Prioritising home care needs: research with older people from three ethnic minority community groups

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Abstract
This paper draws on research with three minority ethnic community groups in Manchester. The aim of the study was to examine and prioritise social care needs. Focus groups were chosen as a way of beginning discussion about these issues. The findings suggest that some quality issues are relevant to all communities of older people. However, some were specific to the community groups. This paper describes some of the lessons learned about running focus groups with people whose first language is not English and suggests some considerations for future research.

Keywords: focus groups, home care, minority ethnic communities, quality assessment

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Introduction
One of the principles in the National Service Framework for Older People (Department of Health 2001) is that the differing needs of different communities should be acknowledged when delivering services to older people. This is recognised as particularly important for older people from minority ethnic communities. The implications for service providers are immense. There is overwhelming evidence that service providers neglect the needs of people who suffer from a ‘triple jeopardy’ (see Turkington & Dixon 1998 for a review of the evidence): the disadvantages of getting older, of racist discrimination and of the failure of health and social services to meet their needs.

There has been much research showing that minority ethnic communities have particular problems with accessing health and social services. In addition, access problems may reduce the effectiveness of treatment, especially if service provision is insensitive to needs (Thomson et al. 1999, Social Services Inspectorate 1998, Age Concern England & Commission for Racial Equality 1995, Butt & Mirza 1996, Modood et al. 1997, Ahmad & Atkin 1996a). However, some local authorities have taken special action to recruit home carers/helps from minority ethnic groups. There is little evidence of how well these initiatives work and ethnocentrism – that is, the dominance of traditional professional cultures – applies equally to both health and social care provision (Askham et al. 1995).

Increasingly, researchers are examining what older people from ethnic minority communities need from service providers (Blakemore & Boneham 1994, Askham et al. 1995, Bowes & Dar 2000). However, as Bowes & Dar (2000) comment:

There has been little research that has looked closely and qualitatively at minority ethnic older people’s own views in the broader context of their lives and beliefs, despite the emphasis on consultation in recent policy. (p. 307)

This paper describes research with older people from three minority ethnic community groups, in which their social care needs were discussed and, more unusually, prioritised.

Methods
The study was carried out in Manchester, a large city in the north of England. In 1994, there were 46 600 people over the age of 65 and 13 500 people over the age of 80 in Manchester. The City of Manchester Social Service Department bought home care services for 3000 of these people. Manchester is calculated to be among the most deprived areas in England according to the Jarmen score (Public Health Directorate 1996).
Manchester includes many minority ethnic communities. The 1991 census showed that 12.6% of the total population of the city were from these communities. However, there are many minority ethnic communities that the census does not pick up. For example, there are long-established Jewish, Polish and Irish communities. The age composition of the minority ethnic communities picked up by the census differed from that of the ‘white’ population. The proportion of people from minority ethnic communities of pensionable age and over in the 1991 census was 4.4%, compared with 20.5% of the ‘white’ population. However, researchers have predicted rapid rates of increase in the number of older people in minority ethnic communities. Blakemore & Boneham (1994) argue that these statistics on minority ethnic communities seriously underestimate the number of people in such communities. This is due to the geographical clustering of communities in particular areas, problems with census underestimates of minority ethnic communities and predicted rapid rates of increase as the cohorts of migrants of the late 1950s and 1960s reach retirement age.

Study aims
The study was designed to achieve three aims:

1. a description of the views of older people on the quality of home care and the priority they attached to the dimensions of quality;
2. the exploration of ways in which their views can be heard and have an impact on the quality specification of the services delivered; and
3. the production of a manual for local authorities on how to access the views of older people on service quality.

Ten per cent of the population for whom home care services were being purchased by the City of Manchester was sampled randomly in the autumn of 1999. The sample was designed to reflect proportionately the number of people under the age of 80 and over the age of 80. A total of 104 people were involved in the study out of the 292 sampled. In addition, focus groups were held with three minority ethnic groups.

Older people were given the choice between participating in a focus group and having a home-based interview. Separate focus groups were set up for people from three minority ethnic community groups. This paper concentrates on the lessons learned from running focus groups with people whose first language was not English. The study is described in full in the final report (Raynes et al. 2001).

The benefits and challenges of focus groups have been debated widely (see, for example, Krueger 1994, Morgan 1997, Carey 1995, Wilkinson 1998, Dreachslin 1999). Dreachslin (1999) states that the advantages include the lower cost per participant compared with individual interviews, the flexibility to pursue ideas and the possibility to locate and value views within a particular social context. It has been suggested by Wilkinson (1998) that:

Focus groups are a particularly good choice of method when the purpose of the research is to elicit people’s understandings, opinions and views, or to explore how these are advanced, elaborated and negotiated in a social context … If, by contrast, the purpose of the research is to categorise or compare types of individuals and the views they hold, or to measure attitudes, opinions or beliefs, focus groups are less appropriate – although they are, of course, sometimes used in this way … ’ (p. 187)

Therefore, the aim of our focus groups was not to collect individual views on quality services but to facilitate debate around the issues for these groups. However, as Esposito (2001) points out, qualitative reports on cross-language research tend to provide little information regarding translation issues. This is a strange omission given that a qualitative approach is often cited as a way of contextualising accounts and debating meaning construction. Language constructs as well as describes the social world, and language differences may be crucial in examining access to services and evaluating service provision.

There were two separate sets of focus groups in the study. At the first-stage focus group, the participants were asked three questions:

- What services are you getting from any source to enable you to live independently in your home?
- What makes for good-quality services at home?
- In an imaginary world when we could have anything we wanted and not pay for it, what would make for quality services to maintain your independence at home?

In the second-stage focus groups, the statements that had been generated in the first stage as features of quality in home care services were ranked by the participants using the paired comparisons approach. This method allows each item that has been chosen as defining quality to be compared with all others. It is a way of obtaining a view about priorities. Each of the features identified at the first-stage focus group were printed on numbered cards. At the second-stage focus group, the participants worked on a one-to-one basis, making the comparisons, which were recorded on a separately prepared grid. People who chose an interview were asked the same three questions as focus group members. They were also asked to consider the quality dimensions
generated by the focus groups in their area and to carry out the paired comparisons.

As Manchester is a multiethnic city and many languages are spoken, the researchers wanted to include people in the research who did not speak English as their first language. It was felt that it was important to try to include in the research at least some of the non-English voices that can be heard in Manchester every day. Definitions of ethnicity have long been debated by researchers and we will not rehearse these arguments here (see, for example, Ahmad & Atkin 1996a, Blakemore & Boneham 1994). The contested basis of census definitions of ethnicity and arguments for the importance of language and religion, for example in definitions of belonging to particular communities, were taken on board by the researchers. One of the main lessons from such research is the importance of local context for definitions of ethnicity and for appropriate consultation over service provision. For this reason, and as one of the aims was to look at a group research technique, it was decided to work with existing community groups. The groups’ own definitions of ethnicity were used in the study.

The social services department had established a Black Consultative Community Care Forum (BCCCF) and members of this sat on the local steering group of the project. As a result of meeting with the BCCCF and the steering group, three minority ethnic groups were approached to take part in the research. The first was the Wai Yin Society, a locally based Chinese group that runs a variety of support activities for members of Manchester’s Chinese community. Two Asian groups volunteered to take part in the study. This convenience sample was selected to explore the suitability of the methodological approach. We are not arguing that these three groups are representative of minority ethnic communities in Manchester or that the individuals taking part in the focus groups represent the communities to which they belong. The aim of the study was to begin to engage in a debate about the feasibility of conducting focus groups with people who do not speak English as their first language. Esposito (2001) comments that this is a much-neglected area of research, and convenience samples are an accepted way of including populations that are hard to involve (Dreachslin 1999).

The Wai Yin Chinese Women’s Society conducted the focus groups for people from the Chinese community. The society was set up in 1988 and now has funding from a range of sources, including the National Lotteries Charity Board, the social services department and the Mental Health Social Care Partnership. The society is a community resource for all Chinese people in Manchester and provides a wide range of services, including: an ‘elderly project’, which aims to provide a luncheon club in a social club setting; information and advice; organised cultural and social programmes, and increased social interaction. It targets men and women over the age of 60. Members of the luncheon club were asked to participate in the research.

Two focus groups were arranged by Wai Yin, with 10 people in each group (one for under-80s and one for over-80s). Eighty per cent of the luncheon club members are female and 20% are male; these proportions are represented in the composition of the focus groups. The focus groups were conducted in Chinese and Haka. The material was translated into English at the end of the first stage so that the cards could be prepared. These were then translated into Chinese for the second-stage focus groups.

The Elderly Asian Development Group is one of a number of Muslim community groups in the city. The group caters for Bangladeshi and Pakistani men. It has a newsletter in both English and Urdu and holds a forum on a monthly basis. Ten men agreed to take part in the research. All were well educated and under the age of 80. The entire process was conducted in English at the request of group members and facilitated by a member of the research team.

The Longsight/Moss Side Community Project is funded by the social services department and provides a variety of activities for Bangladeshi and Pakistani communities, including support services for older people and training for staff. The project is also trying to develop an awareness of what home care services could provide. There were five men and four women in the focus groups; they were considerably more disabled than those in the first group and more mixed in terms of age. The group was facilitated by an Urdu-speaking member of the local community, assisted by a scribe who wrote up the dimensions of quality in Urdu. These were then translated into English to enable the preparation of the cards for the second stage. These were prepared in Urdu by the University of Salford translation department and checked with the group facilitator. Not everyone in the group could read Urdu but all could understand it. Individual Urdu or Punjabi volunteers were recruited to carry out the paired comparison rankings in the second stage.

As in the main study, because some focus group members were unable to read, responses to the questions were written on a flip chart. These were then read back to the group to check their accuracy and to enable those who could not read to remain involved and to participate. In the second set of focus groups, where the paired comparison technique was used to prioritise attributes of quality home care, the content of each card was read out to the older person by the individual researcher working with them.
Results

People in the main part of the study who came to the focus groups or took part in interviews referred to features of home care that we classified into one of six categories (see Box 1).

Older people under the age of 80 also considered the need for company, feeling safe and having more money to be important. The over-80s raised two concerns not mentioned by the under-80s: having things to occupy your mind and having ‘robots’ to do jobs.

We now go on to examine the quality attributes picked up in the focus groups with the minority ethnic community groups. The aim here is to draw out some of the lessons learned from the focus groups rather than discuss findings (see Raynes et al. 2001 for the full study).

The Wai Yin group

Some members of the under-80 Wai Yin group had never heard of home care services and were looking after themselves. Others used a paid service, getting an hour a week, and others were looked after by their spouses.

This group came up with 28 attributes of quality. The top-ranked attributes have been grouped in Box 1. There are attributes of a quality service common to this and other groups of people under the age of 80, such as a flexible service focusing on their needs, trained carers, and aids and adaptations. However, there are clearly ‘Chinese categories’. These include: Chinese interpreters in hospitals and with doctors; an emergency call system available with a Chinese-speaking person at the receiving end; a more spacious Chinese day centre with ease of access and various activities, and carers who speak English and Chinese.

As with the younger group, there were some people in the over-80s group who had never heard of home care services and who were looking after all aspects of daily living themselves. There were also people paying an hourly charge for a cleaning service and others who were getting help from members of their family. There was a very strong view in this group that ‘I would rather die than live in an aged home’ but this was matched by the view that ‘having a Chinese aged home where diet, communication and language posed no problems at all’ ‘might make living other than in your own home not quite so intolerable’. Views about neighbours as sources of help were mixed: ‘some are excellent,’ it was said; others said ‘there is no communication between the neighbours; a few elderly people died in the room and this was only discovered after several days’.

This group came up with 18 descriptions of a quality service and seven of these had a strong focus towards needs specific to Chinese people. The others fell into categories already developed: the organisation of services, aids and adaptations, money and transport. Focusing on the attributes particular to Chinese people, a good-quality service is one in which:

- there are Chinese interpreters at the clinic;
- there are Chinese wardens, especially at night;
- there are Chinese-speakers to read letters, fill out forms;
- there is transport to Chinese day centres;
- there is a Chinese older person’s home;
- there is a Chinese day centre; and
- there are Chinese- and Haka-speaking carers.

The Elderly Asian Development Group

Ten male members of this organisation agreed to become involved in the research. At an initial meeting, there was some clear hostility to the project. A number of issues were raised. It was stated that no-one knew what home care was. There was a need for leaflets in Urdu and Punjabi to be distributed to Mosques to inform people about their entitlements. It was pointed out that in India and Pakistan, many services to support older members of the family were bought in. Certain tasks were regarded as only to be carried out by members of low-level castes. Examples of this were hair cutting and dealing with soiled clothing.

The main points that this group made were their lack of awareness of such services and the lack of assistance of any kind that they received. The families in

Box 1 Dimensions of home care

| 1 | What carers do. For example, a good-quality service was one in which carers helped with keeping the house clean. |
| 2 | How carers were organised. Examples of good service here include having entitlements in writing and being told who is coming if the regular carer cannot come. |
| 3 | Aids and adaptations. Panic alarms in case of falls, stair lifts and banisters were mentioned in this category. |
| 4 | Getting out. It was considered important to get out and meet people and an organised day out was specified. |
| 5 | Transport. For example, transport should be affordable and accessible as well as subsidised. |
| 6 | Improvements in health services. Older people felt they should be able to see a doctor for a general medical check-up and that they should not be discriminated against. |
some cases did washing, shopping and cooking and some had experience of a district nurse coming in following a hospital episode. They made the point that it was hard for the members of their families to assist them because they had to take time off from their work or their studies. It was very clearly the view of every member of the group that nothing came from social services. If any support was available, it came from their family only. Some help was given with shopping and getting pensions from the Post Office. It was the view of the group that they did not know where to go to buy services. One person said, ‘to qualify for a service you have to be a dead person because they make it so difficult to get’. The basis for this observation was the filling out of forms, which appeared to the man concerned so complicated that halfway through he realised he didn’t qualify. Another person said:

You have to be locked into poverty and not have your children helping you because they will count against you. They, the social services, value the services of children so you deprive yourself of services if your family help you.

The group maintained that the help that is available is focused on manpower and not on aids (like a stairlift) that would make a person more independent. They came up with 25 different features of what a quality service would be to them. These fell largely into the dimensions already mentioned. In their top 10 ranked dimensions were those relating to the organisation of the services and the provision of aids and adaptations. There was a specific dimension to this group related to their families. They wanted them to be rewarded for their help to their parents and assisted in providing that help in other ways. A good-quality service was therefore one in which:

- families are financially rewarded for helping their older relatives;
- jobs for children are brought closer to their family homes.

The Longsight/Moss Side Community Project

This project is trying to develop within the community an awareness of what home care services could be provided. Muslim care workers have been trained. These are often seen as low-caste people in both the Indian and Pakistani communities. Previously, there was a situation where there were no workers from these ethnic groups. Now there are such workers and the project has found that the unwillingness to employ them comes from members of the community.

In this group, unlike the other groups, there was a clear recognition of the existence of services provided by the social services department. Use was being made of these. Three of the nine people were using services provided or purchased by social services on a weekly basis. Only one person in the group did not know about the availability of such services. The services that were being accessed included cleaning, washing and shopping. Two members of the group paid for private help with cooking and shopping.

The group came up with 10 attributes of a quality home care service. Three of these may have been related to their ethnicity:

- the carer should come later in the day when the Asian shops are open;
- permanent staff who know what foods they want, e.g. which meat and vegetables;
- food is prepared to suit the individual.

Discussion

The findings described here suggest that some quality issues are relevant to all communities of older people. In relation to housing needs, Karn et al. (1999) state:

It has been a feature of previous studies of the experiences of minority ethnic groups within the housing system that they have acted as ‘can-openers’ for broader questions about the accessibility and suitability of services for all groups … That is not to deny in any way that these studies have demonstrated the disproportionate impact upon vulnerable minorities of rather routinely (or insensitively) administered, standardised (and ethnocentric) approaches to housing need. (p. 8)

In other words, antidiscriminatory practice is good service provision. However, although not the top priority, some of the quality attributes were specific to the community groups. These findings would seem to support research in other areas with older people from minority ethnic communities that questions presuppositions about a strong desire for ethnic segregation and separate services. For example, researchers have found that separate sheltered accommodation schemes are not always preferred (Jones 1994, 1998). Some minority ethnic communities are prepared to consider ‘mixed’ schemes as long as their language and religious needs were addressed. Jones (1994) goes on to argue: ‘it should not, however, be assumed from this that there is no place for ethnic-specific schemes or that there is no room (or need for) improvement’ (p. 18).

The same point could be made about home services. The starting point should be the investigation of need and views about the importance of particular attributes of quality. Debates may then be more about differences at the point of delivery than about different kinds of services per se.
**Lessons learned**

The three community groups differed in the way they responded to and participated in the research project. Access to the views of these groups was gained through organisations such as those represented in the BCCCF in Manchester. As Bowes & Dar (2000) point out, such organisations act as gatekeepers to different cultural communities in the city. In this study, we were concerned with beginning a dialogue rather than debating which groups represented which people, an issue some of the groups themselves found hard to solve. However, it is important to bear in mind that some people from minority ethnic communities do not use voluntary organisations. Moreover, as Bowes & Dar (2000) again point out, those that do use services from these organisations may lose touch with them as their health deteriorates and will continue to be missed by generic services:

There was thus a suggestion that the links between the community-based, specialist services for minorities and the generic services, including possibly the health services ... were weak, and were not effectively helping these older people as they became trailer and more needy. (p. 317)

Moreover, Ahmad & Atkin (1996b) argue that:

‘Specialist services’, ... although often beneficial, are too often a euphemism for short-term and inadequately funded provision ... Yet, at the same time, mainstream services use the existence of specialist services to absolve themselves of responsibility for ensuring access and appropriateness of services ... (p. 3)

Atkin (1996) stresses that the value of voluntary groups may lie in their potential to empower communities:

The emergence of voluntary organisations that meet the neglected social care needs of minority groups reflects the potential of empowerment and struggle by focusing on strategies, resources and forms of support that black people find helpful. (p. 159)

The people who took part in our focus groups were therefore not intended to represent the communities from which they came. They were selected in the knowledge that they would represent particular ‘strategies, resources and forms of support’ and to investigate a particular issue: is there potential in using the focus group method with people from minority ethnic communities? However, individual interviews still need to be offered to people who did not want to take part in focus groups and who do not use community organisations. Contacting people from as broad a spectrum in communities as possible means using different research methods and ways of contacting people. For example, social workers often have a detailed knowledge of where minority ethnic communities live in their area. Different methods, such as individual interviews, may also have to be offered as a way of involving them in research. Such interviews may provide a different view on service provision and quality. This is an area that would benefit from further research.

For the consultation with these groups to be meaningful, it was necessary to provide clear explanations of the method and facilitate training. There is therefore not only a language issue (indeed, in one case it clearly was not a language issue at all) but also one relating to supporting and encouraging members of these groups to learn the research techniques to enable them to carry out qualitative research of this kind.

The planning of the focus groups in these three different communities took time. It did not fit neatly into the timetable for the rest of the research project. This reflects the lack of resources of the people who assisted us to do this kind of work, as well as the other commitments they had. Esposito (2001) has pointed to the lack of funding available for qualitative researchers to be able to work with people who don’t speak the researcher’s language. Researchers often have to restrict their research to people with whom they can communicate directly because of the costs of translation and interpretation. The added costs also mean that the involvement of interpreters and translators in projects is often limited, even when there are methodological benefits to extending such involvement.

When involving voluntary groups, there is also an issue about reimbursing their time. In our study, the groups were actively involved in drafting, planning and implementing the data collection exercise at each stage of it. They were reimbursed for their services. This is one possible way of moving beyond tokenistic attempts at consultation: training groups to use different methods themselves and then to bring them into the feedback process. If such involvement and resource does not happen, as Williams & Mussenden (1992) have said, ‘consultation becomes a meaningless exercise’ (p. 33).

There is also a consideration that arises from the fact that the services being researched are little known or used by members of two out of the three groups with which we worked. This is more than a matter of providing them with information in suitable formats, although that certainly helps. It illustrates the dangers involved in assuming that concepts used in one language will unproblematically translate into another. Esposito (2001) argues that one of the principles of meaningful cross-cultural research is that it is necessary to have a credible, sound approach to translation. In her study of the health risks and needs of perimenopausal Hispanic women in New York City, she compares audiotaped English translations of focus groups with a professional
interpreter with the audiotaped Spanish account translated into English by a professional translation service. Her method of having a ‘real-time’ interpretation of the discussion in focus groups allows, she argues, for some return of the monolingual researcher’s ability to guide and direct the discussion in response to participants’ comments whilst retaining the original language version. It is debatable where control of the direction of discussion in focus groups should lie if researchers intend to allow perspectives other than their own to have a chance. Concepts may have different meanings in different languages and a handing-over of direction to people who may have different concerns may benefit the research. However, the strength of Esposito’s work lies in her engagement with methodological cross-language issues and the way in which she ties together the method she uses with her belief in the strength of fluid and adaptable exchanges between the researcher and the participants in the focus groups.

Our approach to the two groups that were not run in English was to problematise the concept we were researching. ‘Home care’ was discussed as a concept by the steering group and in the focus groups themselves. It was by doing this that the differences in views were brought forward (see earlier). Ideally, ‘debriefing’ as well as training the interpreters would have followed the focus groups. This involves investigating more than the professional credentials of translators as part of looking at the translation process (Esposito 2001). It means socially situating the interpreter/translator in relation to the research in terms of (for example) gender, age and religion. Qualitative researchers often argue that the social location of the research in relation to research participants influences the accounts produced. If this is the case, then the argument for inclusion needs to extend to include the interpreter/translator as active in the research (Temple 1997, Edwards 1998, Chesney 2000). Our project was the beginning of a process of researching. ‘Home care’ was discussed as a concept by the steering group and in the focus groups themselves. It was by doing this that the differences in views were brought forward (see earlier). Ideally, ‘debriefing’ as well as training the interpreters would have followed the focus groups. This involves investigating more than the professional credentials of translators as part of looking at the translation process (Esposito 2001). It means socially situating the interpreter/translator in relation to the research in terms of (for example) gender, age and religion. Qualitative researchers often argue that the social location of the research in relation to research participants influences the accounts produced. If this is the case, then the argument for inclusion needs to extend to include the interpreter/translator as active in the research (Temple 1997, Edwards 1998, Chesney 2000). Our project was the beginning of a process of investigating methodological issues within the practical constraints to which all research projects have to work. However, the study did allow us to think about future directions and ideals.

The three minority ethnic groups we involved in the study were convenience samples accessed in a particular way and these considerations need to be borne in mind when considering the data. However, we feel that given that the purpose of focus groups is to facilitate group dynamics rather than investigate individual opinions, their use in this project was justified and the rewards in terms of data and community group involvement are huge. Our research has highlighted the strengths of group work with minority ethnic community organisations. It has also pointed to some of the pitfalls and the need to use other methods to hear other, possibly different, voices.

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