

The CNEOPSA Project

Care Needs of Ethnic Older People Suffering from Alzheimer's

SUMMARY

The Policy Research Institute on Ageing and Ethnicity (PRIAE) has been at the forefront of developments in ethnicity and dementia since its inception in 1998. It has now established itself as the leading organisation in this area, which has come under renewed scrutiny with the advent of National Service Framework for Older People standard seven.

The Institute produced a ground-breaking study in 1998 detailing measures to improve provision for ethnic minority people suffering from dementia. This work brought together researchers from the UK, Denmark and France who produced a series of recommendations for good practice.

This was the first such research in this area undertaken in the UK. Although the black and minority ethnic organisations interviewed for the study have been doing some good work in mental health, they have little knowledge of Alzheimer's. Among the majority organisations working in this area, there remains a scarcity of work or printed material for minority ethnic communities,

The study was followed by an innovative video in 1999, which sought to continue informing mainstream and statutory providers of the needs of ethnic minority older people suffering from dementia. Indeed, the then health minister Rt. Hon John Hutton MP declared, 'policymakers, managers, professionals and minority ethnic communities will find important messages in both the film and the booklet'.

The work that PRIAE has done in this area resides on the premise that 'the world of dementia is colour blind and minority communities are dementia blind'. This statement indicates the complexities of working in this area, and the amount of work that remains to be undertaken.

The Institute continues to pursue research in this area in the hope of improving professional practice and securing a better understanding of the impact of dementia on ethnic minority communities.

THE NATIONAL SERVICE FRAMEWORK

PRIAE was a member of the task group that formulated the National Service Framework (NSF) for Older People Standard 7, published in 2001. The Institute played a key role in securing recognition of the shortfalls in provision for sufferers from the ethnic minorities, and this has now been enshrined in one of the key documents driving forward improvements in the National Health Service.

Standard seven of the NSF Older People states, ‘older people from black and minority ethnic communities need accessible and appropriate mental health services.’ It goes on to note, ‘assessments may be culturally biased making it difficult for needs to be properly identified or assumptions may be made about the capacity and willingness of families to act as primary carers for their older relatives.’

Although the inclusion of these observations in the NSF should not be underplayed, there remains a number of actions to be undertaken in order to ensure that problems in the system are overcome. A range of interventions and awareness measures need to be put in place to translate the standard into practice.

For too long, the needs of ethnic minority elders have been met in the voluntary sector, with such organisations acting as *primary* providers of care, information and advocacy. While this represents a failing on the part of mainstream providers, it also means that key knowledge on ethnicity and dementia resides among black and minority ethnic organisations. For this reason, PRIAE used the 1998 study to suggest that a ‘satellite model’ be adopted in the UK.

PRIAE is currently taking the satellite model forward, working with BME age organisations, psycho geriatricians, community psychiatric nurses and other mental health staff.

KEY RECOMMENDATIONS

PRIAE has made a number of recommendations to organisations, professionals and carers in order to achieve change. These remain as valid as when they were first published, and have taken on a new pertinence in light of the NSF.

The essential strategies required are:

- Targeted developments and research must be put in place to assist ethnic minorities in accessing dementia care, as this has been so impoverished in the past. The involvement of mainstream statutory and voluntary providers is crucial due to the resource limitations of the dementia sector as a whole.
- An information and communication strategy needs to be put in place to increase awareness of dementia and support for carers. A number of cultural barriers

continue to prevent ethnic minority groups from recognising the onset of Alzheimer's or seeking outside help.

- A training package needs to be put in place for health and social care professionals, allowing them to engage with the issues and develop their own appropriate strategies. PRIAE has begun running such sessions, and the support we have received indicates a willingness of health care professionals to participate.
- Mainstream organisations need to employ specialist minority ethnic workers, who are well placed to ascertain needs and anticipate problems. This would also help to stimulate appropriate care developments for the future.
- Policymakers need to recognise that minority ethnic organisations are essentially acting as primary providers of care in the absence of mainstream services. This should be reflected in future funding arrangements, as they currently suffer from scarce and short term resources.

FUTURE WORK

PRIAE will be taking forward developments in ethnicity and dementia through the satellite model, which ensures that a baseline of knowledge about this area can be developed. It is only by establishing such resources that the aims of the National Service Framework can be met. We hope that moving forward with this approach will bring an end to the historically piecemeal and inadequate research in this area, and set the climate for genuine change.

REFERENCES

Patel, N & Mirza, et al (1998) *Dementia and Minority Ethnic Older People: Managing Care in the UK, Denmark and France*, Russell House, Lyme Regis

Patel, N et al (1999) *Dementia Matters, Ethnic Concerns*, VHS produced by 5th World Productions, accompanying booklet produced by PRIAE, Bradford

Patel, N (1999) *Black and Minority Ethnic Elderly: Perspectives on Long Term Care* in With Respect to Old Age Research Volume 1, Royal Commission on Long Term Care for the Elderly, HMSO: London

Department of Health (2001) *National Service Framework for Older People*, London

PRIAE

31-31 Park Row

Leeds

LS1 5JD

Tel 0113 285 5990

Fax 0113 285 5999

Website: www.priae.org

Registered charity no 1081930

Registered company no 3898974

**An extract on recommendations from PRIAE's film guide *Dementia Matters Ethnic Concerns*
available from www.priae.org**

1. To the Policymakers and Mainstream Care Providers at National Levels

Minority ethnic elders and their family carers are entitled to the same level and quality of dementia care and support since they are a **part** of society, not **apart**. The CNEOPSA Project recognises that 'all is not well for the majority population' in dementia care. However we have also shown that the absence of developments and knowledge for minority ethnic groups is such, that a strong case is made for urgent investment.

***Recommendation:** It is urgent that policymakers give recognition and resources to support targeted developments and research which enhance minority ethnic participation in determining appropriate dementia care.*

This also suggests the need for mainstream and voluntary (majority) organisations like Alzheimer's Society to develop good resource and power sharing partnerships with minority ethnic organisations and their personnel.

The latter point is emphasised because it is our experience that resources to ethnicity and dementia are very limited: if the established majority organisations simply use this as another avenue for funding and/or omit minority ethnic groups' involvement, the level of developments are likely to be further impoverished.

1. To Persons with dementia, Families, Minority Ethnic Communities and Organisations

In all four countries there is great unmet need on information, knowledge of the disease and how to access care and support (leaving aside the question of appropriateness). There are also cultural taboos and meanings associated with dementia, which may accentuate the delay in seeking the necessary help and support.

***Recommendation:** a planned communication and information strategy is required across different minority ethnic groups. The CNEOPSA film is the first stage in promoting some key messages. But more films are needed to cover specific aspects of dementia care for this target group. This would support family carers and minority ethnic organisations and their managers (noted frequently for having to gear up rapidly on a range of specialist topics, including dementia).*

2. To Professional Carers, Education and Training Bodies

In all four countries health and social care professionals, including General Practitioners, either

- recognise that ethnicity is an issue for them, but that they are not adequately trained nor supported on cultural and anti discriminatory practice **or**
- feel that ethnicity does not affect their dementia care practice.

Since we have established that ethnicity *does* matter - there are distinctive features by virtue of culture, language, stereotypes held by others and experience of discrimination faced by minority ethnic elders - much directed work needs to be undertaken in this area.

Recommendation: *a systematic education and training programme needs to be developed and implemented for a range of health and social care professionals. The CNEOPSA film is a first step in motivating, informing and engaging with this group. The next step would be a dissemination strategy based around the better use of these tools in parallel with developing new resources and approaches in dementia care that are sensitive in meeting minority ethnic elders' needs.*

3. Family Carer's Support Programme

Like the majority group, carers from minorities provide the main care to their family members. However carers from minority ethnic groups, as our work shows, also lack information on how to access care and support services.

Recommendation: *CNEOPSA is proposing that carers are recognised, supported and their views considered on strategies that they may use, and knowledge that they have gained in the process of caring for a relative with dementia. But they also need support, refreshment and relief from permanent caring; CNEOPSA recommends that this aspect be built into the Satellite model since family carers are likely to access minority ethnic elder organisations/associations.*

4. To Researchers and Research Organisations

More research needs to be done to simply build up the knowledge base of this area for the target group. For the CNEOPSA team, questions of who does the research, what, where and how are not just ordinary matters: they have implications for developments and whether there is added value for the minority ethnic communities re: social and knowledge capital opportunities. The CNEOPSA work in Spain and Finland has already spurred related questions on health and social care on a wider basis for minorities.

Recommendation: *There should be a planned programme of research and practice developments. The country profiles should be regarded as providing a baseline of information on the knowledge of dementia care for minority ethnic elders. This should be used to plan and assess future progress.*

Final Comments: In less than two years since the CNEOPSA Project began, supported by the European Commission, Country profiles of dementia and minority ethnic elders have been generated. Furthermore, a framework has been given on how to study this area: much research and development effort has been invested by the team, to say nothing of the opportunities and challenges posed by limited resources, deadlines and transnational perspectives. We have managed these and generated two dissemination tools from this enterprise. The 5th World Production team has crafted our concept and messages into a film medium that we hope speaks to all audiences.

CNEOPSA has thus produced a framework that works, includes people and groups since its objective is to

- raise the profile of dementia among all those involved in the system of care
- generate specific developments to enhance culturally relevant care
- enlarge the resource base of the area and generate social capital, so that people from minorities have sufficient opportunities in employment, research, training and service provision with specific support resources to family carers.

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