



NCPC

National Council for Palliative Care

Ethnicity, Older People and Palliative Care

A joint publication from
PRIAE The Policy
Research Institute on
Ageing and Ethnicity and
The National Council
for Palliative Care

PRIAE Policy Research Institute on Ageing and Ethnicity

PRIAE (pronounced 'preeya') is an independent registered charity working to improve pensions, employment, health, social care and housing, and quality of life for black and minority ethnic older people in the UK and across Europe.

The Institute aims to influence national and European policy and increase and encourage good practice in work with black and minority ethnic elders. PRIAE does this through creating and leading on often 'first of its kind projects' in research, information, service developments, training and consultancy.

PRIAE gratefully acknowledges financial support from the Department of Health for the PALCOPE (**P**alliative **C**are **O**lder **P**eople **E**thnicity) 'Stories that Matter' national project. The project has aimed to: increase awareness of palliative care amongst minority ethnic elders and carers; and increase awareness of their needs amongst those working in palliative care. The project has produced a leaflet and guide for older people on palliative care and has run training workshops for professionals (www.priae.org). PALCOPE Project has been supported by an Advisory Group that included palliative care professionals and minority ethnic elders. The interviews were carried out by the Project Manager, Yasmin Gunaratnam with Neera Deepak during the project. The publication is written by Yasmin Gunaratnam.

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The National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales & Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, national and local policy makers.

NCPC works focused policy units and with external partners across the health and social care sectors to produce practical and policy guidance for health service providers and commissioners. The organisation also runs regular national and regional events based on topics of national importance to palliative care, offering learning and networking opportunities to a broad range of delegates.

NCPC is a subscription based organisation, representing subscribers from across the NHS, voluntary and independent sectors. Subscribers benefit from membership through access to NCPC resources via www.ncpc.org.uk and the receipt of topical briefing bulletins, the new *Focus On* range and major publications on key policy issues as well free delegate places at regional events and reduced rates for national events.

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'Sometimes GPs are the cause of extending the illness. If there is an illness they keep giving you painkillers and keep postponing. In the end you come to know that the disease has become so big and you can't have any treatment.'

(Zulfika, carer)

'...the doctor was extremely kind and helpful and always has been so, even now. If I have any problems, all I need to do is go to the clinic and there is someone there that I can see.'

(Herman, hospital service user)

'If there are services like this what is illness? A person can tackle the most difficult thing.' (Mohammed, hospice service user)

'I couldn't believe how many times we had to keep going backwards and forwards, backwards and forwards to get any help...if you are completely ignorant it's hard work and thank God I was in touch with the community centre, otherwise I wouldn't have been enlightened as to what was available.'

(Geeta, carer of dementia patient)

Aim

This report brings together established and developing work on older people, ethnicity and palliative care from PRIAE (Policy Research Institute on Ageing and Ethnicity) and the National Council for Palliative Care (NCPC). It draws attention to the palliative care needs and experiences of elders from groups most commonly referred to in the UK as being 'minority ethnic'.

The recognition of how multiple and simultaneous disadvantages can affect palliative care needs and experiences is an issue of broad relevance to palliative care - and one that is not restricted to the discussion of old age and ethnicity. In this sense, the report also aims to encourage more complex approaches to inequality in palliative care for all service users.

Key issues

Many elders from minority ethnic groups can live with several illnesses until they die. They can be poor and socially and emotionally marginalised. Their expectations of culturally responsive care are frequently not realised and sometimes they can face racism and ageism in care. Despite such experiences, minority ethnic elders and their carers can live with, challenge and overcome some of these disadvantages in active and creative ways.

Factors that are important in understanding how old age and ethnicity can affect palliative care needs are:

- The numbers of elders from minority ethnic groups in the UK (Butt and O'Neil, 2004, PRIAE 1999, 2005) and in Europe are increasing (PRIAE, 2004) and are projected to increase in the future (Evandrou, 2000a)
- Palliative care services are used mainly by people with cancer (NCPCC, 2006a). Cancer mortality is relatively lower in most minority ethnic groups (Aspinall and Jacobson, 2004)
- Emerging research from the USA suggest that there are ethnic disparities in clinical outcomes for cancer patients and that those from minority ethnic groups can have worse survival rates (Mayberry *et al* 1995; Tammemagi, 2005). Minority ethnic elders can be more likely than white patients to receive inadequate cancer pain control (Bernabei *et al*, 1998)
- Chronic degenerative diseases and co-morbidity, with long periods of ill-health can characterise the illness experiences of minority ethnic elders (PRIAE, 2005)
- Many elders from minority ethnic groups rely upon state retirement pensions and social benefits/allowances as their main sources of income (PRIAE, 2005). They are more likely than white, British older people to live in poor quality housing (Evandrou, 2000b) that can adversely affect their care in the home (Blakemore, 2002; Butt and O'Neil, 2004)
- Despite relatively high levels of satisfaction with health and social care services (PRIAE, 2005), there is some evidence to suggest poorer access to palliative care services for minority ethnic elders (Lowdell *et al*, 2000).
- Wider studies show that access to services for minority ethnic groups can be limited (Koffman and Higginson, 2001), particularly by the 'gate-keeping' of GPs (Smaje and LeGrand, 1995)
- The majority of minority ethnic elders live with other people, however older women are more likely to live alone than men. Higher proportions of Black Caribbean older women live alone than older women from South Asian backgrounds (PRIAE, 2005)

Terminology: lives behind the categories

Box 1: Stories that matter

'I had cancer in Madagascar, when I came back [to England], I had a letter from the hospital to come and have my check up...they found the cancer was advanced. In the beginning I got tested twice in a month, followed by them calling me every four to five years.

'I was feeling better and they said that I don't need to carry on anymore [with hospital care], 'If there is any pain you should come back'. After that I had a heart problem. I've been suffering with this problem for five years. I went to America to my brother's daughter's niece. She had had a baby so I went to take care of her during the delivery period... I was not feeling too well. I was forced by my daughter-in-law as she was working and couldn't go herself...

'From there I went for ten days to see another relation...then I went to Africa. The next day [in England], I had a heart attack....the ambulance came and they took me to hospital. They kept me for two weeks....As I have cancer, they said I had to come back for a check up. So I continued my check-ups...'

(Gujarati-Hindu patient interviewed in Gujarati,PALCOPE @PRIAE)

What do we mean by ethnicity? There is considerable debate and misunderstanding about what the term ethnicity means. In this report it is used to refer to identifications with a group - real and imagined - based upon culture, language, religion and/or geography. Country of birth and/or nationality are not reliable indicators of ethnicity as they can exclude second and third generation groups (Modood *et al.*, 1997) and can also exclude the complicated experiences and ties of those who have experienced multiple migrations (see box 1). Although most readily associated with visible minorities, such as people from Black Caribbean and South Asian groups, it is important to recognise that everyone has an ethnicity.

Broad categorisations of ethnicity can be useful for quantitative research and at population level needs analysis, however they do not have the same value when providing individualised, holistic care to patients and carers. There can be cultural, religious and linguistic differences within ethnic groups (such as amongst those categorised as 'Indian' or 'African') and the meanings of ethnicity, culture and faith in individual lives can vary in unpredictable and surprising ways. NCPC's reports *Opening Doors* (Hill and Penso, 1995) and *Wider Horizons* (Firth, 2001) provide discussions of the literature on ethnicity and palliative care (up to 2001). *Wider Horizons* also has made detailed recommendations for research, policy and service developments in palliative care (see box 2).

Box 2: Recommendations from *Wider Horizons* (care issues)

- Hospitals and hospices need to provide culturally sensitive palliative care with adequate interpreting/advocacy services, a culturally sensitive disclosure policy, and adequate discharge policies. This involves on-going in-service training in anti-discrimination as well as cultural competence
- Dietary and religious requirements should be discussed fully with users on an individual basis, so that there is provision for special needs, including water for ablutions, prayer time/space, skin, hair and hygiene needs and appropriate clothing or gowns for patients.
- Ethnic minority staff should be recruited where possible, and advocates/interpreters made readily available.
- Ensure that if a home care is the preferred option, the financial and support needs of carers are taken into account, allowing for sensitive handling of the position of informal carers vis a vis their own communities. This has resource implications.
- Appropriate Day Care has to ensure dietary needs are met on an individual basis, that there are carers and/or interpreters speaking the appropriate languages and both emotional and practical support can be offered.
- Anti-racism and anti-discrimination policies have to be firmly established and met at all levels of care, including protection from racist patients.
- Community support should not be taken for granted and the involvement of children in caring needs to be monitored.
- The significance of family in many communities has to be recognised as a matter of policy, and appropriate provision made for large numbers to visit dying inpatients in separate rooms.

(Firth, 2001 p. 92)

Who are older people? The terms 'older people' and 'elders' (the term used by PRIAE) are not related in any straight forward way to chronological age. NCPC's cross-cutting Older People Policy Group (see box 3) have argued that account needs to be taken of the 'dramatic variations in health status, participation and levels of independence among older people of the same age' (NCPC, 2006b, p.2). In addressing experiences of old age amongst minority ethnic groups, the use of the terms 'older people' and 'elders' in this report aim to recognise the effects of varying social disadvantages, resources, life-styles and self-identifications on experiences of age and health (see Evandrou, 2000b). For instance, Patel (1999) has identified an incidence of 'early ageing' amongst some minority ethnic elders related to poverty and unemployment, with some people in their 50s using day centres and other services targeted at those of state pension age and over. Our use of terminology therefore recognises the ways in which ethnic disparities in

employment, income and health can impact upon identifications and experiences of being and 'feeling old'.

The palliative care needs of older people are recognised to differ from those of younger people. In its report *Better Palliative Care for Older People* (Davies and Higginson, 2004), the World Health Organisation identified the following factors as characterising the needs of older people:

- Multiple chronic medical problems of varying severity rather than acute illnesses.
- A cumulative effect on health greater than for any individual disease, typically leading to greater impairment and needs for care.
- Higher risk of adverse drug reactions and of further conditions caused by the medical treatments given.
- Minor problems having a greater cumulative psychological impact
- Acute illness building upon existing physical or mental impairment, economic hardship and social isolation.
- A tendency for under-assessment and under-treatment of symptoms compared with younger people.
- The population needing end of life care becoming much older and much larger.

NCPC :Older People Policy Group

The aim of the National Council for Palliative Care's multi-agency, multi-sector, multi-professional Older People Policy Group is to provide clarity on the particular characteristics of palliative care need for older people. The promotion of equity in service provision and care is a central concern. The guiding vision is that all older people who have palliative care needs will receive responsive and high quality palliative care. This should be tailored to meet their individual needs and preferences, allowing them to exercise some choice and control rather than being passive recipients of services. Furthermore it should be available equitably, without barriers deriving from age, diagnosis, culture, religion, gender, sexual orientation or other personal and social factors.

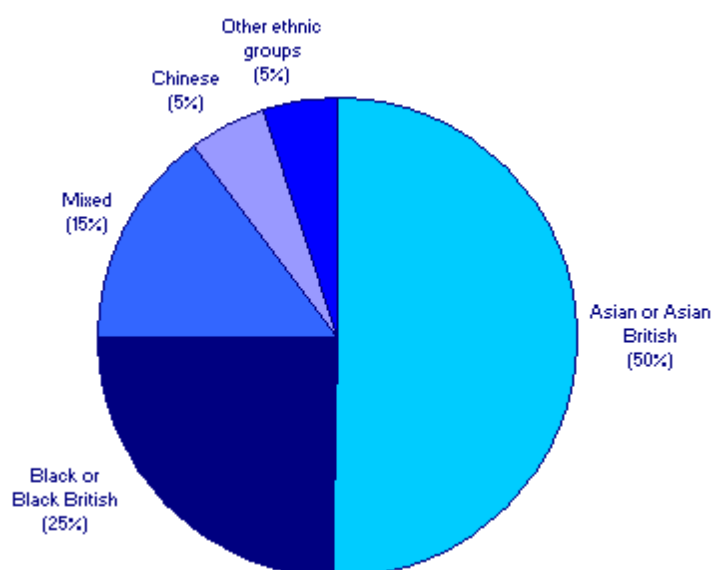
The accepted domains of palliative care need may include physical, social, spiritual, and psychological components but for older people there may be differences in the expression of these needs and in the service and care requirements in order for them to be met. This is consistent with the life experience, priorities and expectations of older people and services should have the flexibility to manage these appropriately. As dementia becomes increasingly common with advancing age, this is an additional consideration in developing and delivering palliative care to older people.

Ethnicity and Age – the demographic context

According to the 2001 census (ONS, 2001) around 12% of the UK population are from a minority ethnic group. A population breakdown for the main minority ethnic groups can be seen in Figure 1. The majority of minority ethnic groups live in England (approximately 9%), although nationally there is significant variation in the geographical distribution of populations, with minority ethnic groups being concentrated in urban areas.

Geographical differences in where minority ethnic groups live and variations in the size of populations can have effects upon the consistency and quality of culturally responsive palliative care. For example, some palliative care professionals in multi-cultural areas have regular contact with service users from minority ethnic groups and are developing knowledge of their palliative care needs. Others in areas that are less diverse and/or have smaller minority ethnic populations can have considerably less experience and awareness of how ethnicity and culture can affect the needs of patients and carers at times of death and dying. Information sharing (Firth, 2001), professional education (Gatrad *et al*, 2003), guidance and 'committed policy attention' (Smaje and Field, 1997) to the palliative care needs of minority ethnic groups have been seen as important in ensuring greater equity and consistency of palliative care.

Figure 1: Ethnic minority populations in the UK (ONS, 2001)



The numbers of minority ethnic elders in Britain has risen considerably in recent years (PRIAE 2003; Butt and O'Neil, 2004), although they are still in a minority amongst older people. In the 2001 census (ONS, 2001) they accounted for 3.5% of people aged 50 and over (around 672, 000). The most comprehensive data on ethnicity and old age in Europe can be found in the Minority Elderly Care (MEC) project, led by PRIAE (Patel, 2003). The MEC research explored the needs and experiences of 27 minority ethnic groups in ten countries: United Kingdom, France, Germany, Finland, the Netherlands, Spain, Bosnia-Herzegovina, Croatia, Hungary and Switzerland (see box 4).

Box 4 PRIAE Minority Elderly Care (MEC) Research

Major research in ten European countries:

- 25 minority ethnic groups across Europe
- 3277 minority ethnic elders
- 901 health and social care professionals
- 312 voluntary organisations

UK research (London, West Yorkshire and Scotland):

- 390 face-to-face interviews with minority ethnic elders
- Three minority ethnic cluster groups (7 languages)
- 53% South Asian, 23% Chinese/Vietnamese and 24% Black-Caribbean
- Interviews conducted in the first language of the informant.

The European and UK MEC research summaries can be downloaded from www.priae.org

Table 1 shows the age distribution by ethnicity of the population in Britain. The minority ethnic groups with the oldest median age are those who categorised themselves as being 'Black Caribbean' (median age 33), with 'Asian Other' (median age 32) and 'Indian' and 'Chinese' (both with a median age of 31) being the next oldest groups (Patel, 2003). PRIAE has identified an 'age bulge' of elders from these particular ethnic groups, currently aged between 45-65, that is consistent with patterns of post-war migration and settlement in the UK of those who migrated as adults in the late 1950s and early to mid 1960s. .

Table 1: Age distribution by ethnic group in Great Britain, 2001

Great Britain	Percentages		
	Under 16	50 and over	85 and over
White	87.9	96.5	98.9
Mixed	2.9	0.3	0.2
Black Caribbean	1.0	0.7	0.2
Black African	1.3	0.2	0.1
Other Black	0.3	0.0	0.0
Indian	2.1	1.1	0.3
Pakistani	2.3	0.5	0.1
Bangladeshi	0.9	0.1	0.0
Other Asian	0.5	0.2	0.1
Chinese or Other	0.8	0.4	0.1
All ethnic groups	100.0	100.0	100.0

Source Census 2001, ONS; Census 2001; General Register Office for Scotland

Ethnicity age and palliative care – demography, epidemiology and need

Key demographic characteristics of the population that have been identified as influencing the need for palliative care are: age, gender, ethnicity/religion, socio-economic status and household composition (Tebbit, 2004). Areas with high proportions of older people in their locality have been recognised as having higher levels of need and as requiring more resources for palliative care (NCPC, 2003). It has also been suggested that areas with high proportions of people from minority ethnic groups may need greater resources to pay for interpreting services and for the education and training needs of palliative care professionals who will require 'an understanding of the different approaches taken by different cultures to end of life issues' (Tebbit, 2004, p.12).

Despite the broad relationships between demographic characteristics and the need for palliative care, there are difficulties in using demographic data on ethnicity to assess the palliative care needs of minority ethnic elders and to monitor services. This is because there are a range of factors - many of which are not fully understood - which affect service needs and how people use services. Research suggests that there are two factors that are of particular importance:

- ethnic differences in the patterning of diseases;
- culture and lifestyle differences and changes (which in turn can affect disease and service needs.)

Disease patterns and ethnicity

The presence of life-limiting and chronic, degenerative conditions varies in relation to both age and ethnicity. In general, the incidence of cancer increases with age, although, as Help the Aged (2005) point out, the disease experience of older people is varied:

‘...the proportions dying of cancer as a primary cause decrease with age and the proportions dying from circulatory and respiratory disease as primary causes increase with age. People who die from chronic, degenerative diseases other than cancer tend to be aged over 65 years and to have a prolonged illness trajectory...’ (p.31)

Because minority ethnic populations have younger age structures than white, British populations (see table 1) the incidence of cancer within these groups is lower. Epidemiological research has further shown that cancer mortality amongst minority ethnic groups is lower, even when age differences are taken into account

(Smaje and Field, 1997). In comparison to white, British populations, cancers tend to be less common for those categorised as Scottish, Irish, 'West Indian' and South Asian migrants (across Sikhs, Muslims and Hindus) in England and Wales (Harding and Rosato, 1999). However, mortality ratios for lung cancer are higher for male, Irish and Scottish migrants, and are also relatively high for migrant women from Scotland and Ireland (Wild and McKeigue, 1997).

While cancer may not be as prevalent within minority ethnic groups, other life-limiting and chronic degenerative illnesses are:

- There are higher rates of coronary heart disease amongst Pakistani and Bangladeshi groups and higher levels of hypertension in Black Caribbean groups (Modood *et al*, 1997)
- Mortality rates associated with diabetes are higher for South Asian and Black Caribbean groups and end stage renal failure is significantly higher amongst South Asian people with diabetes, compared to white, British diabetics (Aspinall and Jacobson, 2004).
- In general, elders from minority ethnic groups are more likely to report being in poor health and that activity in their daily lives has been restricted due to illness or injury (Evandrou, 2000).
- The most prevalent life-limiting diseases amongst elders from Black Caribbean, South Asian and Chinese and Vietnamese backgrounds are coronary heart disease and cardiovascular conditions, with other chronic and co-existing conditions being diabetes, arthritis/rheumatism, lung/breathing problems, osteoporosis and kidney problems (PRIAE, 2004).
- There is an excess of deaths from stroke amongst Black Caribbean elders, high rates of coronary heart disease amongst elders from South Asian backgrounds; and high rates of diabetes amongst elders from the Caribbean, Africa, Asia and the Middle East (Lowdell *et al*, 2000)

The relatively poor levels of ill-health, inequalities in the burden of disease and co-existing conditions amongst minority ethnic elders are of specific relevance to palliative care. Ethnicity related differences in the meanings of disease (CancerBACUP, 2004) and variations in the length and experience of symptoms and pain can also affect palliative care needs. Co-morbidity can lead to the under-diagnosis of a life-limiting illness and can also place greater demands upon palliative care professionals and family carers, who have to manage more complex needs (Help The Aged, 2005).

Greater attention is now being given within the palliative care field to the needs of older people with chronic, degenerative illnesses. The World Health Organisation (Davies and Higginson, 2004) has urged a move away from prognosis centred palliative care:

'Because it is more difficult to predict the course of many chronic diseases affecting older people, palliative care should be based on patient and family needs and not on prognosis' . (p.15).

The NICE guidance on supportive and palliative care (2004) has further recognised that while palliative care provided by specialists will be required to meet the needs of a small number of patients with complex needs, palliative care should be provided by generalists to all patients irrespective of their disease or care setting. NCPC has drawn attention to care homes for older people as a significant site for end-of-life care (Froggatt, 2004), with approximately 21% of people over the age of 65, who die each year, dying in care homes (ONS, 2000). Issues of equity relating to the accessibility and the standards of palliative care provided to older people in care homes have been identified as areas that need further examination and guidance (Froggatt, 2004). It is not clear at present, how relevant current care home service models will be for minority ethnic elders in the future, although there is some evidence that geographical inequalities in the provision of long-term residential care for older people in inner city areas may affect patterns of service use (Boyle and Smaje, 1993).

Although there is increasing recognition of the disadvantages older people can face in accessing palliative care due to disease and care setting, it is important to note that there are presently inadequate data that examine the impact of racism on health inequalities and experiences of illness for minority ethnic elders. Yet as Aspinall and Jacobson (2004) highlight:

'Recent research (Nazroo 2003, Karlsen and Nazroo, 2002) has found strong independent associations between reported experience of racism and perceptions of Britain as a "racist society", household social class, age, sex and various mental and physical health indicators which show reasonable consistency across different ethnic groups. In some areas of medical research and practice ethnic disparities in health continue to be attributed to genetic and non-specific "cultural" explanations. However, the emerging evidence base suggests that socioeconomic factors and the experience of racism may be amongst the most important causes of these disparities.'

(p.12)

Cultural and lifestyle changes

Differences in disease and illness patterns are obviously important in addressing the palliative care needs of elders from minority ethnic groups. Yet, alone they do not provide in-depth insights into how the lives of minority ethnic elders can affect health and illness. Clearly, these experiences are most relevant in understanding both the ethnic patterning of disease and how palliative care services are needed and used. For instance, cancer incidence rates amongst migrants appear to be converging to rates similar to that of the receiving population within one or two generations (Ziegler *et al*, 1993, Harding and Rosato, 1999). Referred to as the 'migrant effect', such convergence suggests that there are cultural, socio-economic and age related factors that affect how different groups maintain and/or adapt their

lifestyles once they have settled in another country. Such variations can have an impact upon health and disease, yet knowledge about the size and nature of this impact is limited. As Field and Smaje (1997) point out with regard to cancer:

'...it should not be assumed that the patterning of cancer is immutable. The fact of migration considerably complicates analysis, and it cannot be assumed that disease patterns observed among now elderly 'pioneer' migrants will be replicated in more recent generations' (p.150).

In addition to epidemiological changes in minority ethnic populations, there are important socio-economic differences between groups that need to be recognised. For example, different minority ethnic groups have varying experiences of deprivation, household composition and social networks, all of which can affect palliative care needs and choices.

The EMPIRIC survey (2002) involved a combination of quantitative survey interviews (4281) and qualitative interviews (117) with people from Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese and Irish groups. The survey found the lowest levels of confiding/emotional support in the oldest age group among Irish and Black Caribbean people. Among those in the Indian group, this pattern was reversed. PRIAE's MEC survey (PRIAE, 2005) found significant gender differences amongst elders from minority ethnic groups, with 30% of women living alone compared to 18% of men. The groups with the highest proportion of women living alone were African-Caribbean (45%) and Chinese/Vietnamese (32%), compared to women in the South Asian groups (23%). Although, it is unwise to draw inferences from these findings into the associations between household composition and care needs, the data suggest that there may be fewer home based caring resources for African Caribbean older women, which may impact upon their choices and options for place of care and death as well as their emotional experiences of illness and dying.

In addition to differences in household composition, elders from Indian, Pakistani and Bangladeshi backgrounds can face particular disadvantages because of poor housing conditions and overcrowding (Evandrou, 2000b; PRIAE 2004; Butt and O'Neil, 2004). Using General Household Survey data, Blakemore (2002) suggests that low quality housing amongst the poorest minority ethnic groups can mean that these groups are more likely to 'lack the amenities and improvements which make it easier to care for frail older people' (p.127). While poverty and poor housing can affect illness experiences and care choices for all ethnic groups, it is important that palliative care providers are aware of and understand some of the specific ways in which religious and cultural practices can affect and transform the small, everyday detail of experiences of care in the home for minority ethnic elders and those caring for them (see box 5).

Box 5: Stories That Matter

'He had trouble coming up and down and if he had to do his namaz (prayers), if he had to have a bath, or to do the wujju (ceremonial wash), he would have a lot of difficulty. We requested them to make a bathroom upstairs...the authorities kept saying 'today, tomorrow, today' in this way two years passed by, but they didn't make the bathroom. When his condition deteriorated, we had to assist him by holding him, bringing him down, helping him sit in the bath, taking him out of the bath, this was all very difficult. I'm a bit upset because of this, if this (upstairs) bathroom was there, it would have been much easier.'

(Pakistani, Muslim carer, interviewed in Hinkoo, Urdu and Punjabi, PALCOPE@PRIAE)

Palliative care service inequalities: age and ethnicity

'I live not far from here (hospice) and sometimes I'm walking down, you know and I just didn't know that there was a hospice there. I didn't know anything about a hospice, nothing. I said to her (GP) 'I'm going to be in a hospice' after I knew and she said 'What you go there for? My doctor said that 'What do you go there for?'

(Black Caribbean patient, interviewed in English)

Research evidence shows that it is inequalities in the organisation and *ad hoc* development of palliative care services, *together* with the effects of social exclusion and disadvantage that can produce inequalities in access to palliative care. A 'Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals' (Ahmed *et al*, 2004) has identified the following problems as restricting access to palliative care:

- The heterogeneity in palliative care service provision in different localities (a form of 'postcode' lottery).
- Lack of understanding amongst professionals about whom to refer, and when.
- Resistance by some professionals to share care or to refer patients to palliative care services.
- Reluctance by many patients and carers to be referred to palliative care, due to misunderstanding or fear of the service's association with death and dying.

- Perception that palliative care is only for cancer patients.
- Missed opportunities due to cultural background or being in institutional care.

PRIAE's MEC research provides further insights into the particular barriers that elders from minority ethnic groups can face in accessing health and social care services. The UK research found that minority ethnic elders expected more information about services and also expected greater levels of culturally responsive service provision:

'It is clear that there is an information gap in health and social care. The biggest gaps between expectations and perceptions relates to information about services, and the availability of information in one's own language.

Having staff of the same ethnic group was a high expectation for the South Asian and Chinese/Vietnamese elders and the provision of places of worship, being able to talk freely about religious needs and having staff of the same gender was most important for South Asians.' (PRIAE, 2004, p.4)

Issues identified in the MEC research as relating to cultural insensitivities in services and care can also be found in the palliative care research on ethnicity (Haroon-Iqbal *et al*, 1995; Koffman and Higginson, 2001), but are less evident in the research on palliative care and older people. Factors that NCPC (Firth, 2001) have identified as leading to ethnic inequalities in palliative care service use include:

- Weaknesses in referral systems and inadequacies in information provision for hospital consultants and GPs on palliative care services and their appropriateness for minority ethnic patients.
- Lack of information in different languages about palliative care services.
- Inadequate interpreting and advocacy provision for service users and carers who do not speak English.
- Inadequate multi-faith support.
- Failure to involve different communities in palliative care service development and review.

NCPC's 'Minimum Data Sets' Project (2006) shows that for 2004/2005 amongst palliative care patients:

- 96.6% were 'white'
- 1.29% were 'black'

- 0.91% 'Indian/Pakistani/Bangladeshi'
- 1.16% 'Chinese/other/mixed'

These data are similar to those in the equivalent report for 2003/04 in which NCPC (2005) concluded that:

'It is not possible at the moment to gauge the effectiveness of palliative care services in meeting the needs of ethnic minorities.' (p7)

From research into the palliative care needs of older people and those from minority ethnic groups, it can be seen that old age and ethnic and cultural difference respectively, raise specific challenges for the provision of equitable palliative care. A report on older people, ethnicity and health in London (Lowdell *et al*, 2000) found evidence of differential and late referral to acute and community care services, including palliative care. Factors identified by the researchers as affecting access and referral for minority ethnic elders were:

- Low levels of awareness of services.
- Services were perceived to be or were of low quality.
- Problems in communication.
- Lack of cultural sensitivity by service providers.

Tackling palliative care service inequalities for minority ethnic elders

This section of the report uses narrative accounts from PRIAE's PALCOPE project and examples of service initiatives to provide further insights into the palliative care needs of minority ethnic elders and carers.

Not being taken seriously

Minority ethnic elders and carers can feel that a patient's experiences and symptoms are not taken seriously by doctors. Advocacy, intervention and support from family and friends can make a significant difference to some older people's care. Bill, a Black Caribbean patient with cancer of the pharynx, and a smoker, waited thirteen months for his cancer to be diagnosed. His daughter, Maureen felt that despite Bill's smoking, investigations for cancer had not been made. Anxious about the deterioration in Bill's health and rapid weight loss, Maureen by-passed her father's GP and phoned a hospital oncologist and asked him to see her father. The following extract from Bill's interview (conducted in English) is an account of his experience of waiting for a diagnosis:

'I had problems, I went to my doctor about it. He sent me to the hospital, but as many times as they sent me, they can't seem to diagnose what was wrong with me...they did everything. Six times

I've been there and the doctor tell me 'Oh you're all right, it's only a sore throat and that goes on for one year...and I know what's wrong with me before that...because I couldn't eat and I keep telling them that for thirteen months and my daughter get on to X (a cancer centre) and I know it right away. I could have stopped going through this pain if the doctor had only sent me there. I've been through a hard time, I know it.'

Despite primary care being a key referral point to palliative care, people from minority ethnic groups can express particular dissatisfaction with GPs (Airey and Erens, 1999; Koffman and Higginson, 2001). Bradford PCT are attempting to improve the primary care experience of those with palliative care needs who do not speak English through an adapted team 'GP Facilitator' model consisting of a Macmillan GP Facilitator with an attached Nurse Lead and a bilingual health worker, hosted by Bradford City PCT, where greatest needs for advocacy have been identified. The team covers three Bradford PCTs and is funded for 3 years and complements the work of the Macmillian Liaison officers in the Community Palliative Care Team.

Box 6: Joint Leeds Hospices Ethnic Minority Project (2001-3)

The joint project between St Gemma's Hospice and Sue Ryder Care (Wheatfields) was funded by Leeds Health Action Zone to address the palliative care needs of local minority ethnic groups and their perceptions of inequalities in access to hospice services. The project aimed to:

- i. Bridge language and cultural gaps between community and individual need and service response.
- ii. Increase the information and knowledge base of the needs of the ethnic minority communities.
- iii. Develop more inclusive methods to improve the health of ethnic minority communities.

The project appointed a co-ordinator who worked with four community workers who represented the Bangladeshi, Pakistani, Indian and African Caribbean/Chinese communities. Their objectives were to:

- i. 'Meet the needs and cultural practices of the identified community group and address the inequalities of access within the community
- ii. 'Work with an identified group to raise awareness and provide information on hospice services'

The project also developed a database of community organisations, local palliative care related organisations and national organisations with an interest in ethnic minority health care.

(Sue Ryder Care- Wheatfields, St Gemma's Hospice, 2003)

Language

'When I went for a check-up I could not understand. They would ask me to take off my clothes and put on the hospital gown, I would not understand. They would take pictures of my chest (X-ray). They would take the x-ray but I didn't know why or what for. Once the x-ray was done, I would leave the room. I didn't understand why they took the x-ray.'

(Sarla, Gujarati, Hindu cancer patient, interviewed in Gujarati)

People who do not speak English face particular barriers in accessing and using services (CancerBacup, 2004; Cancer Research UK 2004; Firth, 2001; Randhawa *et al*, 2003). For some elders who do not speak English, treatment and care can be mystifying, while also rendering them passive. The inability to communicate with minority ethnic patients and families can also cause dissatisfaction and stress amongst professionals (Spruyt, 1999; Thomas *et al*, 2000).

Initiatives involving multi-lingual and multi-media resources and the provision of interpreters and health advocates (bilingual interpreters trained in health advocacy and the palliative care approach) are developing within the cancer and palliative care fields (see box 7). Greater Manchester and Cheshire Cancer Network has produced a leaflet and audio-cassette '*Palliative Care and You*' in English, Urdu, Traditional Chinese and Simplified Chinese. St Gemma's Hospice and Sue Ryder Care (Wheatfields) have produced a poster, leaflet and audiotape (in English, Urdu, Bengali, Hindi, Gujarati, Punjabi and Chinese) on hospice services. The Department of Health-sponsored 'No Exclusion Clause Project' carried out in Warwickshire Health Authority has developed training for professionals on ethnicity, culture and palliative care and produced a twelve minute video on palliative care for patients and carers (in English, Cantonese, Gujarati, Hindi, Punjabi and Urdu).

Box 7: Macmillan Ethnic Minorities Liaison Officers (Bradford Community Palliative Care Team)

The role of the Macmillan Ethnic Minorities Liaison Officers in Bradford involves:

- Improving and maintaining quality of care to minority ethnic service users.
- Maintaining quality of access to specialist palliative care services
- Liaising between clients and the multi-professional team.
- Helping to identify and assess service user needs.
- Advocacy.
- Advice on religious/cultural issues.
- Interpretation of language and culture.
- Researching the service use and experience of minority ethnic service users.

Evaluation of the role of the first Liaison Officer post has found that the post has improved communication between professionals and service users, led to more accurate needs assessment, and to an increase in the use of hospice services by people from South-Asian groups. The role has developed to include two post-holders (a Pakistani Muslim man and an Indian Sikh woman). The expansion of current provision has aimed to improve care to women service users and to increase the range of languages available.

Despite growing attention to the needs of those who do not speak English, access to trained interpreters, advocates and bi-lingual professionals is highly variable across palliative care services. NCPCC's *Wider Horizon's* report (Firth, 2001) identified the need for national standards 'with nationally validated qualifications for

the training of advocates, linkworkers and interpreters, with specialist training in palliative care and the breaking of bad news' (p.91). This recommendation has not been achieved, but remains highly relevant.

Social and cultural taboos and the challenge for awareness raising

'The issue of better end of life care will not be resolved until health and care staff learn to embrace death as a normal part of life and until we educate the public about dying and what they should and can expect. (NCPC, 2005b)

There is no reliable evidence to suggest that those from minority ethnic groups are any more inhibited or are more anxious about talking about death and dying, although there are differences in the nature of social taboos about illness and death cross-culturally (*Tse et al*, 2003). It is also the case that the stigmatisation of diseases such as cancer (Cancer BACUP, 2004) can vary between different ethnic groups, leading to increased isolation for some minority ethnic elders and their families at times of ill health. Nevertheless, The PALCOPE project found that elders were not always passive in the face of such stigmatisation:

'... [Patients] should discuss their illness and thoughts with others. They shouldn't think about what others will think of them, or that within the family they will tell other people and create barriers for their children's weddings. This is very common within Asian society. They think that if people come to know about their illness, they won't be able to marry their children off, or people may think if the mother had cancer, then the children will also have it. You shouldn't think about this, you should tell others. So they can share your sorrow, they can share your sorrow'.

(Nusrat, Pakistani, Muslim, cancer patient, interviewed in Punjabi and Urdu)

Some cancer and palliative care services are addressing the need to work with minority ethnic voluntary and community organisations to raise awareness of palliative care, dispel common myths and misunderstandings about illness and to promote greater access to services and support (see box 8 below). LOROS hospice in Leicester has developed partnerships with the voluntary organisations 'Coping With Cancer' and a specialist welfare rights service 'The Palliative and Cancer Care Team' (PACCT) based at Leicester Charity Link. The partnership between the organisations has enabled more targeted support to South Asian communities in Leicester. The East Berkshire Macmillan Palliative Care Team, developed a New Opportunities Funded (NOF) project to widen access to palliative

care for South Asian populations in Slough. The Team have used community conferences and the video 'Humara Safar' (produced by the South East Asian Palliative Care Arts Awareness Project) to raise awareness of palliative care. Newcastle PCT have held education sessions, involving quizzes, leaflets and audio-visual media on cancer and palliative care for local minority ethnic groups.

Box 8: Bengali Cancer Awareness and Advocacy Project (Bart's and the London NHS Trust and Social Action for Health)

The Bengali population in Tower Hamlets is the largest outside Bangladesh, it is characterised by high levels of unemployment, poor housing and overcrowding. Research has indicated that Bengali patients are more likely to present with advanced stages of cancer than non-Bengali patients and that healthcare professionals feel that their training is inadequate to overcome language and cultural barriers (Thomas *et al*, 2000). Bart's and the London NHS Trust and the voluntary organisation Social Action for Health established a project in 2001 to raise awareness of cancer and to increase access to services for Bengali people. The project has included:

Two Bengali advocates - one based in the community to raise awareness of cancer and one based in St Bartholomew's hospital to provide advocacy services to patients and carers.

Information - to raise awareness of cancer in oral (through conferences, workshops and health stalls) and written forms.

Training - for community workers and the production of a training pack.

Patient Support Group – for Bengali cancer patients in the community.

Resilience

'Resilience is the capacity to do well when faced with difficult circumstances. That implies the capacities of both resistance and of positive construction.' (Vanistendael, 1998)

The following PALCOPE interview extracts provide examples of how resilience was talked about and expressed in the accounts of minority ethnic elders and carers:

:

'...you [can] become a target because you are a complainer, but that didn't stop me because I wouldn't stop because I didn't want mum hurt in any way. I've got folders

full of complaint letters and apologies and all sorts of things which happened throughout the whole caring for mum.'

(Afshan, Pakistani carer of a stroke patient, interviewed in English)

'How good are your children that they comfort you so much, they ask you everything, they research everything on the internet, including researching all your treatments and drugs.' The children would go to the consultant to ask what drug was most suitable and effective, 'We've read this, we've enquired about that, is this medicine good?' The doctors were very happy with this, she would say 'I will give those medicines' and agree with what the children had said. She would give the same medicine that the children had researched and suggested. My doctor was very happy that my children were very supportive and concerned about me.

(Nusrat, Pakistani cancer patient, interviewed in Punjabi and Urdu)

'Going to the temple was a daily...routine that she would never miss, so I maintained that continuity so that she does not feel any different.'

(Sangeeta, Gujarati, Hindu carer of dementia patient, interviewed in Gujarati, Hindi and English)

'...my friends were very supportive, my family, you know. Even now, if they don't see me for a few days, they'll call to find out if I'm all right. I think they still have it at the back of their head that the cancer may come back if they don't see me for a few days or if they don't hear from me, they'll phone. I've got a daughter in America, she calls and if she doesn't get me, she calls right around the whole family to find out if I'm okay. So with that, they were very, very good, very supportive.'

(June, Black Caribbean cancer patient, interviewed in English)

'Family support is invaluable, we all know this. So if you've got family support, that's half the battle.'

(Herman, Black Caribbean cancer patient, interviewed in English)

The need for professionals to understand and build upon the sources of resilience in minority ethnic patients' and carers' lives is being recognised by researchers and palliative care professionals. St Christopher's Hospice developed an education and training series 'Resilience and Palliative Care' (2005) to promote awareness and discussion amongst health and social care professionals about how they can support and foster resilience amongst service users and professionals in palliative care. The series included discussion of the needs and experiences of different minority ethnic groups and has included presentations from Holocaust survivors.

Education and training for culturally responsive care

It has been recognised that there needs to be two-way education between specialists and generalists in order to provide better access to palliative care for those older people with non-malignant conditions (Davies and Higginson, 2004). However, this recognition has not taken account of the need for education and training to address diversity amongst older people.

Training and education initiatives are developing in the cancer and palliative care fields that aim to develop and support culturally responsive care (see box 9). A joint Masters programme between St Christopher's Hospice and King's College (London) includes teaching on ethnicity and palliative care as a part of its module on psycho-social care. The Proceed Project (Professionals Responding to Cancer and Ethnic Diversity) funded by Cancer Research UK has used research with health professionals to produce web-based training and education resources for primary care and continuing care professionals (www.proceedonline.org). The resources consist of a DVD, a workbook (with guidance for the facilitation of professional learning) and a website. Topics covered in the resources are: cancer and ethnic diversity; language and communication; culture and cancer; working with families; working with uncertainty; learning organisations. The project has advocated the incorporation of the learning materials into existing educational and training programmes to 'support the ethos of 'mainstreaming' rather than delivering 'diversity' as an optional extra.'

Box 9: Communication and cultural awareness training course - Dept of Cancer and Haematology (Guy's and St Thomas's NHS Foundation Trust)

The Department of Cancer and Haematology developed an innovative four day course, accredited by the Royal College of Physicians, for all healthcare professionals caring for cancer patients. The course combined formal teaching with practice focused interactive discussions, experiential learning and role-play using actors. Each course was supported by a black psychotherapist who attended all sessions and facilitated discussion and reflection by course participants. The Department produced 10 videos using actors and health care professionals as a part of the course and which were used to explore psycho-social and ethical aspects of care.

Evaluation of the experiences of 68 participants who took part in the courses found that:

- Language and cultural barriers exacerbated professionals' difficulties and distress and the value of cultural awareness training was recognised as an important component of the training courses
- Breakdown in communication between members of Multidisciplinary Teams and the perception of being undervalued within the team were important sources of stress
- Participants perceived a significant improvement in their self-confidence levels at end of the course and this improvement was maintained three months after the course.

n

Conclusion

In drawing upon the findings of research and insights from service developments in the palliative care field, key factors that are important in providing care that is responsive to the needs of minority ethnic elders and carers are:

- Services that listen and respond to the views and experiences of minority ethnic elders and carers at all levels and that can demonstrate the influence of elder's and carer's views in service planning, decision making and individual care plans
- A multi-dimensional approach to equity in service planning, commissioning and provision. In relation to the specific needs and experiences of minority ethnic elders and carers, this approach should be capable of taking account

of the multiple and simultaneous nature of social disadvantages, the specific demographic characteristics of local populations and the geographical distribution and funding of services

- Targeted awareness raising initiatives and outreach work on palliative care that includes the provision of information in languages and media that are responsive to the variations in language and literacy within different minority ethnic groups
- Education, training and support for health and social care professionals on inter-cultural care, race and age equality and the provision of person-centred, holistic care to minority ethnic elders and carers
- The provision and advocacy and interpreting services for elders and carers throughout the patient pathway

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