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How a link nurse ensured equal treatment for people of Asian origin with dementia

People from black and minority ethnic communities are under represented in mental health services. A trust introduced an Asian link nurse to help address this

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A review of services for older people with dementia from black and minority ethnic (BME) communities in Wolverhampton found that these groups were under represented in mental health services. Problems included a lack of information about and awareness of services, confusion about the mental health condition and a reluctance to ask for help.

The review also highlighted that the proportion of older people with dementia from BME groups is set to increase significantly.

It made several wide ranging recommendations to improve access to and uptake of services for these groups, which led to the creation of an Asian link nurse role specifically for Punjabi speaking people of Asian origin.

This practitioner is a qualified community psychiatric nurse, who speaks Punjabi, related languages and English, and understands the relevant cultural issues.

This model has been used elsewhere and we believe it should be adopted more widely to ensure equal access to culturally appropriate services for older people from BME groups.

INTRODUCTION

By the end of the 20th century, Wolverhampton had become a multi ethnic community (Ballard, 1994). While many of those from black and minority ethnic (BME) groups are young now, the number of older people of Asian and African Caribbean origin is projected to rise dramatically over the next 20-30 years, with a corresponding change in the ethnic profile of dementia (Table 1).

By 1999, health and social care agencies in the city had become aware of this, and were also aware that older people from these groups were under represented in mental health services.

In the same year, a multi agency meeting to review the health of those from BME communities took place (see Background box; discussed here and in Jolley et al, 2009).

This review led to further research, conducted by Dementia Plus, the Dementia Service Development Centre for the West Midlands (which has now merged with *for dementia* to become *for dementia plus*). The resulting study, entitled *Twice a Child*, reviewed relevant literature, engaged with local community leaders and organisations, and identified and interviewed people with suspected dementia and their carers from South Asian and African Caribbean communities (Jolley et al, 2009; Moreland et al, 2005).

The findings led to wide ranging recommendations in several areas, including a five year plan for BME groups and voluntary organisations, which highlighted the need to:

- Give dementia a higher priority;
- Develop partnerships – planning, monitoring and delivering services;
- Learn from other service areas as well as places such as Bradford, which also have ethnically diverse populations;
- Help develop support groups;
- Provide culturally appropriate day, respite and residential care;
- Contribute to training and the distribution of information, such as the African Caribbean pamphlet *Sound Me Doctor*.

A policy decision was made to appoint a community psychiatric nurse to work as an Asian link team leader, to help implement these recommendations.

BACKGROUND

- Wolverhampton's 1999 multi agency review of all aspects of health in black and minority ethnic communities received presentations on current and projected demographic characteristics, as well as outlines of services available to older people with dementia and similar conditions.
- Calculations suggested the number of people with dementia of South Asian and African Caribbean origin would increase from 3.6% to 9.8% of the total number of older people from 1991-2011.
- Figures on service use showed that BME groups were not using them in the numbers predicted. Anecdotal evidence suggested the reasons for this included confusion over whether some conditions were illnesses or simply part of the ageing process, reluctance by families to ask for help and staff insensitivity when people did approach statutory agencies.

PRACTICE POINTS

- The Asian link nurse has played a vital role in providing information and education about dementia and related conditions for older people of South Asian origin.
- This service model should be repeated in other areas with high numbers of older people from black and minority ethnic groups.
- Difficulties may arise in basing a service on one specialist practitioner, and sufficient funding is important to avoid burnout. Consequently, the Wolverhampton service is considering appointing a social services equivalent professional and starting a multidisciplinary, multi agency team. Extra nurses may also be appointed.

SERVICES IN THE CITY

In 2001, nearly one fifth (19%) of Wolverhampton's population was over retirement age. People of South Asian origin constituted 14% of the city's population (Office for National Statistics, 2003) (Fig 1 shows religion), with other BME groups making up a further 8%.

The mental health service for older people was organised as three multidisciplinary community mental health teams for three different areas of the city. Families of South Asian origin live in all three areas; the dominant faith is Sikh and the main language Punjabi.

When the Asian link team leader post was set up, mental health services for older people consisted mainly of assessment beds, a memory clinic and day hospital, and a joint social service and healthcare resource centre. Two residential homes provided specialist nursing care for people with advanced dementia.

Harjinder Kaur, who was already an established community psychiatric nurse in one of the community mental health teams for older people, was appointed as the Asian link nurse for the city, initially part time. This nurse speaks fluent Punjabi and English and has knowledge and understanding of all the Asian languages and cultures represented in Wolverhampton. Her remit has been to implement several recommendations of the 1999 multi agency review and the Dementia Plus 2001 report (Jolley et al 2009). Activities so far have included:

- **Promoting knowledge, understanding and sensitivity of cultures**: the link nurse undertook in-reach developments, where services are taken to people or facilities, rather than waiting and responding to referrals, in health and social services in Wolverhampton, especially in residential and day care centres. Here, she introduced Asian cultural symbols and gave staff some basic training in Asian languages. While useful, this aspect of service development requires constant staff development to take account of staffing and service changes. An Asian carers' support group (Box 1, overleaf) was set up to provide a social, learning and communication forum for carers of Asian origin;
- **Contributing to the development and distribution of information in different formats and languages:** leaflets on dementia were produced in each of the four main Asian languages. Audiotapes of the leaflets were developed for those unable to read, or whose preference was for aural rather than visual information;
- **Providing outreach within communities:** the link nurse developed personal contacts with older people with dementia and their carers in the Asian community. In many cases, she developed these relationships further, via the Asian carers' support group for which the link nurse was initially responsible, and the more general help and advice she gave while visiting and supporting older people with dementia. The link nurse also gained access to a variety of community venues such as temples, where she provided information and gave talks and presentations. She also sought out facilities such as local radio, newspapers and community publicity rallies, and gave talks and interviews;
- **Identifying and making use of vehicles for publicity:** other resources such as videotapes on dementia were bought and made available to community groups through Dementia Plus;
- **Preparing for client and carer involvement:** the link nurse made herself available at all times to people from the Asian community who wanted to discuss how to identify dementia and the procedures for formally doing so;
- **Involving communities in the planning process:** planning groups involved in health and social services, and the voluntary sector can consult with individual families or with the Asian carers' support group; here, the nurse acted as a reference point and conduit. Being known to the main agencies, she was able to put them in touch with individuals or groups who are willing and equipped to give evidence from a user or carer perspective from the South Asian community;
- **Supporting improvements in primary care:** the link nurse contributed to training in identifying dementia and providing appropriate services in three weekly half day sessions, which took place during the project's early days and included GPs, practice nurses and ancillary staff. It was well received and led to extra referrals to the specialist service; further talks are planned. Links with Dementia Plus were important in establishing follow up research on carers' experiences;
- **Encouraging liaison in acute hospital settings:** liaison around older people with mental health problems at the general hospital was functional but not well developed until recently (2004). Issues relating to people of South Asian origin are passed, where appropriate, to the community mental health team for older people, which now passes them on to the link nurse. A liaison service for home treatment was set up with a base in the accident and emergency department at the local hospital;
- **Piloting alternative services:** the link nurse has been involved in a number of developments, either directly or in an advisory role. These have included introducing Asian cultural artefacts such as pictures and paintings at day care centres, as well as training for staff in elements of language and culture. More services are now

FIG 1. 2001 CENSUS: OVERALL VIEW OF WOLVERHAMPTON – RELIGION

Source: Office for National Statistics (2003)

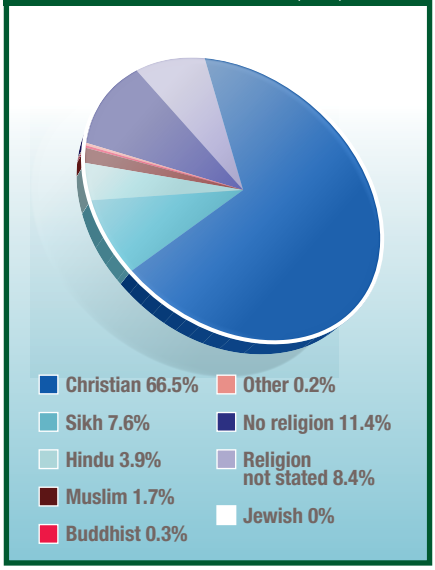

TABLE 1. CHANGING ETHNIC PROFILE OF PEOPLE WITH DEMENTIA IN WOLVERHAMPTON (PREDICTED)

	Number	% white	% Asian	% black
1991	2,321	96.4	2.6	1
2001	2,732	94.1	3	2.9
2011	2,957	90.2	6	3.8

Source: based on prevalence rates from Wolverhamptom City Primary Care Trust (2005)

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delivered at home, calling on the link nurse where necessary to ensure they are as appropriate as possible;

- **Improving and increasing access to services:** this has perhaps been the challenge that underpins all others. While the predicted number of older people of Asian origin with dementia and similar conditions is increasing, this was not reflected initially in referrals to relevant agencies (see below for details on the link nurse's caseload). Nonetheless, enhancing knowledge, understanding and access has been the most obvious and most important success of the new appointment;
- **Supporting community and voluntary groups:** the link nurse established an Asian carers' support group in 2001 (Box 1). The group now has more than 100 affiliated members, with 20-30 carers regularly attending monthly meetings. The local authority provided support to employ an administrator to manage meetings and activities. The Asian women's group Asian Women's Adhikar Association (AWAAZ) now has full responsibility for running the group, in liaison with the link nurse;
- **Helping to ensure day, respite and residential care is culturally appropriate:** While some initiatives have taken place in this area, particularly at the Blakenhall Resource Centre, staff in the service cannot be complacent. There has been a small but steady increase in the use of personal, direct payments (tinyurl.com/direct-payment-page) in the Asian community. Under this system, families will contract individuals to undertake defined care work rather than receiving care via commissioned agencies. While this reduces the problems of multiple carers, staff recruitment and turnover remain a significant problem.

Specific developments to date have included cross cultural food awareness and tasting sessions, excursions and special celebratory social events at times such as Diwali.

Caseload

Since this innovation began, the specialist service has notified the link nurse of any referrals for older people of South Asian origin. She has contributed to their assessment, care planning, treatment and aftercare, following clients and supporting families.

By 2006, the link nurse had a caseload of 88 clients with mixed diagnoses. The ongoing caseload includes new referrals, which have varied from 25 to 40 per year, and others from previous years. Client contacts have risen from 473 in 2003 to 652 in 2006 and have remained at that level.

The rate of contact per population at risk is now higher among people of South Asian origin than in the general population.

BOX 1. ASIAN CARERS' SUPPORT GROUP

The Asian carers' support group was set up in 2001, and usually meets monthly.

More than 100 carers are registered with the group, which now has a dedicated part time support worker from the Asian women's group AWAAZ. Usually around 20-30 carers attend each month and the meetings feature a variety of activities. Speakers make presentations about issues such as diabetes, managing drinking and high blood pressure, telecare and personal payments.

Carers also enjoy social activities, including planned excursions to local amenities and trips further afield. The group also tries to give carers different experiences, and a recent example was a visit to a Chinese restaurant.

The Asian link nurse often attends meetings and events, providing informal advice and assistance, such as service liaison or personal advice on managing issues related to dementia.

MEETING THE CHALLENGES

There is little doubt that health and social care services should prioritise the challenge of reaching out effectively to older people from minority groups (Oommen et al, 2009; Livingstone et al, 2002; Royal College of Psychiatrists, 2001).

Research consistently demonstrates the relatively low levels of engagement among all BME communities in the UK and US, and identifies blocks and beliefs that underpin the "triple disadvantage" of age, ethnicity and mental health problems (Hinton et al, 2004; Livingstone et al, 2002; Rait et al, 1996).

There are calls to identify models of good practice in providing information, education and sensitive services (Oommen et al, 2009; La Fontaine et al, 2007; Ayalon and Areas, 2004; Karrier and Hall, 2002).

Initiatives to counter the imbalance and failings of services point to the need for information and education (Daker-White et al, 2002; Royal College of Psychiatrists, 2001). Primary care is often singled out for criticism as blocking access to specialist care out of ignorance and misunderstanding (Knapp and Prince, 2007).

However, specialist services are not without fault either, as they lack staff with language skills and are unprepared to modify environments to make them acceptable to minority cultures (Purandare et al, 2006).

The Department of Health (2005) discussed the advantages and disadvantages of both mainstream services and culture specific facilities.

Asian link nurse project

The Asian link nurse initiative has been extremely successful in implementing many of the ideas that emerged from the 1999 multi agency review in Wolverhampton.

The nurse's commitment and personal attributes have played a key part in the project's success: she has been both part of the community and part of healthcare

BOX 2. CASE STUDY – EDUCATING THE FAMILY

Rupinder Kaur is a 91 year old Sikh woman who lives with her three sons and their wives and children. Her GP referred her to the Old Age Psychiatry Service, saying she was confused and agitated.

On assessment, Mrs Kaur was confused and aggressive, ordering the CPN Asian link nurse and the old age psychiatrist to leave the house. The family were distressed about her behaviour and, during the family assessment, it became apparent they had no knowledge of mental illness or dementia. Mrs Kaur had been behaving in this way for several months and it was only when she became extremely agitated and aggressive that the family sought professional help. She was diagnosed with Alzheimer's disease.

Mrs Kaur was offered day care but this was not appropriate as the language barrier made her more agitated. At this point she required one to one care, particularly at mealtimes. As a result she attended day care at a specialist mental health home where she receives one to one care from staff of Asian origin familiar with her culture and Punjabi language.

While arranging Mrs Kaur's care plan, it was important to keep the family updated.

However, their lack of knowledge about dementia led to conflicts between them. The family were therefore educated about the condition using information sheets in different languages and a video, and the link nurse offered them support and advice, which helped them to better manage Mrs Kaur's care.

services, providing a reliable source of help, information, education and enthusiasm. The process has involved encouragement, understanding and championing from within the community rather than exhortation from afar.

This process and its success have been echoed in London (Goodorally, 2008) and Nuneaton (Mirza, 2008).

The case studies in Boxes 2 and 3 show the importance of maintaining contact with family members and remaining active in managing care for people with dementia, as it affects the whole family rather than just one person.

** All names have been changed.*

CONCLUSION

The Asian link nurse has succeeded in increasing effective contact between specialist old age psychiatry services and older people with dementia from BME groups.

This practitioner has played an important role in disseminating information about dementia and related conditions and in educating the South Asian community and professionals on the help available.

In addition, a vibrant and effective group for carers offers support and a source of constructive criticism and guidance for service commissioners and providers. We would recommend this model to other communities. ●

BOX 3. CASE STUDY – PROVIDING SUPPORT FOR CARERS

Banta Singh is a 58 year old Sikh man who lives with his wife. His GP referred him to the Old Age Psychiatry Service, and he was assessed and diagnosed with early onset dementia, and offered day care.

Mr Singh is a baptised Sikh and therefore cannot eat particular foods and ingredients. At mealtimes he became continuously agitated and disruptive as he was unfamiliar with the food offered, such as a jacket potato. As a result of this, his wife, who was his carer, withdrew him from the day care as she felt his needs were not being met.

Mr Singh was then offered the option of having a carer come to sit with him to offer his wife some respite care, but a lack of Asian male carers meant this service was also inappropriate for him. His wife is now caring for him full time, with help from her son who lives nearby.

As with all carers, Mr Singh's wife was offered carer support. She continues to attend the carer support group where she can have a break and socialise with others, and also has the opportunity to raise any matters of concern. The link nurse continues to give her support and advice in managing Mr Singh's care.

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