Care and support for older people and carers in Bradford: their perspectives, aspirations and experiences

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This study explored the needs, aspirations and expectations of older people and family carers from a range of ethnic communities in Bradford, regarding both formal paid care provision and help from family, friends and neighbours. The focus was on the accessibility, acceptability, appropriateness and responsiveness of services. The study found cross-cultural similarities as well as cultural specificities in experiences and expectations.

Key points

- Irrespective of cultural or ethnic background, older people shared common expectations about caring relationships and access to services, as well as similar experiences of service delivery.

- Emotional aspects such as communication and trust were seen as the basis for effective and lasting relationships with both family carers and paid care staff. Some older people and carers expressed a preference for receiving care from staff or neighbours from their own community or neighbourhood.

- Older people and carers had strong views about what constituted ‘good practice’, judging the quality of services in terms of ‘the way they used to do it’ themselves. To understand these expectations, care staff had to be able to communicate effectively with them.

- There was a strong sense that services were run more for the convenience and budgets of service providers than for the benefit of the individual older person. Failure to understand the influence of lifetime experiences and cultural background could mean that individual preferences were not acknowledged.

- There was a general worry about what help would be available for older people who lived alone, with no family nearby, if they became unwell.

- Across all groups there was a desire for flexible, tailored services. Older people wanted more say in how and where they lived, the quality of their food, and who provided ‘that bit of help’ in their homes.

- Older people and carers often lacked information about the availability and function of services, and the progress of their assessments. They needed more help or time to think through the services offered to them, as the information was often complex and given at a time of crisis.

- Service providers need to be more culturally competent, avoiding and challenging ageist attitudes and assumptions about ethnic communities.

The research

By a team from Leeds Metropolitan University.
Introduction

The increase in the number of older people in the United Kingdom has resulted in several key government strategy documents addressing the implications of an ageing population for future services. These have sparked off a range of local initiatives. In Bradford, local targets include promoting the well-being of all older people so that they can play a full part in civil society, and improving the quality of life of dependent older people.

Although a number of studies had been carried out about or with older people in Bradford, Darlow et al. (2005) in their review ‘Researching Bradford’ noted a general lack of studies on issues of social care in Bradford and criticised existing studies for being too focused on specific ethnic communities (Pakistani, Bangladeshi, Indian) to the exclusion or under-representation of others.

Findings from existing studies

The 1991 census showed that the Bangladeshi and Pakistani communities, but less so the Indian community, had a high child dependency rate compared to the White British majority. It is therefore more likely that young adults and middle-aged cohorts of Bangladeshi and Pakistani carers face a ‘squeeze’ on their resources from both old and young dependants at the same time.

The 1991 census also showed that, because the demographic bulge of the migrant generation of the 1950s and 1960s from the Caribbean is quite tightly compressed in terms of time, this cohort of adults will start to age simultaneously in the African-Caribbean community and may present increasing care needs.

Several studies show that minority ethnic multigenerational households in contemporary Britain are not necessarily able to meet all the needs, especially the self care needs and the social and emotional needs, of their older dependents. The idea of self sufficiency in care in Asian immigrant communities (‘they look after their own’) was often shown to be unfounded.

In most households, regardless of their ethnic background, care of an older person or someone with disabilities tends to fall on one person only, usually a woman.

The preference of older people for formal and informal sources of support need not be mutually exclusive. The majority of the Asian-Indian and White British participants interviewed by Sin (2006) said they would like to use one or more available public services at some stage, regardless of their current use of public services and of the quantity and quality of informal support they received.

Potential barriers and factors that may restrict minority ethnic people from using health services were identified at three levels:

- Patient level; these barriers relate to patient characteristics, e.g. age, gender, ethnicity, lifestyle, etc.
- Provider level; these barriers relate to provider characteristics, such as medical procedures and practices, communication style, skills and translation.
- System level; these barriers relate to the organisation of the health care system, such as referral systems, the medical paradigm and organisational factors.

All these barriers were linked to the particular situation of each individual. Therefore, although some barriers were more likely among minority ethnic individuals, generalisations are not possible.

Services can fail to match older people’s needs in different ways, relating to:

- needs arising from short-term illness being overlooked;
- emotional needs being overlooked;
- inequity;
- inadequacy; and
- fragmentation.

Findings from this study

Shared expectations about service provision

This study identified seven common expectations among participants when they received help from professional care providers:

- To get some help with everyday tasks which they find difficult due to their age.
- To establish a caring relationship in which the recipients do not simply have a passive role. They
wanted their personal history and current needs to be heard, and responded to.

- To receive a flexible package of services tailored to their personal circumstances, needs and preferences and not decided by service providers on the basis of service priorities.
- To receive help that meets their high expectations of good practice (i.e. professional and ethical standards) and respects their personal dignity.
- To receive more information, preferably from a local source, on support and care they may be entitled to.
- To be able to receive care and support from care staff or neighbours from their own community, when this is preferred.
- Not to have to pay for service provision, particularly when older people are just above the threshold of having to pay and when the service is considered to be minimal or redundant. Older people resented being forced to draw on their life savings to pay for services.

These expectations were common to people from all the ethnic groups interviewed. A major effort is needed by formal care providers to understand the personal experiences of older people. This understanding is relevant for two reasons:

- It helps to develop person-centred communication, which is valued and expected by older people; and
- It is fundamental to understand older people’s needs, as well as their attitudes and beliefs about care and support, especially when they have different cultural backgrounds and culture-specific needs.

**Common experiences of service provision**

For many participants, paying for help through the adult services department was a financial burden. They resented drawing from their savings to pay for services because they wished to leave their life savings to their families.

Many participants reported very long waiting lists for ramps and stair lifts. Lack of information about the progress of their assessments led to frustration, and for many having to follow up needed and expected services and information was an added burden.

Participants thought that, in recent years, the quality and extent of available services had become poorer.

**Social services do far less than they did twenty years ago. They would clean houses, they would do washing; they will not do those kind of jobs now. They help people get up from a chair, not lift them, because of health and safety.**

(Polish female carer, 54, living with husband and disabled mother.)

Some participants reported episodes in which they or others had been discharged from hospital late at night to empty houses, without a previous check as to whether there were support networks (e.g. family and neighbours) available. Participants also described experiences of poor coordination between different service providers, which were a source of major frustration and disappointment.

Participants described how they had often missed out on services and entitlements through lack of information and follow-up communication. Many were not clear about whether they were eligible for services such as the local Access Bus, free TV licence, housing adaptations or Carers Allowance.

Older people and their carers said they needed more help or time to think through the services they were offered, as they took longer to process complex and large amounts of information. They said they needed to be given information at different points in time, not just immediately after a health crisis as they often underestimated the impact on their life at this point. They also preferred to receive information at local places such as doctor surgeries.

Older people and carers gave examples of ageist attitudes and assumptions about ethnic communities among GPs, in hospitals, and in care homes. BME older people did not expect care staff to replicate all behaviours relating to their cultural or religious beliefs, but did want respect and dignity.

**Specific needs and expectations about service provision**

Older people caring for non self-sufficient adults with learning difficulties felt strongly that a protocol was needed to take care of such dependent adults in case their only carer was taken away by ambulance and hospitalised.

Religious beliefs framed many of the Muslim older people’s expectations, for example prayer rooms in housing services and halal food. Those from minority ethnic communities expressed preference for a diet based on their own national food. However, they emphasised that the provision of food in residential settings or through delivery services such as ‘meals on wheels’ should also aim for quality in the preparation of food, and attention to individual preferences.

Some older people experienced major financial constraints. This was particularly stressed by Bangladeshi older people. These study participants experienced poverty after their retirement and expressed frustration about not being able to receive help or information from services on this matter.
Importance of emotional needs

The study participants shared common views about the importance of emotional needs, particularly communication and trust, to establish effective and lasting caring relationships. However, this similarity in the participants’ views did not necessarily imply a similarity in their preferences for how services should respond to their emotional needs. In addition, specific sub-groups of older people, such as widowed women and men, presented specific emotional needs beyond communication and trust.

By ‘communication’ the study participants primarily meant awareness and responsiveness of care staff to older people’s personal caring preferences and individual backgrounds. However, for older people of minority ethnic backgrounds who were not fluent in or could not speak English, communication also meant the removal of language barriers.

By ‘trust’ the study participants meant personal safety when having ‘strangers’ visiting them, but also their need to have confidence in their care staff before they could give them tasks that they could no longer do themselves, which they felt were important to their well-being and quality of life. Trust took time to develop, but could be facilitated if there was a previous connection between the older person and care staff. These connections did not necessarily imply a common ethnic background between care staff and the older person.

Another strong theme was loneliness and social isolation, often aggravated by physical health problems. The wish to be able to get out and about was common. Older people living alone with no family nearby worried about becoming unwell if no one was available to help them.

Conclusions

This study identified a number of key messages for services to consider:

- Older people and carers share common expectations, regardless of their ethnic and cultural background, about the quality and equity of services.
- Older people have a common desire to retain their independence for as long as possible and not be a burden to others.
- Older people also have individual expectations, aspirations and desires based on their life experiences, cultural, religious and ethnic background.
- Older people and carers are concerned about the availability of help for older people who live alone, if they become unwell.
- Carers and older people base their judgement and evaluation of care services on ‘the way they would do it themselves’.
- Good communication should develop trust, ensure that information is timely and understood, and enable older people and carers to have control over their care packages.
- Older people need more time to process complex information about service entitlements and benefits.
- Many carers and older people miss out on benefits and services they would be entitled to because of the complexity of accessing them.
- Older people’s and carers’ resourcefulness can offer solutions that are individually tailored and examples of ‘thinking outside the box’.