Developing dementia services for an Asian community

The under-representation of ethnic minority populations in dementia services has been a long-standing concern of researchers and service providers (Milne, 2002). National evidence suggests that service development is only now coming to terms with the fact that the populations that immigrated in the 1940s are ageing.

There is an urgent need to develop appropriate health- and social-care services to meet age-related needs, including dementia. Across the UK there is a scarcity of specialist dementia services for ethnic minority populations (Mental Health Foundation, 2003).

Since the ‘Forget-me-Not’ reviews of mental-health services for older people (Audit Commission, 2000, 2002) and the implementation of the National Service Framework (NSF) for Older People (Department of Health, 2001), developing appropriate dementia services for ethnic minority groups has been a policy and service priority. The Forget-me-Not reviews served to highlight the paucity of services for ethnic minorities and the lack of coherence in dementia care.

The government requires the NHS and local councils to develop protocols for the diagnosis, treatment and care of all patients in their area with depression and dementia. Assessing the needs of family carers is also a priority.

Projects focusing on the needs of people with dementia from ethnic minority groups are supporting the achievement of policy goals by informing service development and good practice. One such project is working with an Asian population in north-west Kent; it is based in a dementia care charity (Alzheimer’s and Dementia Support Services) in Gravesend, and is funded by the Mental Health Foundation.

The key aims of the project are to:

- Investigate the nature and extent of dementia among older people from the community and their families
- Explore what kinds of services and support older people and their carers want
- Determine how best to take forward service development

The local context

Nearly 70% of the ethnic minority population in north-west Kent reside in the Dartford and Gravesend area, of which Gravesend is a part (Figures 1 and 2).

The 1991 Census data evidences that the Asian population forms the single largest ethnic group in the area, and 81% of the 15,000 ethnic minority people are thought to be of Punjabi Sikh origin. This population has been established in north-west Kent since the 1940s when the first immigrants arrived. They migrated as a result of active recruitment by the British government, to offset severe shortages in the labour force following the Second World War.

The early settlers to north-west Kent originated from a few villages in the state of Punjab in North India where the small number of families knew each other well (Saheli, Writers Group, 1994; Ilyas, 1998). They were primarily young males who intended to stay temporarily, achieve economic prosperity and return to India to support their extended families. They considered a trip to England to be an opportunity of a lifetime and a reality for only a lucky few.

Thus, over a period of time, as these early settlers became financially secure, they chose to send for their friends and family members to share their good fortune. As a result, the community grew and became established. In fact, at one time it appeared as though the whole village, with its social order and relationships preserved, had been transported to Gravesend (Pamneja, 1997).

Community members continue to be close and tend to know each other very well.

Most of the early migrants came from unskilled farming families and took up manual jobs in local factories. Although over the years many have moved onto more skilled occupations, the community is still largely working class. More recently, the area has seen an influx of Asians from the Midlands and the north of England; most have moved to north-west Kent as a result of marriage.

As the younger, second generation of immigrants have become adults and married partners from different backgrounds, their priorities, beliefs and values have changed. This change continues and is accelerating, with particular implications for traditional support structures and family care relationships. It also exposes a need for services for older people with long-term health problems.

The development of dementia services for the Asian population in north-west Kent has been slower than in many other parts of Britain. This may be owing, in part, to the unique history and experiences of this population as well as the fact that it has been rather isolated and separate. Only now is it evident that there is a significant number of people with dementia in this area and concerns are being raised by service providers and some ser-

In a project funded by the Mental Health Foundation, Viniti Seabrooke and Alisoun Milne investigate the need for dementia services for an Asian community in Kent.

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Emerging evidence: key issues

Although the project is not completed, a number of themes have emerged from the fieldwork.

Are they still 'looking after their own'? 

Initial findings indicate a degree of conflict between the expectations of older generation Asians and the aspirations of their younger second-generation offspring.

While there remains a strong desire to fulfil the expectations of their parents, it is becoming increasingly difficult for younger people to 'look after their own'. The myth that Asian families provide care to their older relatives remains strong (Social Services Inspectorate, 1998).

The second generation immigrants engage with the indigenous population far more than their parents and have to contend with high degrees of cultural conflict and racism. The resulting conflict between the 'traditional' and the 'western' has undermined family bonds and assumptions about intergenerational reciprocity.

Thus, the question about whether older Asians with dementia are being adequately supported by their families arises. Concerns have been expressed by both primary and secondary health-care providers about the reluctance of Asian families to acknowledge the existence of mental ill health, including dementia, and the lack of preparedness of relatives to ask for support from services.

At the same time, hard-pressed GPs – including a number of Asian GPs – do not regard dementia care as a priority and have a vested interest in 'leaving well alone'.

Such practice may, at times, be colluding with a cultural norm that leaves an older person with dementia in an unsatisfactory situation and their carers stressed and unsupported. The assumption that all family care is of good quality is not an accurate one. As one Asian woman in a focus group commented:

‘Our society is such that we look unfavourably on people who have to ask for help and therefore we are too embarrassed to ask for help.’

In particular, problems can arise when the role falls upon a daughter-in-law who may not only be looking after her own family but also working to contribute to the family income.

One of the related consequences of GPs and other health-care professionals failing to engage with dementia-related issues in the Asian population is a failure to facilitate early diagnosis of dementia. This is a specific aim of the NSF for Older People:

‘For older people with suspected dementia, early diagnosis gives access to treatment, allows planning for future care, and helps individuals and their families to come to terms with the prognosis.’ (DoH, 2001)

The early detection of dementia is particularly important for those with a vascular dementia, as two of the known risk factors – hypertension and diabetes – are treatable. Treatment can improve cognition and delay or terminate recurrent cerebral infarctions (Amar and Wilcock, 1996).

Lack of knowledge

Recognition of the symptoms of dementia is a key factor in facilitating a diagnosis of dementia and accessing support (Adamson, 2001). Through delivering a number of workshops entitled ‘What is dementia?’ to the local community, it is clear that there is very little existing knowledge about the disease.

This observation has led to work being carried out in and with the community to raise awareness of dementia, while at the same time taking the opportunity to challenge some of the myths and stigma associated with the condition. The Punjabi language has no word for dementia and, as a result, many Asians do not have any concept of the condition as it is understood in the West. Instead, there is often a very negative view of a person with dementia as ‘having gone mad’ in their old age.

In its early stages, dementia is often regarded as ‘a normal part of the ageing process’. This perception, coupled with the lack of knowledge about treatment and services, acts as a powerful barrier to both users and carers seeking help. The raising of awareness about dementia has proved to be of paramount importance in the project.

Without the first step of acknowledging that dementia exists and that it is not an illness to be ashamed of, it will be impossible to achieve the second-stage aims of improving user and carer quality of life by gaining access to treatment and support, and influencing the development of future services.

Cultural conflicts

In addition to knowing little about dementia, the community is also poorly informed...
Kent County Council is committed to meeting the health- and social-care needs of older people from black and minority ethnic communities, and has embraced the challenge of introducing culturally-sensitive care for older people (Kent County Council, 2002). However, there still remains a gap in the provision of such services for Asian elders with dementia. This situation needs to be addressed as a matter of urgency.

Conclusions

Although research is patchy, there is a growing body of evidence about the prevalence and incidence of dementia among Asian populations and the nature of support needs. In order for local service development to be informed and effective, it remains essential that local studies investigate the specific needs of discrete populations. Geographical and specific population needs differ, as do service contexts and care pathways (Department of Health, 2002).

The north-west Kent project suggests that a number of challenges face service providers in meeting the needs of Asian older people with dementia and their carers. Although the research is not complete a number of issues are clear:

- Much work needs to be done to educate and inform the community about dementia, dementia symptoms, treatment and services
- Existing barriers to service usage by users and carers need to be addressed
- Service providers, particularly GPs, alongside community leaders and carers, need to be involved in planning services that are acceptable and culturally appropriate to the Asian community

Owing to the history and experiences of the community, it may well be necessary to develop separate specialist dementia services for the current generation of elderly Asian people.

The project continues until the end of 2003, it will be able to offer clear recommendations about service development at that stage. NRC


Ilyas D, ed. (1998) Mirrors In the Sand. Saheli Writers Group, Gravesend

Social Services Inspectorate (1998) They Look After Their Own, Don’t They? Her Majesty’s Stationery Office, London

Further information

The Mental Health Foundation is developing a website concerned with mental health in later life. It contains a learning network which includes an area focused on ‘Dementia and Diversity’.

This can be found at: www.MHlii.org/network/network.htm