Definitions

**Palliative care** is the active total care of patients whose disease is not responsive to curative treatment. Specialist palliative care is provided by a multi-disciplinary palliative care team whose members have undergone recognised specialist training. In some situations it is appropriate that specialist palliative care is available to patients and their carers from the point of diagnosis. It may also provide help with symptom management and support in those undergoing potentially curative treatments. Specialist palliative care includes physical, psychological, social and spiritual support with a goal of the ‘best possible quality of life’ for patients and their families.

**Ethnicity** is a quality or characteristic defined by individuals, which may draw upon a sense of identity deriving from religious, geographical, cultural or historical factors. The legal definition which gives protection under the Race Relations Act 1976 and the Race Relations Amendment Act 2000 provides guidance, but it should be recognised that there are other ‘ethnic groups’ which are not minorities, or for whom there is no formal legal protection. In particular, this includes groups primarily defined by religion or language.

**Ethnic Minority Groups** are defined by their membership. For the purposes of the study reported here, groups have been taken to refer principally to the categories commonly used in social policy and defined for use in national and local surveys by the Office of National Statistics (1991 Census) with the inclusion of explicit reference to people of Chinese and Yemeni origin, and implicitly, to other groups such as Vietnamese, African, and people of recent Refugee/Asylum Seeker origin. We have signified this, and the inclusion of all groups distinguished by social exclusion based on race, religion, cultural and national origin, by the use of the term ‘Black and minority ethnic’ or BME, in the text. Resources did not permit extensive research with all possible ethnic groups represented in the area of the study.
Introduction

Recent studies have shown that the minority ethnic groups are under-users of palliative care in the UK at least, and that the services may be insensitive and inappropriate to the needs of these groups. It may also be that GPs under-refer to specialist services for a variety of reasons. Black and ethnic minority patients face the potential obstacles of language and communication difficulties, attitudes that are culture specific, cultural insensitivity and ignorance and racism (overt and covert). (Faull et al 1998 :6)

Nationally, health services and policy makers have expressed their determination to ensure that both NHS and 'third sector' provision should learn from the experience of the 'Stephen Lawrence Inquiry' (Macpherson 1999) and work to eradicate ethnic differentials in health and service access. Race equality issues, both in employment and in service delivery, have become priority concerns which should be addressed in all actions undertaken within the national strategy to modernise the NHS (Alexander 2000: see also Department of Health Response 2000) and responses to the Acheson Report (1998). The NHS Cancer Plan (2000) makes explicit reference to the need to combat inequalities in health. It singles out the role of palliative care in this, while noting the necessity of additional training and support in the principles and practice of palliative care for community-based services in order to meet these dual needs.

The development of services for people living with cancer since 1995 has been largely directed by the framework laid out in the ‘Calman Hine’ report (1995). This recognises that, for the general public ‘Cancer is still regarded … as an especially threatening disease and one which to some extent is still a taboo subject’ (Calman & Hine 1995 :2). Noting this public priority, and the rising incidence of the (collection of) diseases included in this category, partly but not wholly attributable to the ageing of the population, a number of recommendations were made, which have informed the subsequent planning of services, from diagnosis through treatment to palliative care. Central to these have been the adoption of a ‘patient-centred’ approach and user involvement in planning, and the expectation that ‘all patients should have access to a uniformly high quality of care in the community or in the hospital…’ (para 3.1.i).

In order to achieve this, a ‘new structure’ based on expertise and specialist input was proposed, integrating Primary Care Teams, Designated Cancer Units, and Cancer Centres. Palliative Care (chapter 4.5) is seen as central to overall care planning, and should ‘not be associated exclusively with terminal care’, but available from diagnosis onwards. Specific attention is paid in the report to the need for ‘facilities to allow relatives to remain with very ill patients’, and that ‘Spiritual care of patients must be available when required’ (para 4.5.4). Subsequently, a number of Cancer Standards have been developed, and are used for the accreditation of Cancer Centres and services. However, except indirectly, none of these explicitly concern the specific needs of minority ethnic groups, or address the existence of cultural and ethnic diversity among users. We should however note that attention to ‘universality’ (i.e. equality of access), attendance by visitors, and spiritual care, can all be seen to reflect concerns expressed in research and other materials discussing the specific needs and desires of black and minority ethnic groups in relation to health care services.
Development of better palliative care services for cancer to the minority ethnic populations of Birmingham is a priority area for both the service providers and the communities. Research, much of it conducted in Birmingham and Leicester, has demonstrated the lack of access, and indeed low levels of knowledge concerning, palliative and cancer-related services among many minority ethnic groups. Recent research with minority ethnic groups in Birmingham highlighted the worries that many men from the communities surveyed had, relating to cancer (Johnson & Verma 1998), and other studies and development work locally have shown similar interest by minority groups in finding innovative ways of accessing palliative care.

This research therefore reflects a wider national concern with the issue of delivering palliative care equitably in a multi-ethnic, multi-cultural society (some of long standing: Baxter 1989, Rees 1986). It was a general principle of the 1995 Calman Hine report that development should be patient centred and take account of the views and preferences of families and carers. There is, however, very little reliable information nationally on access and uptake of such services by minority ethnic groups. Of all people that die to cancer in any year, approximately half are known to come into contact with specialist palliative care services (Hospice Information Service 1995) but there does not appear to be any ‘ethnic breakdown’ of these figures. A comprehensive study for the National Council for Hospice and Specialist Palliative Care Services (1995) suggested ways of increasing uptake but anecdotal and professional evidence suggests that levels have remained low (Silcocks et al 2000).

Some misleading public and professional perceptions of minority community preferences (e.g. ‘they look after their own’) have been shown to affect referral patterns and to be wrong (DoH/SSI 1998). A number of other explanations have been put forward, including the suggestion that certain religious traditions may inhibit recourse to pain relief, or refuse to accept the inevitability of death. This has also been reported in respect of Judaism, although closer examination reveals that there is a conflict between certain commentators ‘ideal’ views, and the practice of most adherents (Neuberger 1994). The problem remains that some misleading impressions may be retained by practitioners who have read ‘fact-file’ summaries of cultural and religious preferences (Culley 2000). People from minority ethnic groups are, however, less likely to know others who have been in a hospice, had Macmillan or Marie Curie support workers, and to ask their GPs for access to such services (NCHSPCS 1993). Indeed, GPs and others making referrals may be less likely to refer to services which they suspect (or know) will not be able to meet culturally specific needs (cf Chirico et al 2000).

Background

Palliative care is a major area of service provision in which there is very little awareness of the particular difficulties faced by users from minority ethnic backgrounds. The current Manual for Cancer Services Assessment refers to the need to take account of spiritual needs and for multi-agency working, but while its Objective for Topic 7 (palliative care) refers to ‘all patients who need (services)’ it does not lay down any standards that explicitly refer to ethnic or cultural minority needs. There is no systematic data available on this issue, and most of the literature consists of commentaries on existing provision or local perceptions of low rates of access (SETRHA 1994; Iqbal 1994, Iqbal et al 1995). A few papers have discussed...
implications for nurse education (Smith 1996, Nyatanga 1997) but many of these are of American origin (Kole 1998). There is a lack of detail comparing the perceived needs of users and carers, or the pathways to care for different ethnic groups (Smaje & Field 1997). Although an overall lower rate of deaths from cancer among ethnic minority populations in Britain (Balarajan 1995) may explain the slightly lower rate of cancer deaths for Birmingham compared to the national average, there is some evidence for convergence as the population age structures converge. Further, there is also some evidence of excess rates in particular tumour sites (e.g. bowel and buccal cancers) among specific minority groups (Winter et al 1999).

Census data do show that there are higher than expected levels of ‘long-term limiting illness’ among minority ethnic households than would be expected in line with their age-profile (e.g. Owen 1994). However, much of this may be due to occupational diseases rather than degenerative and cancer-related conditions. Nevertheless, it is clear that, despite the currently low reported rates of most common cancers among minority ethnic groups, there is a strong expectation that these levels will grow as the demographic profile of the communities reaches maturity (i.e. as people get older) and as exposure to potentially carcinogenic agents and lifestyles works through the population. For both of these reasons, it may be expected that the demand for palliative care services will increase significantly. It will therefore be very important to ensure that any developments are embedded in mainstream provision and not developed on an ad hoc, short-term project-funded basis.

During the progress of the research our attention was drawn to the significance of neuro-degenerative and other genetically linked disorders which might lead to a demand for palliative care support. Many of these are associated with patterns of consanguineous marriage: an issue which has been researched in Birmingham (notably by Bundey et al) and shown to be particularly associated with the communities of Pakistani origin. A recent article in the Guardian newspaper described several case studies from Birmingham, and cited research by Mamoona Tahir (specialist registrar in public health, Birmingham) as evidence for infant mortality rates among the Pakistani community being 2.5 – 3 times those for other groups, and that Pakistani babies are 10 times more likely to suffer an inherited metabolic disorder (Haslam 2001). These matters are, however, difficult to raise in discussion and the cause of some controversy: We did not encounter any research data on which needs assessment could be based, or expressions of concern from community members that these needs were not being met. This latter is perhaps not surprising, and the possibility of such a need should be kept in mind when planning services.

Cancer and Minority Ethnic Groups

In general, there seems to be a lower incidence of most forms of cancer among minority ethnic groups. The reasons for this are unclear and may relate to environmental factors (exposure to trigger factors) as much as ethnicity, although changes can be expected in the UK-born population as it ages. Certain forms of cancer related to diet and lifestyle (notably smoking and the chewing of paan - a mixture of areca nut, lime, betel pepper leaf and sometimes tobacco and spices) are associated with some South Asian population groups, and oral cancers are particularly more common among Bangladeshi people. These, however, may be seen as linked to ‘lifestyle’ or behavioural factors - HEA interventions have already been dedicated to
bringing about a greater awareness of risk factors and change in these groups. Less explicable are reported excesses in Liver (SMR 910) and Gall Bladder (SMR 538) cancers among Bangladeshi men (Balarajan and Raleigh 1997). The same, relatively recent, data also show rather lower than expected rates of cancers among Bangladeshi women, in particular deaths from Breast (SMR 16) and Cervical (SMR 51) cancers. Despite high smoking rates, Lung cancer SMRs for both Bengali men (SMR 82) and women (SMR 54) are significantly lower than the national. However, mortality data for the UK also suggest that at present and in absolute terms, neoplasms are the top-ranking cause of death among Chinese men and women and (in a small sample) the most common cause of death among Black Caribbeans (Gill et al, 2001).

A recent systematic review of health care access for minority ethnic groups (Atkinson et al 2001) identified a small number of relatively recent articles in the area of cancer. Out of these, eight papers met quality standards and were reviewed, including four in the grey literature. These were divided into articles analysing cancer mortality data (2 papers), and those considering treatment (1 paper), screening for cervical, breast and oral cancer (3 papers), and palliative care (3 papers - all of which were found in the grey literature). The review was conducted before the publication of the paper by Kelvin Karim, and did not consider the paper by Winter et al, which concentrates on epidemiology rather than access questions.

The two general papers on cancer mortality (Swerdlow et al 1995, Bahl 1996), although not directly examining access issues, can provide useful information on the types of cancer services which ethnic minorities may need to access. These two articles demonstrate generally lower mortality rates from cancer among ethnic minorities, while highlighting a raised risk of oral cancer and liver cancer (linked to chewing of paan and transmission of hepatitis respectively). The mortality rates reported by the Health of Londoners Project indicate that mortality from prostate cancer is also higher than average for Londoners born in the Caribbean & West Indies and the Rest of Africa. Similarly, the Health of Londoners Project analysis of admissions data indicates significantly lower, or not significantly different, admissions for all cancers and ethnic groups apart from: significantly higher admissions for cancer of the digestive organs in the Chinese population, and significantly higher admissions of Black Caribbeans for cancer of the prostate and breast.

In terms of literature on access to treatment, the one article identified (Bahl 1996) presents examples of cultural factors which might influence acceptance of treatment, although no evidence is presented to indicate the extent to which these are important in practice. In general, there was an absence of any literature indicating inequalities in cancer service provision (apart from palliative care - see below), once patients are diagnosed. However, this cannot be taken as proof that there are no issues associated with access to all types of cancer treatment. For example, although there is a recognised need to target ethnic minorities for bone marrow transplant donors, this did not appear as an access issue in the literature surveyed; unlike renal transplants, where interventions have been reported in the literature.

Even though the review uncovered no direct evidence of late presentation as indicative of access barriers, there was evidence of poor uptake of population cancer screening programmes (i.e. cervical and breast). In addition to these studies, Box
(1998) also highlights low uptakes of cervical screening. The authors report on a project in London (Scanlink) which has identified a number of factors limiting uptake of screening. These include poor knowledge, misconceptions, language barriers, and lack of awareness of advocate services. Another paper on low uptake of breast screening (Hoare 1996), also identifies administrative problems due to inaccurate addresses as an important barrier to access, indicating that overall between 35% and 40% of invitation addresses were inaccurate for Asian women in South East and West London. In addition to consideration of existing population screening programmes, a further paper considers the possibility of oral screening (Pearson et al 1999). The authors identify very high levels of paan chewing among Bangladeshi adults (more in females) combined with a tendency not to attend for dental check-ups, and therefore conclude that there is a need to take action to encourage more screening. However, no assessment of the effectiveness or cost-effectiveness of such screening is presented. There was no literature on ethnic minorities and colorectal cancer, which is the next population screening programme likely to be introduced in the NHS.

In terms of oral health, one article (Pearson et al 1999) assessed the use of dental services in a sample of Bangladeshi adults living in Tower Hamlets. This demonstrated the existence of language difficulties and a perception that check-ups are of little value as being associated with low uptake, together with high risk behaviour in terms of paan chewing, especially among women. Another study (Williams et al 1995) examined dentists’ perceptions of the difficulties they encounter in providing dental care for British Asians. This identified language as the major barrier to care. Wider use of link workers was advocated by the authors, together with ensuring that contracts relating to dental care specifically address the needs of minority communities. Other research on general dental health indicates that being a member of a minority ethnic group in the UK does not necessarily correspond to having poorer oral health. These papers link to a much larger literature on ‘link workers’ and advocacy approaches to improving health care access.

One area in which the literature demonstrated barriers to access for ethnic minorities was in palliative care. Three papers reviewed (Iqbal 1994; Hill and Penso 1994; Powell 1999) all report low uptake of palliative care by ethnic minorities. A consistent finding in all these studies is the importance of poor communication as a barrier to access e.g. lack of information provision in appropriate languages. Recommendations made by researchers include improved interpreting services and appropriate literature; more systematic referral arrangements with GPs; and improved ethnic monitoring in palliative care.

In general, the cancer literature reviewed contained no evaluations of interventions to improve access, although there were descriptions of possible interventions. The main conclusions of published research relevant to the care of people from minority ethnic groups with life-limiting or malignant conditions can be summarised as follows:

- Overall, while there is no evidence of differential access or outcomes for most forms of cancer treatment, the literature reviewed does raise questions in the area of access to, or uptake of, screening services, and access to (and provision of sensitive) palliative care. No research evaluating interventions to address either of these areas was identified in the literature.
The literature appears to demonstrate that low levels of cancer knowledge among ethnic minority populations are an important barrier to access. However, there is some research in progress which will address this area. One study is currently examining prostate awareness among elderly Pakistani men (Barbara Williamson, Airedale General Hospital). Another is examining cancer beliefs in various ethnic groups (Turkish/Kurdish; Greek/Cypriot; Irish; Nigerian; African-Caribbean, white) in North London (Middlesex University, funded by the King’s Fund). Furthermore, a study will shortly be completed in Leeds (Waqar Ahmad) identifying how patients and families of white and South Asian origin perceive cancer, their information needs, and the best ways of providing care. No interventions designed to improve knowledge were reported in the literature reviewed, and no studies to assess interventions were found in ongoing research.

There appears to be some evidence of a need for staff training (including work on anti-racism or to combat stereotypes) as well as educational work with communities. No research (completed or in progress) which addresses these aspects of cancer services has been identified.

Since that review, there have been a small number of other papers published of relevance to this research, although many of them have been largely descriptive or oriented to raising awareness of cultural differences (cf Anderson 2000). The value and role of advocacy workers has been promoted by a major review in London (Silvera & Kapasi 2000). A small experimental project in London is evaluating a cancer advocacy service for the Bengali community (Thomas et al 2000). The role of self-help groups has also been described, and specifically found to be helpful in increasing efficacy among Chinese patients in Hong Kong (Mok & Martinson 2000). It is one of the themes of this review that strengths may be found within the cultural and national traditions of the communities of minority ethnic origin living in Britain.

Statistics on Disease Frequency and Service Uptake

The information base for planning any health care service development is crucial – yet in the case of cancer and palliative care services for black and minority ethnic groups there are regrettably very few data available. Every service provider that we contacted was asked to supply details of its activity levels from ethnic monitoring information. Most have agreed to supply what they can, but none of the providers active in Birmingham had this information immediately available, and in some cases we were advised that the current systems in use did not allow them to obtain this information without ‘trawling’ all the patient records by hand. We present below what was available to us at the time of compiling the report, noting that the difficulty of extracting and reporting of such data is itself a potential source of unequal access.

We also note that there is a very poor level of data at the national or regional level relating to the incidence or prevalence of cancers (and other conditions requiring palliative interventions) among black and minority ethnic groups. There is an established understanding that the general level of cancer mortality is lower among people born in former ‘New Commonwealth’ territories (Balarajan & Soni Raleigh 1997; Balarajan et al 1984; Swerdlow et al 1995). This may be variously attributed to their demographic profile, exposure to carcinogenic risk factors, or lifestyle (including low levels of smoking and alcohol use among certain groups, and raised levels of fruit
and vegetable consumption). Analysis of data from death certificates and cancer registry files as well as from other administrative sources of morbidity information has been hindered by reliance on ‘place of birth’ as the only generally available proxy measure of ethnic origin recorded.

Mortality rates indicate that lung cancer is lowest among those born in South Asia (highest in those born in Ireland and Scotland). Mortality from prostate cancer was higher than average for Londoners born in the Caribbean & West Indies and the Rest of Africa. Similar findings were reported by Muir (1996), who highlighted particularly high mortality rates from Prostatic cancer among men and Cervical cancer among women from the Caribbean, and Lung cancers among African women, even though these were still lower than for the national population as a whole. Oral cancers among those of South Asian origin are also recorded as higher than the average, especially among women. Muir’s migration-based data also underline the relatively high rates of cancers overall among people born in Ireland and Scotland.

The introduction of a requirement to collect information on ethnic origins in the contract minimum data set (hospital admitted patient records), from April 1995, has been widely ignored or at least, under-performed nationally and within the West Midlands region (Aspinall 1999; Lay-Yee et al 1998). North & South Birmingham, with respectively 23.99% and 15.88% of their population recorded as belonging to ‘bme’ groups in the 1991 Census, returned 17.9% and 9.21% respectively of their users as belonging to minority ethnic groups, in their first year’s HES (Hospital Episode Statistics) data. A further 54% of patients in North Birmingham, and 70% of those in South Birmingham, were said to be ‘Ethnic Group Not Given’. Clearly this provides an unacceptable margin of error for analysis (Lay-Yee et al 1998). The data quality audit specifically noted poor coding of ethnicity in Medical Oncology and Surgery. It does appear that these problems are being remedied, but there remain great problems in obtaining access to reliable data from which to make estimates of prevalence, from which some idea of likely levels of need for palliative care could be obtained.

Data was available from the Health of Londoners Project analysis of hospital admission data for admissions for a number of cancers (Bardsley et al 2000). This indicated significantly lower, or not significantly different, admissions to hospitals in London for all cancers and ethnic groups apart from significantly higher admissions for Cancer of digestive organs (Chinese) and significantly higher admissions for Cancer of prostate and breast (Black Caribbeans). There was no data on palliative care.

Gill et al’s (so far unpublished) analysis of data from the Longitudinal Study and Office of National Statistics death certification data for the four years around the 1991 Census confirms the generally lower levels of deaths from cancers in most minority groups. They do, however, observe that neoplasms were the top-ranking cause of death from both men and women of Chinese origin, with circulatory diseases second. These findings are still consistent with an SMR for men of 96 and 88 for women, partly because of the generally youthful age profile of the community. Certain sites were very significantly over-represented among Chinese people, notably lip, oral and pharyngeal cancers (SMR 493 males, 581 females).
More recent techniques have made it possible to analyse the data in the Cancer Registry using software that ‘recognises’ names of South Asian origin (Nam Perchan, a computer program written in Bradford, and originally validated through use of Electoral Roll registration information in Bradford and Coventry). This is believed to provide data with better than 90% sensitivity and specificity, but can only be used to identify people likely to belong to ‘South Asian’ ethnic groups (specifically, Indian, Pakistani and Bangladeshi), and not those with African or Caribbean origins or of Chinese, Vietnamese or Arabic backgrounds. We present below some relevant information derived in this way, as a means of identifying an expected level of need.

Winter et al (1999) analysed the information from the Cancer Registries of Thames, Trent, West Midlands and Yorkshire regions, to provide estimates of cancer incidence for the residents of those areas. These four regions contain the majority of the UK population of non-white ethnic minority origin, and around 80% of the estimated national population of south Asian background as well as 57% of the total population of England (according to 1991 census estimates). Overall, an estimate of 1.1% of cases in the registries was identified as having a South Asian name – rather less than half the ‘expected’ proportion in the population. However, closer examination of the data reveals a more complex picture, when taking age into account. In particular, rates of cancer were significantly lower among males of south Asian origin combined with the remainder of the population: but significantly raised in respect of certain sites: namely cancer of the hypopharynx, liver, gall bladder, and Hodgkins disease. Among females, rates were generally also lower but significantly raised for cancers of the tongue, mouth, liver and gall bladder, thyroid, hypopharynx & oesophagus, and myeloid leukaemia. While rates of breast cancer were lower, they represented a larger proportion of cancers among Asian women, as did lymphomas in both sexes. These findings reflect the earlier studies, in drawing attention to the raised likelihood of oral, liver and gall bladder cancers in people of south Asian origin.

Consideration of age standardisation reveals, further, that there is at least some degree of convergence, and that rates are higher among ‘British Asians’ than among people in India. In particular, it is shown that among the UK South Asian population aged under 30, the rates of cancer overall, and specifically in the sites identified (notably Lymphoma, Leukaemia, and surprisingly, among those aged under 14, colorectal) were not lower, and could be higher than the comparison population. At specific site level, the data are based on small numbers, but overall, it appears that younger people of south Asian origin are likely to experience a diagnosis of cancer at rates that may exceed those of the white population. This clearly has implications for future service provision.

Silcocks et al (2000) used data for Leicestershire residents (1990-1997) from the Trent Cancer Registry to examine the likelihood of people with an Asian name dying of cancer in a hospice. This was an admittedly crude proxy for use of specialist palliative care, but produced significant effects. Adjusting for age, deprivation scores, sex, or cancer sites did not explain the fact that ‘Asian patients with cancer are half as likely to die in a hospice as non-Asian patients’.
Bibliography


Archibald G 2000 The needs of South Asians with a terminal illness *Professional Nurse* 15,5 :316-320

Atkinson M, Clark M, Clay D, Johnson M, Owen D, Szczepura A 2001 Systematic review of ethnicity and health service access for London *Coventry: Centre for Health Services Studies, with Mary Seacole Research Centre and CRER.*

Atri J, Falshaw M, Gregg R, Robson J, Omar RZ, Dixon S 1997 'Improving uptake of breast screening in multi-ethnic populations: a randomised controlled trial using practice reception staff to contact non attenders' *BMJ* 315 :1356-1359


Bahl V 1996 Cancer and ethnic minorities: the Department of Health’s perspective *British Journal of Cancer* 74 Supp XXIX S2-10

Balarajan R 1995 ‘Ethnicity and variations in the nation’s health’ *Health Trends* 27,4 :114-119


Baxter C 1989 *Cancer Support and ethnic minorities and migrant worker communities* London: Cancerlink


Box V 1998 Cervical screening: The knowledge and opinions of black and minority ethnic women and of health advocates in East London *Health Education Journal* 57,3 :3-15

Cancer Care Ethnic Minorities Communities Group 1999 *Improving accessibility and information services for Asian communities relating to cancer and palliative care* London Cancer Care

Carers National Association 1998 *Policy Briefing: Black and Minority Ethnic Carers*


Chiu LF, Heywood P, Jordan J, McKinney P, Dowell T 1999 Balancing the equation: the significance of professional and lay perceptions in the promotion of cervical screening amongst minority ethnic women *Critical Public Health* 9,1 :5-22


Department of Health Response 2000 (see website: www.doh.gov.uk/race_equality)
Department of Health Social Care Group and Social Services Inspectorate 1998 They Look after their own, don’t they?: Inspection of community care services for black and ethnic minority older people London: DoH/SSI


Doyle YG, Conway M 1992 Transferable deaths during 1990 for residents of Camberwell Health Authority Public Health 106,6 :449-456

Effective Health Care Bulletin 6:4 October 2000 Management of upper gastro-intestinal cancers


Field D, Hockey J, Small N (Eds) 1997 Death, Gender & Ethnicity London: Routledge

Fleming J, Ward D 1996 The ethics of community health needs assessment: searching for a participant centred approach in Parker M (Ed) :284-294

Fountain A 1999 Ethnic Minorities and Palliative Care in Derby Palliative Medicine 13,2 :161-162

Gaffin J, Hill D, Penso D 1996 Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities British Journal of Cancer (Supplement) 29 :S 51-53


Haworth EA, Soni Raleigh V, Balarajan R 1999 Ethnicity and Health 4 :93-99

Haworth M, Lennard R, Sadiq A 1997 Asian interpreters and palliative care Palliative Medicine 11,1 :77

Haslam J 2001 Harsh Troth Guardian newspaper (Society supplement) 14 March pp6-7

Hall P, Stone G, Fiset VJ 1998 Palliative Care: how can we meet the needs of our multicultural communities? Journal of Palliative Care 14,2 :46-49

Hoare T 1996 Breast screening and ethnic minorities British Journal of Cancer 74 Supp XXIX S38-41

Iqbal HH 1994 Palliative care service use by black and minority ethnic groups in Leicester Leicester: Coping with Cancer / Leicester Health Authority

Iqbal HH, Field D, Parker H, Iqbal Z 1995 The Absent Minority: Access and use of Palliative Care Services by Black and minority ethnic groups in Leicester in (Eds) Richardson A, Wilson-Barnett J (Ch5, pp83-96)

Johnson S, Harrison B, Faull C 2000 Hospice at Home: A pilot project of a new service in Birmingham – report for the cancer and palliative care coordinator and commissioners Birmingham: St Mary’s Hospice

Joint Planning Group 1998 Commissioning Palliative Care Services: A Strategy for the City of Birmingham (unpublished)


Lees S, Papodopolous I 2000 Cancer and men from ethnic minority groups European Journal of Cancer Care 9:221-229


Matheson LM, Donnigan MG, Hole D, Gillis CR (nd) Incidence of colorectal, breast and lung cancer in a Scottish Asian population Health Bulletin (Scotland) 43/5 :245-249

McAvoy BR, Donaldson LJ (Eds) 1990 Health Care for Asians Oxford: OUP


Mitchell D 2000 Addressing spirituality: spiritual and social aspects of terminal illness and pain Palliative Care Today 8,4 :50-51

Mok E, Martinson I 2000 Empowerment of Chinese patients with cancer through self-help groups in Hong Kong Cancer Nursing 23,3 :206-213

Muir CS 1996 Epidemiology of cancer in ethnic groups British Journal of Cancer 74 Supp XXIX

Mulrain G 1993 A paper on bereavement in ethnic minorities Bereavement Care 12,3

National Council for Hospice and Specialist Palliative Care Services 1995 Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and minority ethnic communities Occasional Paper 7, London: NCHSPCS

National Council for Hospice and Specialist Palliative Care Services 1993 Guidelines for the creation and implementation of an equal opportunities policy London: NCHSPCS

Netto G 1999 ‘I forget myself’: the case for the provision of culturally sensitive respite care services for minority ethnic carers of older people’ Journal of Public Health Medicine 20,2 :221-228

Neuberger J 1994 A Jewish perspective on palliative care Palliative Care Today 3,3 :32-33


NHS Information Authority 2000 Cancer Dataset Project: Consultation Document (version 1.2)

Notta H 1994 Asian Link Palliative Care Today 3,3 :34

Notta HK, Hanson L 2000 Care of a dying Sikh child/young person: A guide for staff members Birmingham: Acorns Children’s Hospice


Palliative Care Assessors Checklist (New Opportunities Fund/NHSE) (www.doh.gov.uk)

Palliative Care Team Annual Report 2000 University Hospital Birmingham

Papadopoulos I, Lees S 2000 Exploring the personal health beliefs with respect to cancer of people from various ethnic groups: methodological issues Conference paper: Transcultural Nursing & Health Care Association, Leeds

Parker M (Ed) 1996 *Ethics and Community* Preston: UK Centre for Professional Ethics, University of Central Lancashire


Pfeffer N, Moynihan C 1996 Ethnicity and health beliefs with respect to cancer: a critical review of methodology British Journal of Cancer 74 Supp XXIX S66-72

Powell B 1999 Improving accessibility and information services for Asian communities relating to cancer and palliative care Leicester: Cancer Care – Ethnic Minorities Group

Raja-Jones H 1999 Breast screening and ethnic minority women: a literature review British Journal of Nursing 8,19 :1284-1288


Rawaf S 1996 Assessing the health needs for cancer services for people from minority ethnic groups British Journal of Cancer 74 Supp XXIX S35-37

Rees D W 1986 Immigrants and the hospice Health Trends 18 :89-91

Rees DW 1990 Terminal Care and Bereavement in (Eds) McAvoy BR, Donaldson LJ (pp304-319)


Selby P 1996 Cancer clinical outcomes for minority ethnic groups British Journal of Cancer 74 Supp XXIX S54-S60

Scully C, Bedi R 2000 Ethnicity and Oral Cancer The Lancet: Oncology 1 :37-42

SETRHA 1994 Palliative Care service provision for black and ethnic minority groups London: South Thames Regional Health Authority


Silvera M, Kapasi R 2000 Health Advocacy for Minority Ethnic Londoners: Putting services on the map London: King’s Fund

Smaje C, Field D 1997 Absent minorities? Ethnicity and the use of palliative care services in Field D, Hockey J, Small N (Eds)

Smith JW 1996 ‘Cultural and spiritual issues in palliative care’ Journal of Cancer Care 5,4 :173-178

Swerdlow A, Marmot M, Grulich A, Head J 1995 Cancer mortality in Indian and British ethnic immigrants from the Indian sub-continent to England and Wales British Journal of Cancer 72,5 :1312-1319

Tebbit P 1998 Palliative Care 2000: Commissioning through Partnership London: National Council for Hospice & Palliative Care Services

Thomas R, Deary A, Kaminski E, Stockton D, de Zueew N 1999 Patients’ preferences for video-cassette recorded information: effect of age, sex and ethnic group European Journal of Cancer Care 8 :83-86

Thomas V, Richardson A, Saleem T 2000 The efficacy of bilingual health advocacy in ethnic minority patients with cancer Nursing Standard 14, 26 :32-33


Wyatt P 2000 Spiritual needs: use of focus groups to identify and address spiritual pain Palliative Care Today 8,4 :52-53
Appendix Summary of papers reviewed in a Systematic Review

(reproduced for information, from (Atkinson et al 2001))

Overview
Eight papers were reviewed in this disease area, including four in the grey literature. These consider cancer mortality (2 papers), treatment (1 paper), screening for cervical, breast and oral cancer (3 papers), and palliative care (3 papers - all grey literature).

The papers on cancer mortality (Swerdlow et al, Box 1996) confirm lower mortality from cancer among ethnic minorities but highlight raised risk of oral cancer and liver cancer (linked to chewing of betel/paan and transmission of hepatitis respectively). In terms of the literature on treatment (Box 1996), the article reviewed provides examples of cultural factors which might influence acceptance of treatment. More broadly, the literature does not appear to indicate any inequalities in cancer service provision once patients have accessed services. However, although there are reports of a need to target ethnic minorities for bone marrow transplant donors, this does not appear to be a problem which is discussed in the literature surveyed, unlike renal transplants (see section 3.2.3).

The review uncovered no evidence of late presentation as an important issue associated with access to services. However, there was evidence of poor uptake of cancer screening programmes (cervical and breast). Some papers referring to screening are mentioned here, but this topic is discussed more fully in section 3.3.5 (Health improvement/promotion). There were no articles uncovered in relation to colorectal cancer, which may be the next national screening programme to be introduced; this is currently being piloted in Scotland and England (Coventry & Warwickshire). One paper below on screening highlights low uptake of cervical screening (Box 1998). This paper also reports on a project in London (Scanlink) which has identified important factors to be poor knowledge, misconceptions, language barriers, and lack of awareness of advocate services. Another paper on low uptake of breast screening, identifies major administrative problems with inaccurate addresses and that Asian women who have been resident in the UK for 5 years or more are more likely to attend for screening. Possible interventions are suggested. A third paper on oral screening identifies very high levels of paan chewing among Bangladeshi adults (more females) and a tendency not to attend for dental check-ups.

The one area in which the cancer literature does appear to demonstrate poor access for ethnic minorities is in palliative care. This is currently mainly in the grey literature. The three papers reviewed (Iqbal; Hill and Penso; Powell) report low uptake of palliative care by ethnic minorities. Consistent findings are poor communication; lack of information provision in appropriate languages. Recommendations include ethnic monitoring in palliative care, more systematic referral arrangements with GPs, and improved communication, interpreting services, and literature.

The literature reviewed contained no evaluation of interventions to improve access, although there were descriptions of possible interventions.
(i) Scale of the problem:

Swerdlow et al (1995) have analysed data for the period 1973 to 1985 on cancer mortality in ethnic groups. Chief areas of mortality included digestive system cancers, respiratory system cancers, bone, soft tissue, and skin cancers, reproductive-related cancers, urinary tract cancers, the nervous system and endocrine cancers, and Lymphomatic system cancers. Cancer amongst the British older ethnic group was greater than within the equivalent Indian group. Moreover, the authors argue that raised risk of oral and pharyngeal cancer and liver cancer in Indian ethnic migrants are related to known risk factors. They therefore argue for preventative interventions to prevent betel quid chewing, and transmission of hepatitis in the Indian ethnic population.

Bahl (1996) presents what is described as the Department of Health’s perspective on cancer and ethnic minorities. It is suggested that there has been an increase in cancer related mortality amongst ethnic minority groups. It is also indicated that in terms of screening, treatment, and palliation, cancer services are not always accessible and sensitive to the needs of the ethnic minority section of the population. Mortality from cancer is generally lower amongst ethnic minority populations than for the majority white population with lower rates of death from breast and cervical cancer in people born in the Indian subcontinent and African Commonwealth. However whilst those from the Caribbean also have low death rates from breast cancer, their mortality from cervical cancer is raised. Due to the ageing nature of the ethnic population it is considered that deaths are likely to increase amongst individuals from minority ethnic communities, since cancer deaths predominantly arise in those over 55 years. Also, whilst current mortality from lung cancer is low amongst ethnic minorities, there is evidence from the Department of Health’s lifestyle survey that smoking is a considerable risk factor in ethnic minority men. There is also a high incidence of oral cancer in those from the Indian sub-continent, which is associated with widespread chewing of tobacco, which is carcinogenic in the Bangladeshi community.

(ii) Cancer treatment:

Bahl (see above) also highlights some problems which might arise in relation to the treatment of cancer if treatment is seen to conflict with religious requirements and beliefs. This part of the paper is based on expert opinion, rather than reporting study findings. Examples provided include a Muslim patient with faecal incontinence, or a colostomy as a result of bowel cancer which would be considered to be spiritually as well as physically polluting. Moreover hair loss amongst Sikhs may pose a problem in the event of chemotherapy, since having uncut hair is a religious requirement. It is also suggested that in relation to religious and cultural issues based upon modesty, many minority ethnic women would prefer to discuss women’s health issues with a same sex provider, and the absence of an appropriate sex doctor may be a barrier to service provision especially for gynaecological examinations. The author also draws attention to the role of the Scanlink project on cervical cancer in Newham in terms of raising awareness about cancer amongst black and minority ethnic women and encouraging the establishment of services which are more sensitive to cultural needs, although there is no formal evaluation. Finally, the author also argues that there may be a greater need for written information for minority ethnic patients and their carers about palliative services.
(iii) Screening:

**Box (1998)** reports low cervical cancer screening levels among ethnic minority groups. The authors then go on to discuss the Scanlink project on cervical cancer in Newham. This was designed to ascertain black and minority ethnic views on cervical screening; collecting information on knowledge levels about cervical cancer and smear tests; and conducting awareness classes for ethnic women on cervical screening and screening. It is reported that research was conducted as part of the Scanlink project. Focus groups were run for health advocates. Also interviews were held with 11 facilitators who carried out cancer awareness sessions within the Scanlink project, which provided them with training and remuneration. Questionnaires were also completed by black and minority ethnic service users. It was found that out of 172 service user respondents, 165 knew little about cervical smear tests. There was a general lack of awareness that health advocates could be booked in to provide attendance during screening. This in part appeared to be due to the fact that the advocates revealed that they did not advertise their availability for such consultations because they feared they might be swamped with excess demand for their services. Advocates also suggested that the quality of their relationships with medical professionals was sometimes not what they would wish. It was concluded that there was a need for improved staff training for those involved in cervical screening so that interpreters and advocates are used as appropriate, and so that patients who consent can give informed consent. This paper is also discussed in section 3.3.5.

Similarly, **Hoare (1996)** conducted an analysis of breast screening amongst ethnic minorities including the Japanese, Chinese, Arabic, Asian, Indian. Whilst ethnic minorities are not in the high-risk group for breast cancer, attendance for screening was reported to be low. On the basis of their analysis it was concluded that Asian women who had lived in the UK for 5 years or more were significantly more likely to attend screening than women who attended for screening who had arrived more recently. Significant problems arose because invitations were sent to addresses where the women no longer lived, perhaps due to inaccurate HA registers, which resulted in non-attendance. Overall between 35% and 40% of invitation addresses were inaccurate in South East and West London. This paper is also discussed in section 3.3.5. The author argues for intervention to tackle low rates of screening in Asian women.

**Pearson et al (1999)** consider oral cancer screening. The authors assessed the use of dental services in a sample of Bangladeshi adults living in Tower Hamlets using a multi-centre cross-sectional study in 4 general practices. All adults surveyed were in the 40+ age range, and were assessed in the context of an interview. Results were obtained for 158 subjects (slightly more women than men). Overall 33% of the sample were tobacco smokers, whilst paan was chewed by 78% of the sample. Significantly more females than males added tobacco to their quid and chewed more often than males. Despite the fact that many of these individuals were at high risk of oral cancer, there was a general tendency not to attend dental practices for check ups. The authors conclude that there is a need to both encourage preventative interventions to avert high risk behaviour, and to take action to encourage more screening.
Cervical Cancer Screening:

A decade ago, Doyle (1991) conducted a survey of 400 Ealing residents to ascertain the response to call/recall letters issued by the FHSA (for cervical cancer screening). The analysis was conducted to assess the reasons underpinning a less than 33% response rate following invitations to attend for cervical screening. Non-responders and responders were matched as closely as possible in relation to age, locality, and ethnic background. In this district Asian groups constituted around 19% of the district population. Also 10% of the district population is of European mainland descent, 7% is of Irish descent, and 5% of African and Caribbean descent. Within the sample there was weighting to the Asian community (34.5% in the sample of 400 women, compared with 19% in the population at large). A corollary of this was that there were also lower proportions of people from UK backgrounds (41% in the sample compared with 59.3% in the population), hence the sample was biased.

A questionnaire was used in order to find out what factors might underpin the reasons for poor responses. Analysis of the data (comprising all the racial groupings already indicated) suggested that 23 were in fact attenders who had defaulted because they had already had a smear. Also of 61 deemed to be non-responders, 18 stated that they had not actually received an invite. Of those in attendance for screening (n=166), overall 37 opted for a change of screener, and 37 also experienced discomfort during screening (although they did not comprise of exactly the same sample of women). Overall 18 (48.6%) requested a change of venue (e.g. from clinic to GP); whilst 19 (51.4% mainly wanted a female screener). Overall 99 women requested further medical checks, and amongst Asian women the most common request related to cardiovascular screening, and basic information about menstruation / menopause.

The fact that non-responders to the questionnaire were more prevalent amongst the Asian community, could be the result of language barriers in relation to the questionnaire. Also there is no indication that the initial call/recall letters had been supplied in other languages, which could potentially be a major cause of non-response to call/recall letters (amongst those who cannot speak English). The authors seemed to place the emphasis upon updating the target list of women to boost response rates, as it was suspected that many call/recall cards were going to addresses where patients no longer lived, a particularly acute problem amongst Asian women were 44% of blank questionnaires went to women who no longer lived their. Also the multi-lingual nurse noted that ethnic minorities were frequently unaware of the existence or importance of cervical screening, especially Asian women. It is argued cultural issues need to be addressed, and that the service needs to be less fragmented, and more use be made of videos for health education at home. It is somewhat unfortunate that we could find no indication about whether or not call/recall letters were normally sent in appropriate languages, since if translation did not happen it may in part be responsible for low questionnaire response amongst Asian women.

Box (1998) points out that a survey for the Health Education Authority in 1994 suggested that 85% of women living in the UK had had a cervical cancer screening test. Unfortunately however the figures amongst some ethnic minority groups are lower. For example the figure is 70% amongst Asian women, 54% amongst Pakistani women, and 40% amongst Bangladeshi women. The percentages screened within 5 years of the survey date are: 74 (all UK), 66 (Indian), 45 (Pakistani), 34
The authors then go on to discuss the Scanlink project on cervical cancer within Newham. It was designed to ascertain Black and minority ethnic views on cervical screening; collection information on knowledge levels of Black and minority ethnic women about cervical cancer and smear tests; and conduct awareness classes for these groups on cervical screening and screening. Research was conducted as part of the Scanlink project including a literature review involving an assessment of previous research on cervical screening, and on Black and Minority ethnic women in particular. Also focus groups of health advocates were conducted; Also interviews were held with 11 facilitators who carried out cancer awareness sessions within the Scanlink project, which provided them with training and remuneration. Questionnaires were also completed by Black and minority ethnic service users.

It was found that out of 172 service user respondents, 165 knew little about cervical smear tests. There were common misconceptions relating to the purpose of the test, the notion of pre-cancerous changes, pain, and fear that a positive test would inevitably mean death. Some women objected to being touched or scrutinised in private places, other felt that cervical cancer could not be treated, whilst yet others thought that they could catch cervical cancer in consulting rooms. Language also acted as a barrier discouraging some women from attending, and letters for smear tests were sometimes ignored if no one could translate for the women. Of particular concern was the common perception amongst the women that cervical cancer was a problem for Western women and not for themselves. It was concluded that there was a need for improved staff training for those involved in cervical screening so that interpreters and advocates are used as appropriate, and so that patients who consent can give informed consent.

Chiu et al (1999) examine the impact of professional and lay perceptions in the promotion of cervical screening amongst minority ethnic women. The authors argue that no attempts have so far been made to study the complexity of the issues involved in an intercultural context, or the possible contribution of women’s experiences to low uptake rates for cervical screening. They therefore suggest the use of a participatory action research (PAR) approach to pinpoint factors attributing to a persistently low participation rate amongst minority ethnic women (from African / African Caribbean, Arabic, Bengali, Cantonese, Urdu / Mirpuri, and Vietnamese backgrounds). The PAR technique can also involve a planned intervention into a practical problem. It is characterized by a cycle of ‘change’ through the process of problem identification, solution generation, and putting solutions into practice. It is also argued that the empowerment philosophy underpinning PAR can help to break down barriers. The authors used focus groups as a vehicle for participation. There were a total of 6 mini focus groups involving 27 minority ethnic women. The sample of women comprised 4 African / African Caribbeans, 4 Arabic individuals, 5 Bengalis, 5 Cantonese, 4 Urdu / Mirpuri, and 5 Vietnamese participants. Also smear takers perceptions were sought using a sample of 6 smear takers.

The call / recall system was thought to be ineffective with the non-westernised women, with culture and language barriers often affecting health-seeking behaviour. Smear takers expressed the view that South Asian women often lacked independence because of the male dominated culture thus they would often attend with a husband which they felt often made obtaining a smear difficult. The authors argued docility was effectively a sexual stereotype affecting health-seeking behaviour. South Asian
women were also perceived as lacking an understanding of preventative measures because of their culture, which were thought to impact upon their health education. Smear takers felt health education was vehemently rejected by the Asian community in order to preserve their traditional culture. This was criticised as operating as a “convenient justification for shifting the responsibility to minority ethnic women for lack of communication and opportunistic health education during smear taking.”

Concerns were raised about smear takers justifying their own communication difficulties by questioning the ability of the English speaking relative or interpreter to interpret accurately what was being said. Other concerns were raised about dysfunctional communication, and insufficient regard for patients dignity. It is also argued that smear takers can reproduce an asymmetrical power relationship through the misuse of translators. The smear takers were reluctant to concede that they should provide minority ethnic women with knowledge concerning cervical screening, and there was a tendency to shift responsibility for health education and communication to the minority ethnic community.

All except 1 of the minority ethnic women had undergone one or more smear tests, but the focus groups they attended revealed a surprisingly high degree of ignorance about the purpose and procedure of the test. The women proved to be keen to obtain information and explanations in relation to preventative health. Women aired concerns about the apparent lack of information about the test. Some of the women thought the smear test was something to do with childbirth (as they tended to happen after post-natal examinations). Moreover, the majority of the women did not realise that the test should be undertaken regularly. Also their inability to communicate, and the way in which they came into contact with the service led some women to feel obliged to accept it, even though it was offered without explanation, which highlights a problem of a lack of targeted education. The women often wanted an advocate or interpreter, and would have preferred a lady doctor and perhaps a day when Asian women could attend together.

**Breast Screening:**

**Hoare (1996)** conducted an analysis of breast screening amongst ethnic minorities including the Japanese, Chinese, Arabic, Asian, Indian. Whilst ethnic minorities are not in the high-risk group for breast cancer, low attendance levels are reported to be a problem. Moreover, some Asian women found the concept of preventative screening difficult to understand. The author argues for intervention to tackle low rates of screening in Asian women, including perhaps the use of videos and leaflets to encourage women to come in for screening.

**Atri et al (1997)** report on a randomised controlled trial (RCT) to establish whether a 2-hour training programme for GP reception staff could improve patient uptake in ethnic patients who had failed to attend for breast screening, and whether women from different ethnic groups would benefit equally. The study was a controlled trial, randomised by general practice. It involved 2,064 women aged 50-64 who were registered with practices within the London Borough of Newham, and who had failed to attend for Breast screening. The outcome measure was the number of patients attending breast screening. The results indicated that the use of practice reception
staff to chase non-attenders resulted in better utilisation of breast screening than in the control group (9% vs. 4%). The improvement was best however in Indian women, with 19% having screening after the intervention, compared with 5% in the control group. In the ‘Other’ ethnic group, which contained numerous other ethnic minorities, the response to the intervention was less impressive than amongst the white control population (6.6% for the intervention group vs. 4.3% for the control group). Where translation was required, this was undertaken by the use of a translated letter rather than interpreters. It is conceivable that had the women been approached by phone by someone who spoke their language, there might have been an even more positive response from ethnic minority women.

(iv) Access to Palliative Care:

In the grey literature, Iqbal (1994) evaluated palliative care uptake in ethnic minorities and assessed access to and appropriateness of services in relation to cultural issues. The study also tried to identify barriers to increased uptake of palliative care in Leicestershire amongst Whites, Black Caribbeans, Indians, Pakistanis, Chinese, and Asians. After an initial pilot study a structured questionnaire interview was carried out with 15 patients and 18 carers. The patients were mainly Asian (n=9). Patients were recruited from multiple sources, support groups, hospitals, outreach workers, etc. Overall two thirds of the patients spoke English with the remaining one third requiring a translator. Despite this 40% of the patients would have liked information translated into a language other than English, with only 27% receiving any information about their illness, either verbally or written material, in their native language. Perhaps more importantly, only 1 patient received information in a minority language outlining the palliative care services available locally, which led to very low awareness of different services by patients. Approximately half the group of patients reported that they had experienced racism during their hospital stay or treatment. Moreover numerous problems were identified including: poor communication; lack of Information provision in appropriate languages; and lack of local information networks for black and minority ethnic groups. The principal recommendations were therefore to address these issues. Unfortunately, because of the small sample size the analysis lacks robustness.

Hill and Penso (1994) describe a study looking at the low uptake of palliative care by minority ethnic groups. Three areas with high ethnic minority population had an in depth review of their use by, and provision for, the ethnic minority population. Low uptake of the services in all 3 areas was found and several factors were identified which contributed to this low uptake, including the lack of accurate data on the ethnicity of palliative care users. Firstly, death from cancer occurs mainly in the over 55 age group, and the ethnic minority communities have different demographics, with a smaller proportion of elderly people, and some older people migrating back to the country of origin later in life. Secondly, the palliative care team deal principally with care of cancer patients and the rates of cancer incidence and deaths are lower than those for the indigenous population. Finally, there was also a lack of information about the palliative care services made available to ethnic minority patients and their carers. The authors state that there is, however, some use of palliative care by ethnic minority groups and this use will rise as the demography of the group changes. The report recommendations build on the study's findings and identify the need to provide culturally sensitive services in respect of language, religion, spirituality and dietary
needs. Information about these services then needs to be disseminated to the ethnic minority communities. Further needs are: to ensure that reliable ethnic monitoring is in place in palliative care, and more systematic referral arrangements are in place with GP’s to ensure that people potentially benefiting from the service are referred at an early stage. There was also an identified need for staff training to meet the needs of the ethnic minority patients. The authors consider that, until these areas are targeted effectively, it is likely that barriers to ethnic minority members accessing palliative care will remain.

In another, more recent grey literature report from Leicestershire, Powell (1999) evaluates whether there is a need to improve communication, interpreting services, and literature for Asians needing to access cancer and palliative care services. A seminar was organised (with attendees from both statutory and voluntary sectors) in order to consider accessibility and information services for Asian communities for cancer and palliative care. Various actions were identified in order to improve access including: developing links with community leaders; establishing a central point of contact for information, translating services, and interpretation; having details of ethnic origin collated within medical records, and details of the patient's preferred language. It was also suggested that translated material needs to be reviewed and that a two-tier interpreting service should be developed involving a top tier of dedicated professional interpreters, and a secondary tier of bilingual and multilingual health care professionals. The use of link-workers was also advocated to provide advice and support to clients in their own language. It was also argued that healthcare staff ought to be given mandatory cultural awareness training, and that training should also be provided in schools within the city. A multi-faith worker was suggested, and inter-agency cooperation and a joint strategy. It was also suggested that the health authority should prioritise ethnic minority, and local authorities should create a 12 point check list similar to one adopted by a local community health council.

Note: this review did not seek to cover all relevant literature relating to cancer and ethnicity: it was conducted before the publication of other papers referred to in the main report and is included here only for information. It is part of a larger report submitted to the London regional office of the NHSE. The references cited, however, are included in the bibliography of the report.