enter the emergency department it feels very routine. The staff there don't seem to really be that concerned about stroke patients. You're very much a – you're on a conveyor belt of a system due to go into the stroke ward and everything seems to be a formality really. (Female carer, 43 years)

Principles of respect and compassion, central to definitions of patient-centred care (Goodrich 2009), featured strongly in the explanations that many participants gave of what it meant to be treated like a human being:

Well, if the staff could treat us like individuals and if they could be more sympathetic to us. I know that what they're doing for patients is obviously correct, but the people who go in with patients, such as myself taking my wife into the hospital, instead of being totally indifferent, they could at least come, provide, well some little snacks for people who are there hours on end waiting . . . At least, ask if you're alright and reassure that help is on the way for your wife or husband, whoever, and be treated a bit more kindly, which did not happen at all, you know. (Male carer, 63 years)

A striking finding was that even small gestures by staff to see and connect with the 'person in the patient' – smiling, using their name, asking if they were OK – could make a big difference to people's experience of being in hospital. One person, for example, recounted how the smiling faces of the nurses on the ward helped her to feel less despondent about being taken for an unpleasant procedure:

The nurses was lovely nurses, there were four, five, you know. Smiling faces, and you feel like, thanks God. And you don't feel sorry for yourself, because they send you with a smile and that don't cost anything. (Female patient, 71 years)

### *Helpfulness and responsiveness*

The image of good nursing care that was conveyed by participants comprised two main elements: nurses anticipating needs and proactively offering help

(helpfulness) and responding to individual requests for assistance in a courteous manner (responsiveness). It was clear that helpfulness and responsiveness behaviours strongly influenced patient and carers' perceptions of the quality of care provided. People shared a range of different experiences on this theme, but it was the more negative experiences that were recounted most vividly and often at great length.

Several participants recalled a time when they felt staff had not been helpful, when they had been ignored or forgotten, or when they had needed to get bad tempered in order for something to happen. The time taken for call buttons to be answered was a common source of complaint:

One night I wanted to wee and I was ringing for the commode and when I couldn't get the commode, I had to pull a bath towel and fold it up and shove it between my legs so that it would absorb it and I thought I don't feel good about it. (Female patient, 67 years)

Examples of staff being insensitive or rude were also shared. One person talked about how she started experiencing urinary incontinence as a side effect of a medication she was given:

And one day, I was wet, somebody didn't come about two hours, more than two hours. And I said to them 'I can't control myself because of these tablets'. And, you see, I couldn't walk, so I couldn't go to the loo. So I had to change and everything, wash me and everything, but that took them too long, you know, to do those things. Then nurses, they say 'You worry too much, you know, relax' . . . So that was bit unhappy part for me. (Female patient, 63 years)

The distress of waiting what seemed like an unreasonably long time for her clothes and sheets to be changed was compounded by the nurse's response which this patient felt downplayed her feelings about being in a soiled bed. Another person described what happened after she had complained to a doctor about the way that a particular nurse was treating her:

And the nurse, do you know what she did to me? She just stopped speaking to me . . . What she'd do was, just say her hellos and give the medicine. The barest minimum, just covering her duty . . . I thought, well, I had a word and she didn't like it. I spoke to the Gujarati doctor, he must have spoken to her, and then she just didn't speak with me anymore. (Female patient, 76 years)

### *Preferences for involvement*

Current health policy in England places a strong emphasis on patients being actively involved in their care, championed by the slogan 'nothing about me, without me' (Department of Health 2010a). While very few participants expressed a desire for greater involvement in decision-making, there was nonetheless a widespread expectation that patients and their families should

be kept informed about their care and have their views respected in any decisions taken. Most participants recalled difficulties at some point during their hospital stay in trying to get information about their care, such as the outcome of tests and investigations and the likely timescale for discharge. One older man and his wife talked about having to 'probe and ask' doctors to find out what was wrong with the man's leg, which had been hurt in a fall, and how the problem would be addressed:

Participant: We didn't immediately get told from the doctors what the problem is. . .

Wife: We had to probe and ask.

Participant: The consultant told us after many days what had happened, what they had inserted into the leg and so on.

Wife: In the hospital it was after the operation that we found out.  
(Male patient, 71 years)

Another suspected that his diagnosis was not shared with him until some time after it had been made. He recalled asking nurses what was wrong with him, after he had been admitted with vomiting and diarrhoea symptoms:

But sometimes when we do ask the nurse they don't tell . . . I was asking why this blood pressure is high? I was worried about this thing and I did ask them is it very serious or something like that? They told me it will be alright when you have a pacemaker.  
(Male patient, 74 years)

The lack of information about his condition left the person imagining the worst:

You get so many ideas. It may be something like cancer, maybe something, this or this or this. When you're getting sick, and something goes wrong, there are so many things coming in your mind. (Male patient, 74 years)

### *Involving and informing families*

The critically important role that family and social networks can play in providing care and support to older people has been widely documented (e.g. Audit Commission 2004; Ward, Barnes and Gahagan 2012). Family carers are increasingly identified as a group with whom health-care professionals and services should collaborate, with particular emphasis on involvement around the discharge process to help plan for and support the transition of care (Department of Health 2010b). In our study, communication with and involvement of family members was frequently sought (by both the older person in hospital and the family members concerned) but often not achieved. The most common problem that participants wanted to discuss was the failure of hospital staff to proactively

inform or update families about developments in the older person's care. Often information had to be actively – and in some cases, persistently – elicited, as one participant described:

My next-door neighbour, she went there to visit and when she came back she said 'Oh dear, they're going to take your wife for her operation'. I said 'Nobody told us that'. And they took her to the theatre at nine o'clock and the operation finished on Monday morning at one o'clock. My daughter and I were worried about it, and we rang up several times to the ward but they don't bother to answer or anything ... Then two o'clock in the morning I rang up, I said 'What's happening, why can't you inquire more, she has been having the operation for hours or something'. So the nurse she went to inquire and then she came back and told me 'Oh she has been transferred to intensive care unit'. (Male carer, 76 years)

Keeping family members informed was also very important to the older person in hospital, and when this did not happen it could cause or exacerbate distress. One older woman – who was moved to an intensive care unit (ICU) shortly after admission – told us:

In the morning, about ten o'clock, they moved me to ICU because they found out it was a heart attack. My family did not know at that time, nobody let my husband know it was a heart attack, but they moved me, in the same hospital, in different ward ... I was just telling them, let my husband know that I'm moving, you know, that's what's in my head, to let my family know where I am. (Female patient, 63 years)

Families were also given little advanced notification of discharge, and the experiences shared suggest that there was little direct consultation with family members when planning this aspect of the older person's care:

It felt like the decision had been made – that Mum would be discharged at a certain point and it all seemed very abrupt when the decision is made. It's almost as if the care is taking place and the medical reviews are happening, but then suddenly someone has decided that the person is well ... It's a shock to the family. (Female carer, 43 years)

Only two participants spoke explicitly about a desire to be more actively involved in decision-making processes, both of whom were carers.

### *Language barriers*

Many participants – not just those who were themselves non-English speakers – felt that patients who had no or very limited English skills received a poorer level of care than English-speaking patients. A pervasive feature of the experience of participants who did not speak English was intense feelings of anxiety arising from their inability to understand what was wrong with and happening to them. They also struggled to provide information that might be important to the effective delivery of their care

and ask for assistance when needed. Frequently language barriers left patients feeling helpless and vulnerable:

It's scary to go, to leave your home, you've never done that. And then suddenly, when you've got a language barrier, we can only say 'Thank you' and 'yes' or 'no'. And you don't know what you are saying 'yes' and what you are saying 'no' to. (Female patient, 71 years)

The people who speak the language they have no problem, but the people who don't speak the language, they have got a big problem. They can't say anything, they can't tell what is happening. Suppose if people don't know the language, now suppose they have to go to the loo. They can't say anything, just shouting like. Maybe they know just one word: nurse or doctor . . . People who can speak the language they can explain what is happening. (Male patient, 74 years)

Such communication difficulties hampered interactions with hospital staff and other patients, and substantially limited opportunities for people to be involved in their care, even in the most basic ways such as choosing meals. Given the difficulty that communication posed, some participants chose to cope by themselves rather than asking a staff member for help. One person, whose mother was admitted into hospital following a stroke, explained to us that:

There were many times when Mum would prefer to have asked for some sort of help or assistance and she has said herself that she ignored her own needs and that at times when she would have preferred to have asked a nurse for help to perhaps get to the toilet or perhaps to let someone know that she was even feeling quite nauseous or dizzy, that she didn't really feel inclined to let anyone know. (Female carer, 43 years)

Similarly, one woman reported that she often struggled to use the toilet and washing facilities unaccompanied because she felt that the time-consuming process of trying to explain what she needed was 'putting [the nurses] to trouble'. She observed, and was sympathetic towards, the frustration that staff felt when language differences made communication difficult:

There was just this one problem I had of not being able to speak back to staff, and then they're frustrated. They come to say something and chances are we may not understand and that's not something you can blame them for. (Female patient, 68 years)

### *Interpreting services*

All of the hospitals covered by the research offered interpreting services. However, staff did not always make arrangements for an interpreter for non-English-speaking patients, or sometimes interpreters were not available at the particular time required or at short notice. Consequently, a wide variety of other people had been informally involved in interpreting including

family members, fellow patients and hospital employees in clinical and domestic roles.

Four participants mentioned communicating through Gujarati-speaking domestic staff. In one person's case, the presence of bi-lingual cleaners was given as the reason why a professional interpreter was not requested for her mother:

I did ask on the ward if other people were available to translate things for Mum. But that was just – I was given the reasoning – they didn't have translators because often the ladies who look after making tea or the domestic cleaners could translate and I thought that was very unsatisfactory really, I didn't think that was right at all. (Female carer, 43 years)

At a follow-up appointment, it was suggested to another person that she bring along a friend or family member to translate for her:

Interviewer: Is there no one there to help you [communicate]?

Participant: The staff say to me, you ought to bring someone with you. But who can I take with me? People need to be at their own places of work in the mornings.

Interviewer: Does the hospital not have interpreters?

Participant: Well at first they did but now, they don't call them anymore, they don't call them. (Female patient, 70 years)

Another person received help from a patient in a neighbouring bed, who was able to clarify with a nurse what was happening in her care. The person thought she was being discharged, but it turned out that she was being taken for her operation.

I did have a neighbour, an auntie who was very nice, a Muslim lady, and she said 'Since you don't know the language if there's any problem, just let me know and I'll explain' ... And I said to her 'Will you please help, I'm not understanding this and this', especially around the time of the operation. The nurse gave me clothes to wear, and I wondered why she had left me the clothes, so she [the patient in the neighbouring bed] asked for me about the clothes and we were told about the operation that day. I thought the doctors asked me to go home. (Female patient, 68 years)

Participants were generally very grateful for the help they received from informal translators. Nonetheless, when asked for suggestions as to how local hospital services could be improved, increasing the availability of hospital interpreters was one of the most frequent recommendations made.

### *Culturally appropriate care*

Participants typically identified themselves as having specific requirements due to cultural or religious norms that made them different from people who did not come from an ethnic minority group. Equally, it was also

recognised that many aspects of hospital care—such as dignity and compassion—were important to all older people, indeed to all people, irrespective of their cultural background.

Hospital food was an important issue, particularly among participants of South Asian origin. Many reported that the hospital they were in had not been able to adequately accommodate their dietary preferences, with the poor provision of vegetarian meals frequently mentioned. Two participants talked about surviving on a very limited diet:

I did ask them for Jain food but they said there wasn't any . . . They'd give me yoghurt and bits of fruit here and there. Every lunch time there'd be a pudding and I ate that but not anything else, there was nothing else available and I didn't consume anything else. (Male patient, 71 years)

The lady came, you know, with the trolley, at lunch time. And I asked her 'What have you for the vegetarian?' And she said, 'Something tomato in there, the pasta dish', you know. And I said, 'I can't eat tomatoes, give me something sweet'. And she said, 'There is not much sweet dish also.' So I said 'Have you got any fruit?' She said 'No'. The next time she came I asked her also 'Have you got any fruit?' She said, 'I've told you so many times, there is no fruit'. So I said, 'Give me something sweet, at least I can eat something'. (Female patient, 71 years)

There were a small number of examples shared of what was perceived to be prejudice towards ethnic minority patients. One person, a participant from the gypsy-traveller community, recalled an incident involving an Asian patient in the next bed who spoke very little English. The patient was trying—as the participant understood it—to communicate that she was vegetarian:

As far as I could make out, that's what she was trying to tell them. And this [member of staff], honest, now she was only giving the dinners out, the abuse she gave that woman. And I'm laid there with a mask on, couldn't breathe and I felt like getting out of the bed. Anyway off she went and the poor woman is trying to explain. She come with a yoghurt, she banged it on the table, she said 'Well have that or nothing', and then left that woman there. And she was just, nobody was trying to help her. Nobody could understand her. And I said 'If I could just get off this bed', but I couldn't. I couldn't do nowt about it 'cos I was stuck to the bed. But honest to God, that's just how they treat us, like pigs. (Female patient, 65 years)

Another person described the distress caused by a doctor telling her she needed a triple heart bypass in what she felt was an insensitive and cursory way. His behaviour, she suspected, was due to an assumption that because she was South Asian she would have limited English-language skills. A fluent English speaker, she explained:

He [the doctor] says, 'I can't do anything, you've got to have a bypass', that's all he said, nothing. And then says, 'Move on the bed'. I went there, they took the tube out. And, one of the nurses with me, she says to me, 'What's wrong?' I said, 'How he spoke,

that's not the right way to speak to people, he never explained to me'. For him, I was just cattle, something like that, and that's not right . . . He thought that me being Asian, I couldn't understand what he's saying. But I understood. (Female patient, 63 years)

## Discussion

Patient surveys have long reported that people from minority ethnic communities rate their health care more negatively than white patients. Qualitative research exploring the lived experience of care can help to explore complex issues of this kind in greater depth and provide explanatory insights.

Bate and Robert (2006) propose that unstructured narratives can provide valuable insight into the points along the care pathway where patients' experiences and perceptions are most powerfully shaped. A number of the key themes voiced by participants in this study echo the priorities and concerns of older people more generally when receiving hospital care. Bridges, Flatley and Meyer's (2010) review of qualitative studies of older people's experiences in acute care settings found that, at a time when feelings of anxiety and uncertainty were predominant, older people placed a high value on the interpersonal aspects of care. Positive experiences were strongly linked to patients developing reciprocal and trusted relationships with staff, being seen and addressed as a person, and feeling involved and respected in the care process. A finding common to both this study and those studies included in the systematic review of Bridges, Flatley and Meyer (2010) is that the actions of individual providers could make a considerable difference to an individual's experience, especially when these actions enhanced or diminished feelings of being cared for, respected and understood.

Research has also long reported that communication is essential for a good interpersonal relationship (*e.g.* Ong *et al.* 1995), and this study is no exception. The way that participants spoke about communication demonstrates that it fulfilled both relational and instrumental needs. Echoing Kelly's (2010) earlier findings in relation to the ward experiences of people with dementia, communication was the primary means by which a sense of 'personhood' could be expressed and maintained (or not, depending on the nature of the interactions experienced). Positive interactions which supported a sense of self and preserved dignity helped people to feel safe and connected in – as one participant in our study described it – the 'foreign land' of the hospital environment.

Communication was also practically important in terms of the exchange of information about the person's condition and care. Participants wanted

to be kept informed about what was happening with their care or the care of their family member, to be listened to and have their questions answered. Again, this is a finding which is consistent with broader literature on older people's care preferences. In contrast to the concepts of autonomous and shared decision-making that are increasingly found in health-care policy, older people's views of involvement tend to emphasise building trusting relationships, receiving good information and being respected (Bastiaens *et al.* 2007). Of the 24 participants in this study, only two expressed a desire for a more active role in decision-making, both of whom were carers.

All of these similarities suggest that there are many aspects of the hospital experience – above all, the desire for personalised and humanistic approaches to care provision – which are important to older people irrespective of ethnic background. Care needs and preferences shared by majority and minority populations have also been identified by researchers in the area of maternity services (Puthussery *et al.* 2010; McFadden, Renfrew and Atkin 2013).

Notwithstanding that older people as a group hold a number of priorities for health care in common, experiences were also shaped by culturally specific factors. Several participants commented on a lack of provision appropriate to cultural needs, particularly in relation to dietary requirements. Aside from the obvious health benefits, meeting basic needs regarding nutrition is an essential element of dignified care. As Levenson (2007: 21) notes 'Having some choice of what to eat, when to eat it and whether to eat alone or with other people are all things that we may take for granted and that may form part of our sense of being in control and living a dignified life'. But it was language barriers which emerged as the most dominant theme. The impact of language barriers on service access and acceptability for minority groups, and consequently their contribution to health inequalities, are well documented (Anderson *et al.* 2003; Yeo 2004). Our findings show how they can also strongly shape patients' experiences and perceptions of care quality. This was most powerfully illustrated by the accounts of participants who were interviewed by co-researchers in community languages, showing the value that participatory approaches can have for accessing and understanding the experiences of groups that have been largely marginalised from research.

The lack of a shared language has been shown not only to hamper the development of a therapeutic relationship between patients and providers, but also can act as a clear indicator of cultural difference and separateness (Anderson *et al.* 2003). Consistent with the findings from an earlier study exploring how older people from minority ethnic groups experience hospital care (PRIAE and Help the Aged 2001), there was a widely held view among participants – not just those who were not English speakers – that the

quality of care received depended on a patient's language skills. People's ability to understand what was happening to them, to share important information and to participate in their care was significantly constrained – if not eliminated – where language barriers existed. Often this served to exacerbate the feelings of fear, anxiety and loneliness that frequently accompanied an acute admission. Similar experiences linked to communication breakdown have been reported for several other groups for whom speech and language difficulties are more common, including people with dementia (Manthorpe *et al.* 2011), stroke (O'Halloran, Worrall and Hickson 2012), aphasia (Simmons-Mackie *et al.* 2007) and sensory impairment (Heine and Browning 2002).

This study confirms the findings of previous research, including but not limited to the English National Health Service (NHS), about the poor provision of interpreting services in health services (Alexander *et al.* 2004; Ramirez, Engel and Tang 2008). Accurate communication increases the likelihood of receiving appropriate care, and the availability of professional trained interpreters is considered an important element of culturally competent care (Anderson *et al.* 2003). Moreover, the involvement of professional interpreters has been shown to improve clinical outcomes, as well as enhancing patient comprehension and satisfaction with services (Karliner *et al.* 2007).

People with limited English proficiency received assistance in communicating from a number of different *ad hoc* interpreters, including fellow patients, family members and hospital domestic staff. The involvement of family members in interpreting could be seen as an extension of or might help to facilitate more family-oriented approaches to care and decision-making. There may also be benefits inasmuch as family members can use the interpreting role as an opportunity to act as an advocate and 'culture broker' for the patient (Rosenberg *et al.* 2008). Nonetheless, concerns about confidentiality and the quality of informal translation have been raised (Flores 2005), and reliance on family members may be inappropriate for discussion of sensitive or potentially embarrassing issues. While concerns of this kind were not explicitly raised by participants, it is of note that increasing the availability of professional interpreters was one of the most common recommendations made for improving local services. This resonates with the findings of the consultation that Manthorpe *et al.* (2009) carried out with black and minority older people about local health and personal services. Addressing barriers relating to language issues emerged from this consultation as a major concern.

This study has its limitations, including a relatively small sample and what might be seen as an over-representation of a particular ethnic group, which precludes a more detailed exploration of the interplay between

different ethnic and cultural identities and health-care delivery. Despite these limitations, there are two main implications for practice. First, a number of strategies for improving older people's experiences of hospital care – such as the development of relationship-centred approaches – are likely to benefit all groups, regardless of ethnicity. At the same time, ethnic background does create unique health-care needs and experiences. Language, in particular, plays a crucial role and appears to present a formidable obstacle to the delivery of good quality care, in the technical and experiential sense. Addressing these issues requires more targeted attention and intervention from health-care providers, guided by an understanding of how appropriate and effective care for people from ethnic minority groups can be embedded in mainstream services.

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