

Early intervention in dementia care in an Asian community

Lessons from a dementia collaborative project

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ABSTRACT

The number of older Asians in the UK is increasing placing greater numbers at risk of developing dementia. The emerging need to address early diagnosis is especially prominent in areas where Asian communities are long established. This was the specific focus of a Dementia Collaborative Project in North West Kent. The project, working through a primary care practice, aimed to raise awareness of dementia and to facilitate early intervention and access to specialist dementia services. Using an evaluation methodology adopted by the Collaborative and working through a multi-agency steering group, the pilot project successfully identified an appropriate primary care practice, established a link with a specially trained Asian nurse and devised a set of project materials. By inviting older Asian patients with memory problems to make an appointment with the nurse, and enclosing a culturally relevant information leaflet, older people were encouraged to come forward. Although the number of individual patients identified was small, the project outcomes include: significantly increased referral rates from black and minority ethnic communities to specialist services and greater awareness of dementia-related issues in both primary care and Asian care services. Overall, the evaluation suggests that by engaging with a committed primary care practice it is possible to engage a hitherto marginal group of older people in early intervention in dementia and raise awareness about its benefits. That this approach underpins the development of a larger scale five year project in the same area additionally endorses its relevance for the mainstream population.

KEY WORDS

dementia diagnosis early intervention primary care evaluation
asian communities dementia collaborative

INTRODUCTION

The evidence base in relation to the effectiveness of early diagnosis of dementia is developing apace (Milne *et al.*, 2008). At the same time the number of older Asians at risk of developing dementia is growing. A unique pilot project, led by a specialist dementia care charity and set up under the auspices of the South East Dementia Collaborative, aimed to bring these two issues together by raising awareness of memory problems and facilitating access to early intervention for older Asians in North West Kent. The project was evaluated using the Dementia Collaborative 'methodology' and the lessons that emerged are not only useful to project participants but have wider relevance for the Asian community in the UK and for early intervention in dementia care more widely.

Background

Dementia is a major cause of disability amongst older people; it constitutes one of the most serious, and expensive, challenges currently facing health and social care services in the developed world. At present approximately 700,000 people in the UK have dementia; this figure is projected to rise to over 1.7 million by 2051 (Alzheimer's Society, 2007). Although rates of dementia are lower amongst black and minority ethnic communities (BME) due to their younger population profile, the number aged over 60 is predicted to multiply ten-fold over the next 15 years. The current figure of 175,000 black and minority elders has been estimated to significantly increase to 1.8 million by 2026 as first generation migrants – those who came to the UK between the 1950s and 1970s – reach retirement age (Office for National Statistics, 2002; Age Concern, 2007).

As the Asian population is the largest ethnic minority in the UK, the implications of this ageing shift for health outcomes is particularly significant. Of the 3% of elders belonging to an ethnic minority in the UK, half (1.5%) are Asian (Katbamna & Matthews, 2006). In addition to the risks of Alzheimer's disease, which is predominantly linked to very old age, increased risk of vascular dementia has been identified

amongst some Asian sub-populations; this is due to enhanced levels of hypertension and diabetes (Seabrooke & Milne, 2004). At present there are a higher number of older men with dementia than women; this is a consequence of original patterns of migration to the UK whereby men came over to the UK for employment leaving their wives and families behind (Bowes, 2006). That their wives tend to be at least five years younger is also a factor. Whilst specificity of prevalence of dementia within minority groups is limited, the Alzheimer's Society's 2007 report *Dementia UK* estimates that nearly 11,400 people from ethnic minorities currently have dementia; this represents 1.7% of the overall total. It is noteworthy that 6.1% of the BME group total is young onset cases – that is onset between the ages of 30 and 64 years – compared with only 2.2% for the UK population as a whole.

The importance of the early identification of dementia for older people with concerns about cognitive function is now widely accepted. It is increasingly emphasised as a legitimate goal of policy and practice and is a key focus of the *National Dementia Strategy* (Department of Health, 2009; National Audit Office, 2007). The pivotal role of primary care staff in facilitating this process is well established and there is some recent evidence that increasing numbers of GPs recognise the value of early identification (Milne *et al.*, 2005; 2008). This shift is, primarily, a reflection of its importance for users and their families, the advent of cholinesterase inhibitors and improvements in services for people with dementia and their carers. Access to targeted training for GPs also plays a role as does recognition of the part played by early diagnosis in influencing longer-term health-related outcomes (Turner *et al.*, 2004; Banerjee & Chan, 2008).

Despite this, inadequate detection rates have repeatedly been documented with failure rates estimated as between 50% and 80% for moderate to severe dementia and up to 91% for milder cases (Boustani *et al.*, 2005). Continuing evidence to suggest that 'timely referrals' to specialist mental health services are far from universal, adds additional impetus to the drive for effective

early identification of dementia in primary care (Ilfie *et al*, 2002; National Institute for Health and Clinical Excellence & Social Care Institute for Excellence, 2007).

Local context

Nearly 70% of the ethnic minority population in North West Kent reside in the Dartford and Gravesham area. The Asian population forms the single largest ethnic group. Most are of Punjabi Sikh origin and have been living in the area since the 1940s when active recruitment by the British Government encouraged labour migration to offset post World War II shortages (Office for National Statistics, 2002). The first settlers came from farming families in Punjab, North India. Recently, the area has seen an influx of Asians from the Midlands and the North of England. Community members tend to be close and know each other well (Seabrooke & Milne, 2004).

THE NORTH WEST KENT DEMENTIA COLLABORATIVE PROJECT

The South East Dementia Services Collaborative was established in 2006 under the umbrella of the Care Services Improvement Partnership (CSIP); it was part of a national policy drive to improve service outcomes for people with dementia and their carers. One of its key aims was to facilitate the development of 'good practice' exemplars of innovative services. In the south east region one of the 18 collaborative projects was the North West Kent Black and Minority Ethnic Dementia Project. Its primary aims were to raise awareness of 'memory problems' in older Asians and facilitate access to dementia screening and diagnosis. Its secondary aim was to encourage referrals from primary care to secondary care including the community mental health team for older people, social services and also to specialist voluntary agencies. As was the case for all collaborative projects, this project received no additional funding from CSIP.

The North West Kent project began work in September 2006 and ran until October 2007. It was led by a local well known and trusted voluntary agency – Alzheimer's and Dementia Support Service (ADSS) – and was supported by a multidisciplinary and multi-agency steering group. The project built on the success of an earlier initiative that explored the under-representation of Asian people in dementia services in the area. This project identified a profound lack of awareness about dementia in the Asian community, a need for ongoing information sessions about dementia, diagnosis and dementia-related services and the development of culturally appropriate dementia care services (Seabrooke & Milne, 2004). These findings supported the wider evidence base that people from ethnic minority groups are under-represented in dementia services and are particularly reluctant to ask for help from primary care at an early stage in the dementia trajectory (Moriarty & Butt, 2004).

Project structure and management

The project had a number of interconnecting stages. It began with a 'process mapping exercise' which articulated the 'journey' for the older Asian patient with concerns about their memory. As evidence shows that the time period between a person's recognition that they have a memory problem and making an appointment with their GP varies from 8–32 months, the project targeted resources on reducing this delay (National Audit Office, 2007). Once a patient has taken the initial step of making an appointment with his/her GP, referral onto secondary care for diagnostic tests is the 'next step' in the dementia journey and is relatively quick, usually involving a wait of no longer than four months.

At the same time, the project team conducted a survey of all 39 primary care practices in North West Kent with the twin aims of gauging the level of interest in taking part in the project, and to gather data on practice characteristics – its size, the number of ethnic minority patients registered, and the number of patients they had on their Dementia Register

(QOF)¹. Fifteen responses were received with five practices declaring an interest in being involved; one of the key reasons for unpreparedness was a low proportion of BME patients. A bilingual leaflet (English/Punjabi) entitled *Ageing and Memory Problems: The help available* was also produced providing information on the most common types of dementia, reversible causes of memory problems, and local services.

One large practice which served a significant number of BME patients was chosen as the 'pilot site'. A relationship was established with the practice manager and the newly appointed Asian nurse practitioner, who was keen to engage with dementia-related issues. Care was taken to exclude patients already known to have a dementia diagnosis and/or who were in receipt of support from specialist dementia services. The information leaflet was sent to 167 patients with a letter inviting them to make an appointment to see the nurse practitioner (or GP if preferred) if they had any memory-related concerns; this was to be done within a six-week period. Leaflets were left in the surgery waiting area after the initial six-week period; a number were picked up by both BME and white patients and also by family members.

The nurse practitioner received targeted training from the local old age clinical psychologist – on dementia symptoms, management and treatment, dementia screening and the role and function of specialist/support services. The psychologist was also a member of the steering group. Supplementary advice on appropriate dementia screening instruments was also given by one of the steering group members following an extensive review of measures (Milne *et al*, 2008). The General Practitioner Assessment of Cognition was chosen as the most appropriate screening instrument and as is consistent with good practice the nurse practitioner took bloods from concerned patients to exclude reversible causes (Brodaty *et al*, 2002). The nurse practitioner acted as liaison between the project and the GP practice, disseminated information about dementia

support services and raised awareness about the importance of early identification, amongst patients, their families and staff (Milne *et al*, 2005; Iliffe & Manthorpe, 2004).

Evaluation framework

As was the case for all Collaborative projects, the North West Kent Project recorded its activities and evaluated progress using the collaborative 'methodology'. This utilises plan-do-study-act (PDSA) cycles to effect small changes with the aim of identifying and improving outcomes and ensuring sustainability; it also adopts a focus that is informed by the user's pathway through the service system (Langley *et al*, 1996). The steering group reviewed the project's progress through the lens of PDSA cycles at each monthly meeting. The South East regional collaborative co-ordinator also provided regular support.

PROJECT OUTCOMES

The first Asian patient was seen within three weeks of the letters going out and a further four patients by the end of the six-week period. Three of these patients were referred onto secondary care services following the screening interview and one was being 'closely monitored' by his/her GP (see **Table 1**). It is notable that no Asian patients presented with memory concerns in the three month period prior to the project's implementation.

The project also had a direct impact on the number and quality of referrals to secondary and specialist services. For example, there was a 37% (N=133) increase in the numbers of patients referred to the Jasmine Centre – a specialist clinic for memory assessments during the 12 month period of the project; this compares with 97 referrals during the previous year. Although only a relatively small proportion of these were BME patients, the size of the increase strongly suggests that the project raised awareness of the existence and value of specialist services amongst GPs. As

¹Quality and Outcomes Framework (QOF) is a component of General Medical Services contract for general practices. In 2006/07, the allocation of QOF points was introduced for practices that can keep a register of patients with dementia.

Table 1: Patient details and referrals

Patient No.	Gender	Age	Referred to:
1	Male	68	Secondary mental health services
2	Female	65	GP – for close monitoring
3	Male	66	Alzheimer’s and dementia support services
4	Female ²	93	Social Services
5	Female	66	No referral needed

²This lady was the mother of patient No. 3 and was identified by ADSS during a home visit to assess the 66 year old gentleman for support services. She was referred to Social Services.

referrals came from a range of practices, not just the pilot one, this further suggests that the initial survey ‘sounding out’ practices played a role in raising awareness.

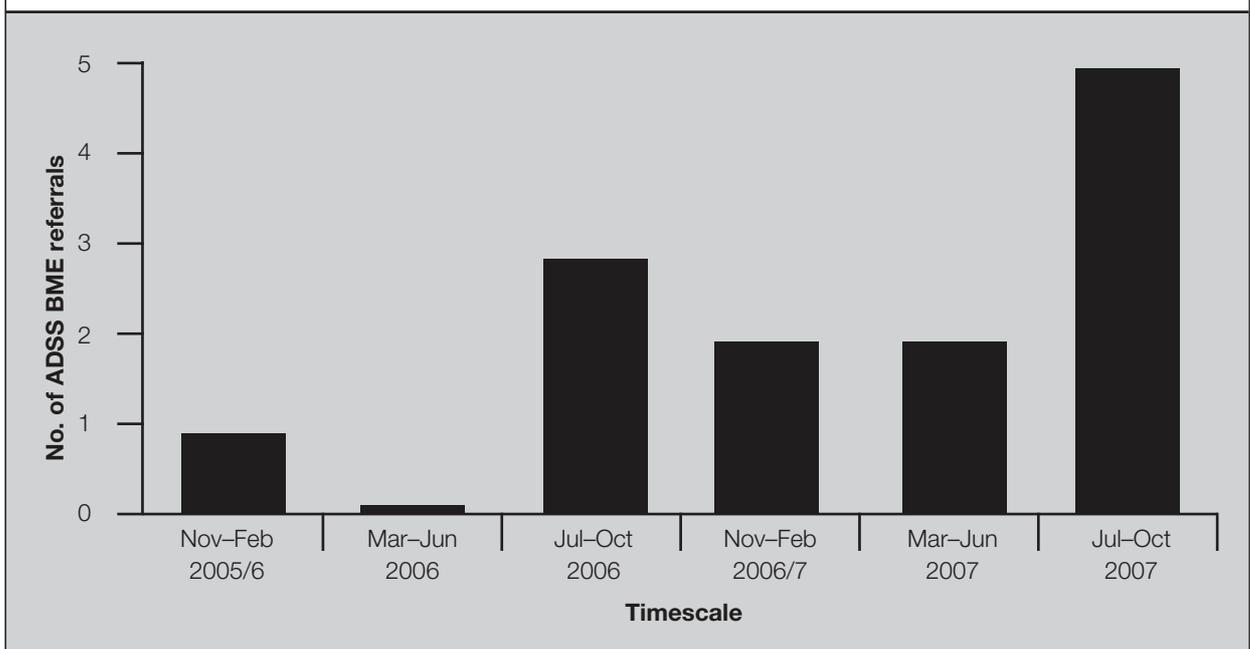
In terms of referrals to services other than health, the number of BME referrals to ADSS also increased from four in 05/06 to nine in 06/07 (see **Figure 1**). Due to illness of the Social Services steering group member, we had no reliable data on referrals to the SSD although anecdotal feedback suggests an increase in needs assessments for users with dementia and their carers and additional requests for respite care.

In terms of the project’s impact on clinicians, the nurse practitioner’s

knowledge about dementia, including assessment and screening, had increased considerably; she had become more aware of the incidence of dementia among older Asians and the needs of carers. There is also evidence that the project helped to raise awareness about dementia and early diagnosis amongst service providers more widely in North West Kent eg. Rethink, amongst BME service providers eg. Guru Nanak Day Centre, as well as members of the Asian community.

The case example outlined in **Box 1**, overleaf, illustrates the role of the project. In particular, it highlights the invisibility of many Asian families to service providers, the need to raise awareness about dementia

Figure 1: ADSS BME referrals 2005–2007



Box 1: Case study – patient referred to ADSS via the BME project

One patient, Mr Tilak (a pseudonym) was referred to ADSS via the BME project for an assessment and home visit. He was a 66-year-old man who was concerned about his memory; he thought himself to be 'forgetful' due to 'missing appointments'. In discussion it became clear that he and his wife were caring intensively, and on a full-time basis, for his 93-year-old mother who lived with them and who displayed severe symptoms of dementia. She was unable to find her way around the home and did not recognise members of her family. Her physical health and mobility were also very poor. The couple had to help her with all activities of daily living and she kept them awake most nights. As a result of the home visit by ADSS she was referred to Social Services as a 'high need' case for assessment and input from services. The family viewed the mother's memory problems as normal 'old age'. Even her son, who had received the dementia leaflet and letter in his own right, had not considered that his mother may have dementia or need help from outside the family. Mr Tilak and his wife were also referred to Social Services for a carer's assessment, which included a discussion about day and respite care, occupational therapy assessment, benefits and carer support groups.

in the Asian community, address the stigma attached to mental health problems, and alleviate carer stress.

KEY LESSONS

Although small scale and local this study suggests that targeting a specific health care intervention at an under-represented group can be effective. It shows that using careful planning and partnership working with a committed primary care practice engaging a hitherto marginal group of users – older Asians and their families – in early intervention in dementia is possible. Sending a letter out from the GP practice inviting patients in for a consultation about 'memory concerns' was clearly an effective way to raise awareness about dementia and engage older Asians in screening and/or referral to secondary care services (Manthorpe & Moriarty, 2009). Raising awareness amongst primary care professionals and other service providers is also of key importance in facilitating 'sign up' to the aims of the project as was the appointment of a nurse practitioner who spoke Punjabi and who had specific training in dementia-related issues (Alzheimer's Society, 2007). Although, over the six-week period, the number of older Asians coming forward for help was relatively small, it successfully set up a 'screening system' which has the capacity to offer an ongoing early intervention service to older Asians *and* other groups of older patients. It is notable that the approach

taken by this project raised awareness of memory problems far more effectively than other more public initiatives with this as their explicit goal. For example, one such meeting at the local Gurdwara attended by over 400 people resulted in only one new referral to ADSS.

Other important findings of the project include: translating information into appropriate Asian languages is useful; help is more acceptable if offered by someone who speaks the older person's own language; and that older Asians need to be offered timely assessment of cognitive function using screening instruments appropriate for use with ethnic minorities (Parker *et al*, 2007). The project also found that in relationship to family carers, it is critical that they are identified and helped to make use of services (Seabrooke & Milne, 2004). The fact that older Asians tend to live with their families and in geographically concentrated communities, makes the need to develop robust *local* responses crucial. The other key dimension of success was collaboration between, and senior sign-up within, those agencies involved in planning and delivering the project. The adoption of a coherent methodology to gather evidence of progress is also important.

CONCLUSION

The increasing numbers of older people from BME communities with dementia presents an emerging challenge to health

and social care services in the UK. Early recognition and diagnosis of dementia is a national policy and practice priority, which not only allows access to medical intervention and support services, but allows patients to prepare for the future and gives them and their families a chance to come to terms with the diagnosis (Department of Health, 2009; Wilkinson & Milne, 2003). As raising awareness is the first stage of the dementia journey, investment in innovative ways to engage elders in primary care initiatives that enhance access to, and effectiveness of, early intervention is pivotal.

Outcomes from the North West Kent Dementia Collaborative Project evidences an approach of engaging effectively with older Asians with memory concerns at an early stage. A number of lessons from this project have national resonance. Many BME populations are 'off the radar' of dementia care services, including early intervention initiatives, and BME elders have been identified as being particularly reluctant to come forward for help for a stigmatising illness that is widely regarded as a '*normal part of ageing*' (Milne & Chryssanthopolou, 2005). The approach piloted by the collaborative project is also more broadly relevant to facilitating early intervention in dementia care in the mainstream population and underpins the funding of a larger-scale project being rolled out by ADSS over the next five years. Continuing to work with primary care practices in North West Kent, the charity will raise awareness of memory problems among elderly people to facilitate early diagnosis of dementia and access to specialist treatment and care. The project will also promote user and carer quality of life and extend community-based living (Department of Health, 2009). ADSS has received funding from the Big Lottery for this project, which is due, in part, to the success of the BME Dementia Collaborative Project alongside wider evidence of unmet need in the North West Kent area.

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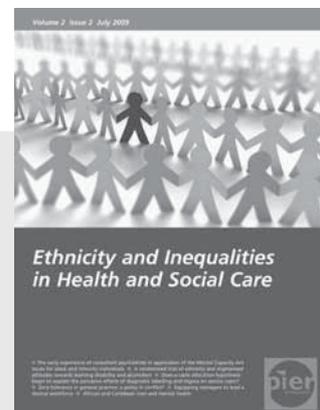
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