Dementia, Ethnicity and Culture:
Outcomes of a research and service development seminar

SUMMARY

In October 2002 the Mental Health Foundation ran a seminar entitled Dementia, Ethnicity and Culture. Its aim was to explore the research and service development challenges relating to ethnic minority elders with dementia.

Participants identified a number of issues facing services. There is no consensus about whether dementia services for people from ethnic minorities should be located in mainstream or specialist provision - the ideal is tailored care. Local authorities should assess need in their area. Particular tips include: extending the role of the voluntary sector; a partnership with the ethnic community and employing workers empathetic to both cultural needs and dementia. There is a widespread need to challenge the existing stigma related to dementia.

Specific research challenges include recruiting participants from ethnic communities and ensuring that sufficient time is allocated to projects that take a qualitative approach. We learned that:

- research needs to be more sensitive to differences between ethnic minority groups
- local research outcomes need to inform local service development
- research findings need to be more effectively disseminated to all concerned.

BACKGROUND

Since the late 1990s part of the Mental Health Foundation’s Mental Health in Later Life programme (Milne and Lingard, 2001a) has focused on the needs of older people with dementia from ethnic minorities and their families, including:

- A research update reporting on a short survey exploring the extent and nature of research around ethnicity and dementia (Milne, 2001).
- Funding a dementia project in north west Kent: Identifying the Needs of Older People from the Asian Community with Dementia and their Carers (Seabrooke and Milne, in press).
- Two of the pilot sites within the nationwide Dementia and Advice Support Service, which meet the needs of ethnic minority populations (Milne and Lingard, 2001b).
- The Mental Health Foundation’s Learning Network on Mental Health in Later Life: the area ‘Dementia and Diversity’ contains information about ethnicity and dementia and can host discussions between stakeholders (www.mhilli.org/network/diversity.htm).
Recent policy developments placing emphasis on meeting the needs of people from ethnic minorities with dementia include: the National Service Framework for Older People (Department of Health, 2001) and the Review of Mental Health Services for Older People (Audit Commission, 2000).

THE SEMINAR

To explore the issues further, in October 2002 the Foundation ran an invitation-only seminar. Participants included researchers, health and social care professionals, policy makers and voluntary organisations actively working with ethnic minorities and dementia.

The aims were to: share and discuss current service development and research projects; identify strengths and deficits in the field; develop networks; identify any gaps in research and areas for further research; discuss ways to collaborate and draw out themes from the seminar.

KEY THEMES

The dimensions of the seminar were complex: both specific to ethnic communities with distinctions between and within ethnic communities; and relevant to all with dementia.

Developing dementia services for ethnic minority communities

Mainstream or separate dementia services: The ideal is to increase cultural awareness within mainstream services, providing tailored care for everyone regardless of ethnicity. This has the advantage of offering choice and improved care to all users. Although issues about food and religious observance are important, blanket assumptions about need and tradition are unhelpful (SSI, 1998).

Learning from other fields: Responding to issues of culture and ethnicity is not unique to dementia care. Drawing on experiences from other fields such as the learning disability sector may be useful.

Different areas require different responses: Well established ethnic communities have different needs from those more recently established. It is important local authorities assess the extent and nature of need amongst ethnic communities in order to plan services and raise the profile of ‘hidden’ need (Department of Health, 2002).

Developing services in partnership: Partnership between service commissioners, community leaders and citizens is vital. There are advantages and disadvantages in employing workers from a specific community: they must speak the same language(s) and understand religious/cultural issues, but most importantly, as with any worker in this field, be empathetic to dementia issues.

Three key service development issues: more use of the voluntary sector; improving quality of and access to services and greater responsiveness to individual need. The complexity of the system acts as a barrier, causing reluctance to use social services. Culturally appropriate home-based sitting services and domiciliary care are particular deficits.
Residential care: Although regarded as unacceptable by some ethnic minorities, people with advanced dementia often need institutional care. Features to improve residents’ quality of life include: female staff for female residents; single sex accommodation; observance of religious and cultural festivals; the design of toilets; appropriate diet and prayer facilities.

Carers and families: Whilst carers are under enormous strain they are often unwilling to ask for help. Culturally appropriate respite services need to be developed. Religious representatives can play a positive role in supporting carers.

Awareness of dementia: Dementia is perceived negatively in some cultures. The resulting isolation undermines service development. Awareness raising user-friendly workshops can be effective, as can providing information in a range of formats.

Diagnosis: Diagnosis of dementia in people from different cultures can be problematic as diagnostic tools are inappropriate, and clinicians may not speak the user’s language.

Training: Training around cultural awareness and racism remains inadequate for many commissioners, managers and health and social care staff. Raising awareness of the needs of ethnic minority populations and challenging stereotypes are particular issues.

Research Challenges

The seminar identified that more research is needed. Current challenges include:

Research participants: Recruiting participants from ethnic communities can be difficult due to the small size of many local ethnic communities, the stigma associated with dementia and the fact that few people from ethnic minorities come forward for diagnosis.

Approaches to research: Different approaches are needed e.g. focus groups are not appropriate where group discussion is not ‘the norm’. At this stage, qualitative research methods which take account of the service users (and carers) views are appropriate to build an evidence base. This is more time consuming which funders need to recognise.

Risks and prevention: Although there is a growing interest in vascular dementia, the research is limited to people from the West Indian community. Whilst this could inform preventive health care, locating the risks in one ethnic group may lead to misconceptions that the health issues researched are a particular issue for that ethnic group.

IMPLICATIONS

Particular research deficits are:

- A limited focus on ethnic minority groups other than South Asian and Afro-Caribbean communities e.g. the Greek, Jewish and Irish communities.
- Exploring the needs of ethnic minority groups living in geographically challenging contexts, such as isolated rural areas.
• Using local research outcomes can only inform local service development.

**Future research and service developments include:**

• Looking at which services are effective for which particular ethnic groups and why.

• Research needs to be more sensitive to differences between populations, including between communities from the same country.

• The needs of, and services for, ethnic minority older people with dementia who migrated from their homeland compared with those who have lived in the UK all their lives.

• Improved dissemination of findings to services, service users, ethnic communities and other researchers is needed. Web based learning opportunities such as the Mental Health in Later Life Learning Network could help here.

**REFERENCES**


7. Seabrooke, V. and Milne, A. (in press) *Developing Dementia Services for an Asian Community: Investigating the Need Nursing and Residential Care*