

# DEMENTIA MATTERS ETHNIC CONCERNS



Produced by the CNEOPSA Project  
Care Needs of Ethnic Older Persons with Alzheimer's



***Dementia Matters***  
***Ethnic Concerns***  
**A FIRST EUROPEAN FILM on**  
**MINORITIES & DEMENTIA**

**With a Country Briefing on the UK, Netherlands,  
Spain and Finland**

**From the CNEOPSA\* Project**  
**(\* Care Needs of Ethnic Older Persons with Alzheimer's)**

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**Dear Reader,**

**Welcome to CNEOPSA Project's Information Booklet and Film.**

*Dementia Matters Ethnic Concerns: Managing Care in the UK, Netherlands, Spain and Finland.*

*It's a long title because we cover so much! We first introduce you to our project before giving you information on the countries we have examined. The section on country profile gives you comprehensive information that will be useful beyond dementia matters. The section on country practice required considerable effort and was based on framework building and research using questionnaires. So that you don't forget the key bits, we supply a summary right at the beginning before the more in-depth detail. Then the conclusion at the end gives you a good short guide on what to do - to really make a difference. Of course we have left you with the choice: to read the booklet first and then watch the film or vice versa. Either way you may want to use both tools several times.*

**Thank you and best wishes from  
all at CNEOPSA.**

## **SUMMARY**

The central finding in this work, irrespective of the constitution of Black and Minority Ethnic (BME) people in each country, is that similar themes emerged on: dementia, old age, BME families and their carers, the role of professional carers, and BME organisations. Below we summarize our main findings after questioning BME organizations, and both professional and family carers.

### **Black and Minority Ethnic Family Carers**

- The concept of 'duty' exists among family carers, and this 'internal' care represents a saving for the authorities.
- Family carers can only sustain this level of care if they are given specific training in dementia care and if their socio-economic position is improved.
- More interaction between family carers and professionals is needed to improve dementia care provided by the family carer.
- BME organisations that recognise the need to support carers, are finding that family carers are turning to them for support and services.
- These BME organisations, and some majority organisations, are working with family carers: providing support networks, information exchange, respite care in community settings and day centres.

### **Professional Carers**

- Difficulties in communication and late referrals result in dementia being diagnosed later in BME elders, accentuating the problems of dementia care given by professionals.
- Professionals recognise that cultural differences constitute a major difficulty in providing dementia care for BME elders.
- Professionals need appropriate 'cultural' training and information to improve their ability to provide dementia care, although they are not asking for a checklist approach.
- Culturally appropriate care is not equivalent to 'special treatment', it simply refers to different requirements. Cultural factors that should be taken for granted in dementia care include: appropriate food and dress, ability to communicate, and the importance of one's own religious and spiritual practices.
- Professionals are recommending the employment of specialist minority ethnic staff who are, however, also trained in the provision of dementia care.
- Health and social care providers must seriously consider how research into dementia care at a local level is researched.

## **Black and Minority Ethnic organisations**

- Black and minority ethnic organisations, in some countries, are playing an effective and important role in managing the dementia care needs of BME elders.
- These organisations recognise that BME elders with dementia encounter two barriers when trying to attain dementia care – communication barriers (including diagnosis) which hinder them actually gaining access to services, and cultural barriers relating to inappropriate care once access has been attained.
- Thus, these organisations are providing information on dementia to BME communities (i.e. leaflets), although audio-visual information may be more useful for these groups, to combat the communication barriers.
- Also, these organisations are recommending a closer look at the reality of BME people so that cultural barriers are overcome: e.g. working directly with families to improve dementia care and using specific therapies (e.g. reminiscence; natural healing; prayer) which may be pertinent to these groups.
- As a consequence these organisations have been financially supported and viewed positively by the mainstream<sup>3</sup> because they provide a 'buffer' against direct criticism of mainstream services' inability to provide dementia care for BME elders.
- However, these organisations need better resourcing if they are to overcome barriers which are, in some cases, exacerbated by legislative changes.
- In countries where it is feasible, a 'satellite model' should be considered, whereby a small group of BME organisations are identified whose task would be to generate specialist knowledge and developments in the dementia care of BME elders, which could be used as a reference for other organisations, including those in the mainstream.

## INTRODUCTION

**Background.** This booklet and the complementary film follow logically from the original CNEOPSA (**C**are **N**eeds of **E**thnic **O**lder **P**ersons with **A**lzheimer's) Project in 1997.<sup>1</sup> The original project was the first of its kind supported by the European Commission. The CNEOPSA Project produced the first book written on this subject in Europe, *Dementia and minority ethnic older people: managing care needs in the UK, Denmark and France* (1998). This book sought to consider the following hypothesis (Professor Marshall)<sup>1</sup>:

*' the mainstream world of dementia is colour blind  
the world of minority ethnic organisations is dementia blind.'*

The study found strong evidence to support this hypothesis, as does this next phase, which includes other countries. The original UK team at PRIAE leads the present CNEOPSA Project, with partners from NIZW (Netherlands), Plan Excel (Spain) and STAKES (Finland). Our aim is to continue to determine the state of knowledge and practice in dementia care for older people from BME backgrounds rather than to focus on *one* aspect of dementia care and/or diagnosis in this target group. We have also not become embroiled in arguments such as 'minorities have more / less dementia than the majority'. The key issue for the CNEOPSA team is that dementia exists; and what is being done about it should be the key concern given our knowledge of under-developments in the area for our target group. Hence we have looked at all the key players in the system of care: the person with dementia, family and professional carers, mainstream care providers, minority ethnic organisations, majority voluntary organisations like the Alzheimer's Society, and policymakers.

### **The purpose of this booklet is to**

- Use the original methodological and analytical approach of CNEOPSA (1998) to establish the Country Profile and Country Practice for the Netherlands, Spain and Finland.
- Communicate key messages through both the film, *Dementia Matters: Ethnic Concerns* (5<sup>th</sup> World Productions), and this booklet.

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<sup>1</sup> <sup>1</sup> CNEOPSA was coined by personnel at the University of Bradford, who also produced the methodology and analytical framework. These people have since set up PRIAE - Policy Research Institute on Ageing and Ethnicity. CNEOPSA is part of PRIAE but is recognised distinctively as a specific project in dementia care and minorities.

<sup>2</sup> See the Foreword in the CNEOPSA book, *Dementia and minority ethnic older people: managing care needs in the UK, Denmark and France* (1998).

<sup>3</sup> Mainstream refers to health care, social care and housing provided by the state.

<sup>4</sup> A preliminary study exploring the current situation of migrants with dementia, the family caregivers and professional care services – Rob Ong (MSc), Ivan Komproe (PhD) and Professor Joop de Jong (MD, PhD).

<sup>5</sup> The term Romany will be used throughout the text.

<sup>6</sup> Except for the research done by the TPO and the NISBO in the Netherlands.

- To increase awareness and to take action to develop culturally appropriate knowledge and practice in dementia care, for the benefit of minority ethnic elders.

**How is the country information attained?** We applied the framework developed by the original CNEOPSA team to establish the following facts in the Netherlands, Spain and Finland: (i) who are the minorities; (ii) what is their socio-economic and health profile; and (iii) what are the current level of developments *vis a vis* dementia care for minority ethnic elders. These broad themes constitute the Country Profile for each country. For the UK we have updated some of the information already published in the original CNEOPSA book (1998). In the Netherlands the study *Migrants and Dementia in the Netherlands*<sup>4</sup>, has been updated.

Regarding the Country practice, we used questionnaire's that had already been applied in the UK. Here we focussed on exploring key issues for families and carers by approaching minority ethnic organisations/associations. Regarding personal care, a separate questionnaire was developed for social and health care professionals. Here we were concerned with the issues they face in working with minority ethnic elders with dementia, their attitudes, and competence on culturally appropriate dementia care.

Because standard questionnaires were applied to all four countries and common themes emerged, regardless of the different groups in the system of care, the Country Practice section is organised thematically. Thus, the findings in this section are synthesised to enable the reader to see where there are common patterns, as well as differences, in each of the four countries. Of particular interest to the reader will be the common issues binding minorities who have experienced social exclusion and discrimination in their respective countries of settlement, irrespective of origin.

In summary, the booklet is organised into three parts:

- The Country Profile, which retains its specific themes (above) to indicate the common as well as distinctive features of each country.
- The Country Practice, which is organised thematically.
- A conclusion with the CNEOPSA team's recommendations.

**The Target Audience** comprises those involved in the system of care, i.e. the person with dementia; family and professional carers, mainstream care providers, minority ethnic organisations, majority voluntary organisations like the Alzheimer's Society, and policymakers. In addition students in dementia care and those interested in mental health and ethnicity in general should find this dual pack, booklet and film, very useful.

**Suggestions for using the booklet and the film.** The information compiled in the booklet was researched and formed the basis for the film. Thus, the film adopts the same themes as the booklet and does not try to cover everything about dementia and minorities in each individual country. We hope that the film based on the themes of diagnosis, communication, carers' issues, models



of care homes and centres that are minority specific, will raise issues and encourage developments. The booklet should provide the reader with a better insight into individual country issues and give a more in-depth background to our findings. Therefore, we recommend that both products be used together as dissemination tools. We welcome you to read, view, use this product, and to ultimately help make a difference to the well-being of the minority ethnic elder person with dementia.

## COUNTRY PROFILE

**Demographic Facts.** A BME presence is found in most European countries today. These communities have arrived in the member states at different times in history, for a variety of reasons, have integrated to different extents and are classified differently. Also the number of BME people in the member states make up different proportions of the total population (see Table 1). In both Finland and Spain a significant BME presence is, generally speaking, a relatively recent phenomenon, whereas in the Netherlands and, notably, in the UK this is not the case. Thus, in Finland the number of BME people has quadrupled in the 1990's, whereas in Spain approximately 600,000 were living legally in the country by 1997, of whom 47% were of European origin. By contrast, a BME presence is not a recent phenomenon in the UK – with the Irish in the 16th, 17th and 18<sup>th</sup> centuries and the Jews, the Poles and other minority groups in the late 19th and 20th century. The main immigration peak in the Netherlands occurred post-war, also a significant period in the UK.

There are both similarities and differences in the reasons for BME people arriving in these four countries. All countries have seen the arrival of BME people, particularly in recent times, for economic reasons, as refugees due to war and as a consequence of human rights abuses in their country of origin. For both the Netherlands and UK there has been a sizeable immigration of BME groups from former colonies. In Finland, there are a reasonable number of émigrés who have returned to Finland from neighbouring Scandinavian and Eastern European countries, notably Russia.

One common factor amongst all four countries is the relative youth of the BME population compared to the indigenous population of each individual country. There are exceptions to this, such as BME people of European origin and from Dutch Guyana/Antilles in the Netherlands, and the Lapps and Gypsy/Romany<sup>5</sup> in Finland. However, future trends are of concern. In Spain the main BME group are the Romany who have a birth rate of 6.1% compared to 1.5% for the majority population; there are a large number of Turkish and Moroccan people in the age range of 55-64 years in the Netherlands; and in the UK minority ethnic groups make up 1.35 % of the 65 years and 4% in the 45-64 years age range. Today's low level developments in dementia care to minorities with a rapid increase in ageing among this group in the future enable us to stress '*urgency*' in many of the recommendations.

**Socio-economic position and research studies.** In all four countries the socio-economic situation of BME people is less favourable than the majority population. In general they have a lower average income, lower education and literacy levels, a higher percentage of unemployment, poorer housing conditions, and tend to under-claim welfare benefits. In the UK this has been driven by discrimination by employers and unions, disparity in earnings and length of working life, and the decline of the manufacturing base (foundries, textiles, transport). In the Netherlands, 50% of Turks and Moroccans of greater than 50 years of age have no education at all and 30% are unemployed compared to 6% in this age group amongst the majority population. In Spain and Finland, the Romany population has additional difficulties in attaining welfare and social benefits due to a lack of internal organization and even disintegration, no representative external body, and as a result of geographical considerations. In all four countries the socio-economic situation of BME people has serious health consequences. This is particularly poignant in the case of the Romany community in Spain where low levels of vaccination, deficient diet, poor dental care, and poor hygiene are common. In the UK the socio-economic situation may contribute to the greater use of services from 55 years of age amongst BME people (i.e. 'early ageing').

**Effects of Legislation.** In **Spain** legislation differs between autonomous regions. For example, in Andalucia the Health Act and Attention and Protection of Elderly Act, both emphasize the integration of the health and welfare systems to benefit the elderly. However, the Foreign Act currently being discussed in parliament is emphasising the right of health services for resident foreigners. **Finnish** legislation, notably laws on patients' rights, emphasises equality including the right of people to live according to their values and habits (i.e. culture), forbids discrimination and highlights the patient's right to be heard. Finland's migration and refugee policy emphasises the effective and flexible integration of BME people into Finnish society and working life. In the **UK** the difficulties BME elders face is exacerbated by reduced welfare services and the NHS and Community Care Act (1991) which introduced the mixed economy of care. Since BME communities are concentrated in inner cities that are already characterised by poor housing and low availability of health resources, legislation is having an adverse effect specifically on BME elders. The effect of the Carers Act 1996, and initiatives such as the Patient's Charter – Mental Health Services 1997 and the forthcoming National Service Framework, on BME elders with dementia is still unclear. In the **Netherlands** as a consequence of ageing amongst BME people, the first initiatives were taken about 10 to 15 years ago. A survey from that time showed that about eighty initiatives were present. Some of them were in the planning stage, whereas others were already in operation. Today a few hundred projects have been carried out and more initiatives are being developed. Issues relating to BME people are now voiced at local and national agendas, special projects are running and policy documents are being written. The government has stated that first generation BME elders cannot be expected to integrate, and research is being carried out to determine where special attention is needed and legislation has to change.

**Research and Print Information.** In all four countries the prevalence of Alzheimer's disease and other forms of dementia (see Figure 1) is not explicitly collected for BME communities. Estimates suggest that the absolute number of BME elders with dementia in Spain and Finland is approximately between 300–500 people. In the UK and the Netherlands these figures rise to somewhere between 1500 to 5000 people. However, these prevalence figures mask a hidden problem. Black and minority ethnic people often have lower life expectancies (e.g. the Romany in Spain and Finland), rarely present to services until later stages of the disease and may show signs of 'early ageing'. Further information can be found in Table 1.

The level of research on BME elders with dementia is almost non-existent in all four countries<sup>6</sup>. However, there is preliminary progress to the extent that print information, namely leaflets, is available in different languages in the four countries. More general research is also looking at the issues of health amongst BME people. In Finland there has recently been research challenging the negative attitudes of health professionals to BME people, as well as research on specific minorities (i.e. elderly Romany). In the UK a number of research groups are assessing the sensitivity of diagnostic instruments to detect Alzheimer's disease amongst BME elders, the barriers they face in the health and social care systems and the level of unmet needs. More recently, the Alzheimer's Society and health and social care providers in the UK have begun to acknowledge that there are issues for BME people. How far this recognition is translated into action remains to be seen.

The lack of research and print information in the mainstream has prompted the development of BME organisations. However, even here many of the organisations do not focus on dementia, are often fragmented and often respond to specific situations as opposed to having well established and resourced programmes (below). Also, almost all these organisations are small voluntary organisations with few employees. For example, in Finland most organisations focus on the rights and cultural traditions of minorities (e.g. the Lapps and Romany) rather than on specific health issues, although there are elderly homes for minorities (e.g. The Russian Charity Organisation). In Spain, of the estimated 230 BME organisations, 100 represent the Romany community (e.g. Romany General Secretariat), although there are more general organisations – SOS Racism – which focus on bringing communities closer together and reporting on racism.

In the Netherlands and UK there are specific BME organisations working with BME elders with dementia. These organisations are promoting new developments such as organising elders from minority groups to assist those with dementia from the same community (e.g. Dutch Islamic Union of Older People) and using group reminiscence therapy in the form of theatre (e.g. Ekta Project – UK). Furthermore, BME organisations in the UK and Netherlands are making available relevant and understandable information on dementia, encouraging BME communities to challenge, understand and negotiate the system of care, acting as resource and reference centres, and helping BME elders with dementia to obtain the services they require. By contrast, most of the majority organisations in the four countries are involved

in promoting appropriate dementia care, but with no specific reference to BME elders with dementia. Exceptions exist such as Alzheimer Foundation in the Netherlands who have taken the initiative to reach out to BME organisations to bring existing knowledge together. Also, in the UK a number of majority organisations have provided literature in different languages and both the Alzheimer's Society and Alzheimer's Concern Ealing have undertaken awareness raising exercises among BME communities.

## **COUNTRY PRACTICE**

### **A. Black and Minority Ethnic organisations actively working with minority ethnic elders with dementia**

Referral's to organisations working with BME communities come from various sources, including general practitioners and other health professionals, social care workers, and families themselves. The fact that families refer elderly relatives directly to BME organisations suggests that BME communities have faith in these organisations. The general practitioner is a key primary health care worker and it is encouraging that this professional is referring the person with dementia to specific organisations involved in the care needs of BME people.

Families from BME communities do not understand or accept that an elder has dementia, and perceive the disease differently from the majority population. Furthermore, the person with dementia is often blamed for being self-deficient. The disease is more easily accepted as 'a part of growing old' or when it can be easily ascribed to a specific physical complaint such as a stroke. Indeed, BME people commonly present to services with somatic complaints and this warrants further investigation, because minorities tend to play down disease.

Information and knowledge on dementia and the care services that are available need to be conveyed to BME groups in a way that is linguistically and culturally understandable. If this information is not clear then the elder often does not get appropriate care and the family carer(s) does not have the information/knowledge to give the appropriate care or access relevant services. Moreover, if a BME elder is diagnosed as having dementia and neither they nor their family carer(s) understand what dementia is, then this inevitably leads to stress and anxiety. The importance of information needs to be considered in light of the fact that BME communities perceive dementia differently (above) and may have different literacy needs.

In some cases it has been argued that BME people wait until faced with dementia before seeking help. However, empirical research suggests that this is not the case and that, to the contrary, demand for information is high. It is clear that information needs to be distributed to minorities in the right format. For example, both family and professional care workers suggest that

minorities read brochures and other written materials poorly even after translation. Indeed for some minorities talking about dementia directly may be the wrong approach.

Although most BME people are less aware of the services available to them compared to the majority population (above), there are exceptions such as the Dutch Guyanese. This example from the Netherlands is interesting because many Dutch Guyanese work within the Health sector and therefore have direct knowledge of the system of care. Although this is the exception to the rule, it illustrates that not only is appropriate information necessary, but that it is achievable, regardless of language, culture and education barriers, if the will exists.

A variety of care approaches are being used by BME organisations. Bodily care such as feeding, going to the toilet and medication are very specific. Personal well being is approached using reality orientation, activities/stimulation (audio/video, games, arts and crafts, keep-fit and tai chi), environmental approaches, person-centred and reminiscence therapy. Alternative therapies including natural healing and prayers, which may be particularly pertinent to BME groups, are also used. However, there is scepticism and concern about some forms of dementia care (e.g. reminiscence therapy) - "theories don't work"...."home-grown" therapies have to be developed.

The difficulties that BME organisations encounter in providing dementia care are widespread. Lack of resources is a major factor for many organisations. Resource problems include financial difficulties and a lack of staff with appropriate skills and/or knowledge of different cultures. Also, the responsiveness of professional staff to cultural needs is inadequate whether in a residential home, day centre or home setting. Thus, cultural factors, personal limits in information and development activities are major difficulties. This highlights the need for specialised staff. Conversely, families also add to the difficulties encountered by BME organisations. Families do not accept the illness, feel guilty because it is their '**duty**' to look after the demented person at home, are unwilling to get outside help, and even interfere with the care provided. Finally, the socio-economic position of families is problematic – for example, housing conditions make it difficult to provide help with physical care.

To overcome difficulties BME organisations are obtaining more information on dementia, increasing practical training for staff, encouraging more inter-agency co-operation, improving staff-staff and staff-client relations (empathising with the person with dementia, helping in family difficulties and making families aware of services available to them), and adding resources (e.g. bilingual staff). Information programmes directed specifically at carers and families are important in overcoming difficulties. For example, helping families identify and appreciate the early signs of dementia. In both the UK and the Netherlands a satellite approach is being developed. It is intended that by investing in a few identified BME organisations new methods, tools and skills, would be developed, as well as adaptation of those already used.

This would allow for the transfer of knowledge and practice between BME organisations and mainstream service providers, thereby accelerating progress.

BME organisations highlight two barriers that BME elders have to overcome in getting dementia care. The first **communication barrier** means that BME elders have difficulty in attaining the same level of services as elders from the majority group. This means that BME elders are either sent home or, if they do acquire a care service, are confronted by secondary **cultural barriers** in a mainstream setting. For example, minorities have different habits, religious needs, food requirements, and wishes. Specific barriers to obtaining services include language (although this is not the case for the Romany or Central and South American minorities in Spain), lack of resources (e.g. assessment facilities) and information, and the stigma of the illness being a form of madness. In addition the complexity of the system of care is itself a barrier.

To overcome the first set of barriers, BME organisations are using equal opportunities legislation in the interests of the elder with dementia, raising awareness and explaining dementia 'personally' by attaining information from experts, and are having more direct contact with families. Day centres do outreach work in the community, act as advocates for sufferers, and involve voluntary community organisations because BME communities trust them.

In overcoming the secondary barriers, organisations are ensuring that the type of food is appropriate and prepared in the correct manner. Religious practice is being encouraged, and when visiting an elderly relative with dementia all members of the family are being allowed to visit at the same time. Using life story techniques (reminiscence), understanding the persons moods, addressing them by personal names, culturally specific music being used, and allowing separate rooms for men and women, which is important in some cultures, are all important developments being pursued. Additionally, services for family carers are seen as important. Specialised professionals who understand the person's culture, language and background are needed. Training for these professionals is highlighted as a necessity.

However, policy changes and research in this area are seen as the ultimate means of circumventing the current problems, and avoiding the problems in countries such as Finland and Spain where the numbers of BME elders with dementia is currently small. In Finland this may be easier than in other countries because Finnish legislation is modern, there are many associations working in the field of dementia, although most do not have collaborations with BME organisations, and the Finnish education system attempts to consider changes in society when planning educational programmes.

## **B. Professional Carers working with minority ethnic elders with dementia**

Professionals have little experience of working with BME elders with dementia. This stems from the problems of diagnosing dementia in BME elders, resulting in few entering dementia care services. Diagnostic issues are partly a consequence of cultural differences where the professional and family cannot agree on what constitutes 'dementia symptoms' and what the family considers 'normal behaviour'. Families often accept symptoms (e.g. forgetting) as a normal part of growing old and/or have no knowledge of dementia symptoms. Also, BME elders often present with somatic complaints, and there are difficulties in distinguishing between dementia and depression due to similar terms being used to describe each by minorities. The latter suggests that diagnostic issues are also a consequence of the tools used, which are not culturally or linguistically adjusted and at times questions/tests appear irrelevant – e.g. an elderly Chinese person not being able to tell the time on a clock is not necessarily a cognitive impairment. Delays in recommending dementia care for BME elders, notably by general practitioners that are often a first source of contact, is worrying.

BME communities are reluctant to approach the services that are used by the majority group, due to the stigma of 'duty' and seeing dementia as a form of 'madness'. The fear that care professionals would recommend placing the elder in a home exacerbates their fears and adds to their 'shame'. Even when BME families are in touch with services and the elder is receiving 'dementia care', contact is often hard to maintain. These cultural and diagnostic issues result in few professionals encountering BME elders with dementia. Even the large Romany community in Finland, many of whom speak Finnish, are rarely encountered by health professionals. Obviously information and knowledge need to be disseminated to BME communities in an appropriate way, and should not simply rely upon translation of literature.

Because of the delay in entry to services, basic assistance and guidance from the professional carer that would ease the burden on both the caregiver and elder with dementia, allowing them to live at home for longer, are often lacking. Furthermore, once in services families are often marginalised and only involved at moments of crises, exacerbating 'guilt' feelings amongst family members and making them more reluctant to continue with the dementia care being provided for the elderly relative (see below).

Professionals cite communication as a major difficulty. This is not simply a language issue since the main minority groups in many countries speak the indigenous language. Communication difficulties result from a lack of knowledge by the professional carer on the cultural needs of BME elders. The professional often has difficulty in understanding why there is disappointment in the dementia care provided, why appointments are poorly kept, and why feedback from family members is not forthcoming. Conversely, BME communities often feel it is impolite to question professional carers, and simply accept the care given even though it is not appropriate, or refuse it without saying why. Communication difficulties resulting from a lack of

culturally appropriate care also result in some BME elders hiding their symptoms, as found in the UK. The value of some activities as part of the dementia care plan are inappropriate for some BME elders – for example, “cake-making was only enjoyed by women”; “only half the participants joined in at a sing-a-long”. Such problems suggest that a person-centred approach may be more appropriate for BME elders with dementia.

The inter-related problems of communication and culturally appropriate care suggest that, on the one hand, awareness and understanding needs to be raised amongst BME families and communities who tend to care for elders at home and only refer them once they are no longer able to cope. On the other hand, professionals need more training, information and resources to care for, communicate with and diagnose BME elders with dementia. Furthermore, once in the system professionals need to involve relatives more in the dementia care plan. Furthermore, although ethnic minority staff may ease some of the problems, they need to be educated in providing appropriate physical care and medication, regardless of their ethnicity.

Professional carers are trying to use solutions to overcome the barriers and difficulties highlighted above. However, most current solutions revolve around language barriers: learning the language or using interpreters for persons with dementia from BME communities. This is particularly poignant in countries like Spain and Finland where the numbers of BME elders with dementia are currently small, and so there may be a tendency to overcome barriers and difficulties with simple ‘language-based’ solutions. By contrast, in the UK and Netherlands the development of organisations which cater specifically for BME elders with dementia emphasizes the importance of non-verbal communication: understanding the culture and cultural habits, the importance of the families participation in dementia care, person-centred care, using a story-like approach to stimulate the person and supporting the family. Even in translating leaflets on dementia BME organizations aspire to make these congruent with the communities perception of dementia. These organizations have been vital in providing information and knowledge on dementia to BME communities in meetings where they feel comfortable and more at ease. The fact that these organizations exist, sometimes with little or no support, vindicates the need for ethnic minority specialists in mainstream care settings and the incorporation of ‘elderly consultants’ from BME communities. Countries like Spain and Finland, that do not currently have large numbers of BME elders with dementia, should consider such developments at an early stage.

Although ‘language-based’ solutions used by professionals are basic, through their own experiences professional carers are making suggestions to improve practice. The importance of exchange meetings between Alzheimer groups and minorities would be useful to collate information on specific issues relating to different communities. This suggestion implies that professionals are aware of their own lack of understanding and information on different cultures, and the importance of culture to dementia care for BME elders. Indeed culture would appear to be more important than even language, since in the UK where numerous professionals use interpreters or attempt to learn



the languages of ethnic minorities, less than half of those questioned actually deem this a requirement in providing appropriate dementia care. By contrast, whilst few professionals involve families in their dementia care practice, many see this as being important in improving dementia care.

Professionals require more training, and need to be better informed about dementia, e.g. in recognising behaviours associated with dementia, such as wandering. Professional carers recognize that information, particularly in the form of materials needs to be disseminated to BME communities to increase awareness and reduce the fear of the illness. In particular, audio-visual materials could be more effective in disseminating information/knowledge amongst BME communities rather than leaflets and other literature, partly due to literacy levels but also as a consequence of the different ways in which minorities gather information. By informing BME communities about dementia, professionals can develop better activities for the person with dementia by receiving input from the communities themselves. To aid in raising awareness and in identifying dementia earlier amongst BME elders, specialist ethnic minority workers could prove invaluable in practice.

### **3. Black and Minority Ethnic Family Carers**

Many family carers do not dissociate dementia symptoms from what they consider a normal part of growing old. Consequently, many are trying to be self-sufficient, to the extent that they hide their problems to the outside world since having an elder in the family acting in a strange and inappropriate way is seen as shameful. In many cases carers are the spouses and are themselves coping with illness. In an example from the UK, Mr B is Chinese and in his sixties. Whilst he suffers from dizzy spells and blackouts, he is the sole carer for his wife with dementia, and has given up work to care. This man is now totally reliant upon benefits, carries out all the household chores and is only receiving the services of a general practitioner.

Mainstream organisations are doing very little work with family carers. In cases where there is contact between mainstream organisations and family carers, carers find that there is a lack of information on dementia and on what services are available to them. For example, in the Netherlands there is a video and CD-ROM providing information on how to cope with bouts of violence, which are common in people with dementia. Unfortunately, not only is the language Dutch, but the material only includes Dutch people and so the advice is not considered useful by BME family carers.

As well as inappropriate material information, family carers are also not using services for more basic reasons. In one example, an elderly Pakistani woman cares for her husband who has dementia, but is unable to attend an Asian lunch club due to a lack of transport. In an example from Spain, an elderly Romany man with dementia is being cared for by a relative who himself has a large family. It is only when a neighbour makes the family aware of services, and actually makes all the arrangements for the elder to be placed in a

residential home, that information on available services comes to light amongst the community. A travesty of the current situation is an example from the Netherlands in which a daughter, who hid her mother because she was ashamed of her behaviour, accidentally realized that services were available to her and her mother. The *accident* occurred when a general practitioner visited her school as part of an information campaign on health problems and gave some examples of situations in which patient and carer needs are not met as a result of a lack of information and knowledge. These examples highlight the need for specific and targeted developments to make information, knowledge and services available to BME family carers.

The lack of information and knowledge of services is inevitably leading to the isolation of family carers. Black and minority ethnic organisations that exist in some countries, notably the UK, and are being recommended in other countries such as Spain, are important in avoiding this isolation. These organisations recognise the needs of BME carers, can access services on behalf of the carer, and are often vital as go-betweens in socio-economic issues (e.g. housing or benefit entitlements). Black and minority ethnic organisations are also trying to reduce the isolation of family carers by supporting local carer networks and holding regular meetings between carers. Furthermore, the burden on family carers is being eased by allowing the elder with dementia to spend time at a lunch club or with someone else from his/her ethnic background. These organisations are also providing information directly to family carers, their families and communities, in an understandable form. This could simply be a matter of explaining to a Muslim family that the food available from a 'meals on wheels' service is halal, what equipment is needed to aid in bathing the elder and how to obtain it, or even providing transport to lunch clubs for elders. Finally, employment is a major problem once care work is over, and BME organisations are working hard to ensure that family carers do not themselves begin to suffer from illness (often depression).

Black and minority ethnic organisations are also catering to other cultural needs of BME family carers and their communities. Family carers feel more comfortable in approaching these organisations rather than mainstream institutions because they often understand their problems better, and are more personal. Professional carers often do not address people by their first names and may not be sensitive to details that are important to the BME carer. For example, sensitivity to the difficulty the family carer may have in conveying what is considered embarrassing information about the elder relative with dementia. Issues regarding women as carer's of male relatives is another sensitive issue for many BME communities. Thus, although within domestic surroundings cultural aspects ('duty') may allow 'gender caring' to be managed, in a home a professional carer who is a woman might present difficulties that need to be addressed sensitively.

## CONCLUSION

This booklet has shown for the UK, Netherlands, Spain and Finland that:

- All four countries are multicultural, multiracial, multilingual and multi-faith.
- There are various reasons for the settlement of BME people in these countries: colonial links, refugee status, economic migration within Europe, and as partners through marriage.
- Demographic trends suggest the number of elders from BME communities will increase rapidly in coming years – ‘today's young are tomorrow's elders’.
- Dementia is not absent currently in these countries, but is invisible.
- Developments today will set the foundation for tomorrow when the demands for *appropriate* dementia care will be much higher. There will also be higher expectations of the quality of care provided.

The CNEOPSA Project has offered two further tools: a booklet and film, both of which are designed not only to raise awareness, but to motivate change from all who are involved in the system of care. Below we highlight the principle messages to the key players in the system of care:

### 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.*

## **So what can be done to implement this recommendation?**

In the first CNEOPSA project (1997-1998) the development of specialist resources amongst a few cross-ethnic elder organisations was proposed. This was because elders from such communities use these organisations; the present findings emphasize this. Also, these organisations are meeting a range of the needs of BME elders, but with limited resources. We termed this the **CNEOPSA - Satellite Model**. In the UK we have been developing this and are currently seeking funding and support from the Government and other bodies. This recommendation of a *Satellite Model* has also been adopted as a way forward in the Netherlands. There is a clear benefit in transferring knowledge and practice, and generating economies of scale in the process. It is likely that some of the developments could also be adopted and adapted to Finland and Spain.

The European Commission can play a major part in facilitating such a development network, by learning and adapting the best appropriate practice in dementia care from the majority, investing specifically in a few identified BME organisations, and, thereby, developing new methods, tools and skills on dementia care. Given the various declarations on reducing health inequalities and promoting social inclusion, our model suggests a practical way forward to address a number of deficiencies in the system of care.

### **2. 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).*

### **3. 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.*

#### **4. 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.*

#### **5. 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 5<sup>th</sup> 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.

With policy commitments, resources, systematic planning, developments and practice, we should at some stage be able to replace the quote at the beginning of this document with the following:

the world of dementia is *for* antiracist - inclusive care  
and the world of minority ethnic organisations is *for* dementia - inclusive care  
(Patel 1998)

Within the European context of change, and in recognising the position of minority ethnic communities, viz. the prevalence of racism, disadvantage, and sources of social exclusion, it has been necessary to introduce Article 13 of the Treaty of Amsterdam. Article 13 states:

*“the council, acting unanimously on a proposal from the commission and after consulting the European parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation”.*

This is a sign in the right direction as we enter the new millennium. We can all make a difference to the quality of life for a person with dementia, since today's young are tomorrow's elders, as the film states.

## Partner information and acknowledgements

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Special thanks to the Alzheimer Society of Finland & its local associations in Helsinki and Lapland, Director Korelin (Helena's Home), Project coordinator Ristenrauna Magga (Association of Social & Health Care matters of the Lapps), Eva Biaudet, Minister of Health and Social Welfare, and Matti Rajala.

The **key organisation** for information was the Alzheimer Society of Finland, Luotsikatu 4 E, FIN-00160 Helsinki, Finland, ([www.alzheimer.fi](http://www.alzheimer.fi); Tel: +358 9 6226 200; Fax: +358 9 6226 2020).

### Netherlands

**Harry Mertens** works in the cluster social policy of the Netherlands Institute of Care and Welfare (NIZW), Postbus 19152, 3501 DD Utrecht, Netherlands. He has specialised in Ageing and Ethnicity in the Netherlands and has produced several films about minority ethnic older people. He is the coördinator of the programme multicultural aspects of Care and Welfare generating many projects and involving black and minority ethnic older people. He was a co-founding member of the European Network on Ageing and Ethnicity. Recently he set up the Ageing and Ethnicity WEB. This initiative uses the internet to give world wide information on issues related to minority ethnic older persons. (Tel: +31 0 30 230 6384; Fax: +31 0 30 231 9641; E-mail: [H.Mertens@nizw.nl](mailto:H.Mertens@nizw.nl)).

**Key organisations** providing relevant information were: Iwan Komproe (Transcultural Psychosocial Organisation), Dirk Kloosterboer (Nederlands Islamitische Bond voor Ouderen), Marco Blom (Alzheimerstichting Nederland), Nisha Arjun (Wooncentrum Transvaal), Frits Reisemus (Wooncentrum Transvaal). The main source of information was the preliminary study Migrants and Dementia in The Netherlands (Rob Ong, Msc, Iwan Komproe, PhD, Prof. Joop de Jong, MD, PhD., 1998). Mainly on the basis of this study an overview of the Dutch situation was produced by Harry Mertens and Iwan Komproe and is incorporated into *Dementia Matters, Ethnic*

concerns. Other relevant literature included: *Dementie en psychische problematiek bij ouderen (1998)*, B. Yilmaz - NISBO, Rotterdam.

NB: There are several organisations in the Netherlands who relate to black and minority ethnic older people. There is also the Alzheimer's Society and their branches. Information on these organisations is therefore not listed here. Details can be obtained from Harry Mertens, NIZW (see above).

## Spain

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**Gypsies Supporting Associations:** Asociación Española Integración Gitana, Cabestreros, 12 bajo, 28012 Madrid (91 4686061); Asociación Presencia Gitana Universal, Av. Galicia, 65 BI 12-2º D, 36216 Vigo – Pontevedra (Tel: 986 377015); ROMI.- Asociación de Mujeres Gitanas, 18010 Granada (Tel: 958 283824); Secretariado General Gitano, Fuencarral, 129-5ºA, 28010 Madrid (Tel: 91 4481098); Unión Romaní, 08002 Barcelona (Tel: 93 3012833); Baja de San Idelfonso 15-3º, Baños Nuevos, 16-4º-2ª.

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## United Kingdom

**Naina Patel** is Director of PRIAE Policy Research Institute on Ageing and Ethnicity at the University of Bradford Management Centre, Emm Lane, Bradford BD9 4JL. PRIAE is chaired by Sir Herman Ouseley (Chairman of the Commission for Racial Equality) and is a first Institute in the UK specialising in ageing and ethnicity which produced the report for the Royal Commission on Long Term Care for the Elderly. Naina designed the CNEOPSA Project in 1996, working with Naheed to generate a trans-national team to produce the first publication on the subject matter. She has specialised in ageing and ethnicity in the UK, was a co-founding member of European Network on Ageing & Ethnicity and managed antiracist/equality in social work developments at the Central Council for Education and Training in Social Work.

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**Naheed R. Mirza** has contributed to PRIAE through its CNEOPSA Project on dementia from the beginning. He is a co-author of its first publication, *Dementia and Minority Ethnic Older People (1998)*. He is also a Researcher at Cerebrus Ltd, Oakdene Court, 613 Reading Rd, Winnersh, Wokingham RG 41 5UA. He was previously at the Institute of Psychiatry. He has specialised in various disease areas, with particular emphasis on Alzheimer's disease.

**Key source of** relevant information for the booklet was the UK section in the CNEOPSA book, Patel, N. Mirza, N. Lindblad, P & Amstrup, K, Samoli, O (1998) *Dementia and Minority Ethnic Older People*, Russell House Publishing (ISBN: 1-898924-33-3; Fax: 01297 442722). The organisations and individuals involved in this original study came from minority ethnic organisations, Alzheimer's Society, Professionals in health and social care mainly from England and Scotland. For the film, the organisations are: Asian People with Disabilities Alliance, West Indian Self Effort Project (W.I.S.E) Ilford Park Polish Home and Dementia Relief Trust (for a collage of China Town). We are appreciative to the time and support given by everyone involved both in the original study and the film.

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NB: There are several organisations in the UK who relate to black and minority ethnic older people. There is also the Alzheimer's Society and their branches. Information on these organisations is therefore not listed here. Details can be obtained from Naina Patel, PRIAE (see above).

**Thank you from the CNEOPSA team to you all - in Finland, the Netherlands, Spain, the UK and to Mr Rasmussen at the European Commission - and to future readers.**

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<sup>2</sup> See the Foreword in the CNEOPSA book, *Dementia and minority ethnic older people: managing care needs in the UK, Denmark and France (1998)*.

<sup>3</sup> Mainstream refers to health care, social care and housing provided by the state.

<sup>4</sup> A preliminary study exploring the current situation of migrants with dementia, the family caregivers and professional care services – Rob Ong (MSc), Ivan Komproe (PhD) and Professor Joop de Jong (MD, PhD).

<sup>5</sup> The term Romany will be used throughout the text.

<sup>6</sup> Except for the research done by the TPO and the NISBO in the Netherlands.