

Research paper

Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom

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What is known on this subject

- Cancer has been relatively less prevalent among members of the UK's black and minority ethnic (BME) communities than in the overall population. However, this is now changing.
- The experience of cancer and of palliative care among members of the UK's BME communities can differ within and between different ethnic groups.
- Increasing cultural and ethnic diversity in the UK population highlights the need to address inequalities in access to information and services for members of the UK's BME communities.

What this paper adds

- This review identifies a need for improvement in the range and quality of studies of the health and wellbeing of people of BME origin in the UK, with respect to cancer and palliative care.
- People from BME communities should be central to the negotiation of the research agenda.
- Health professionals should ensure the sensitive and appropriate capture of ethnicity data in order to support the development of research that addresses the needs of the UK's BME communities with respect to cancer and palliative care.

ABSTRACT

This article reviews 31 articles on ethnicity and cancer/palliative care that were identified during the course of a broader study that aimed to comprehensively review UK research literature on 'race', ethnicity and health published between 2000 and 2005. It considers: epidemiology of cancer in black and minority ethnic (BME) communities in the UK; risks and awareness; screening; and palliative and end-of-life care. Overall, the research studies we reviewed were limited with respect to one or all of: the range of cancers considered, population/sample, geographical area studied, and the meanings and

experiences of cancer for patients and their families/carers. Cancer has been relatively less prevalent among the UK's BME communities than in the general population. However, changes in the incidence and pattern of cancer among BME communities in the UK suggest the need for further research into risk factors as well as the views of service users and providers in order to enhance health promotion and access to appropriate services.

Keywords: BME, cancer, ethnicity, health, palliative care, UK

Introduction

This article critically reviews research into cancer and palliative care in relation to members of the UK's black and minority ethnic (BME) communities, published between 2000 and 2005. While cancer is less common among the UK's BME population than in the overall population, patterns of disease are similar (Gill *et al*, 2001), and the incidence of cancer is rising among BME people in the UK (Karim *et al*, 2000; Lodge, 2001). (In 2001, the UK's BME population included people of Indian, Pakistani, Bangladeshi, other Asian, black Caribbean, black African, other black, Chinese, mixed and other ethnic origins (Office for National Statistics, 2001).) Apparent similarities mask very different experiences of cancer and associated services within and between BME groups and the general population (Department of Health, 2000). Inequalities in access to timely, relevant, appropriately presented information about cancer, its risks, symptoms, management and support available (Deepak, 2004) contribute to the fact that late diagnosis is a notable concern for health service providers in relation to BME people in the UK (Department of Health, 2007).

Improving service provision for all, and reducing inequalities in access with respect to the diagnosis and management of cancer and provision of therapeutic and palliative care services, are espoused aims of contemporary cancer policy (Department of Health/Welsh Office, 1995; Department of Health, 2000, 2007; National Institute for Health and Clinical Excellence, 2004; Scottish Executive, 2001; Welsh Assembly Government, 2006). Yet the relationship between 'ethnicity' and the health of individuals and communities is complex, influenced by socio-economic factors and structural and individual racism as well as the quantity and quality of health services available (Karlsen and Nazroo, 2002a,b). The 2001 census indicated that 7.9% of the UK population identified themselves as belonging to a minority ethnic group. This represented 4.6 million individuals, of whom the greatest proportion were of Indian origin, with people of Pakistani, mixed ethnic origin, African-Caribbean, black African and Bangladeshi backgrounds following. In the UK, Asians (primarily people of Indian, Pakistani and Bangladeshi origin) represented numerically half of the nation's entire BME population (National Statistics Online, 2003). Growing ethnic and cultural diversity in 21st-century Britain creates a need for deep and wide-ranging understanding of the health and illness experiences of BME populations.

Studies conducted over recent decades indicate that people from the UK's BME population tend to experience greater ill health than the general population (Donovan, 1985; Thorogood, 1988; Smaje, 1995; Nazroo, 1997). However, drawing general conclusions is unwise

as a variety of approaches to the collection of data on ethnicity or origin have been taken in individual research studies (Lodge, 2001). The decennial census has only included a question on ethnicity since 1991, revised in 2001, and this question is controversial (Aspinall, 2000). Although ethnicity data collection was introduced in the NHS from 1995, comprehensive ethnicity data capture is not always achieved (Karim *et al*, 2000; Lodge, 2001). Accurate assessment of trends in the health of the UK's BME population and of relationships between ethnicity, intervening variables and health is thus difficult.

The situation is compounded by the influence of social class position on health and illness (Townsend and Davidson, 1982; Cornwell, 1984). Nazroo (1997) noted the cumulative influence of disadvantage over a lifetime, the geographical locale of ethnic minority groups in deprived housing tenure and associated ecological effects, and the consequences of living in a racist society. Analysing cross-sectional data from the *Fourth National Survey of Ethnic Minorities*, Karlsen and Nazroo (2002a,b) state that interpersonal racism and individual perceptions of the dynamics of indirect racism in society each have independent, negative health consequences.

Furthermore, for BME patients, language difficulties can encumber the delivery of effective services, and frequently lead to poor communication and confusion (Yee and Heath, 1997). Recent studies report that language barriers present a major impediment to minority ethnic communities accessing primary health-care (Alexander *et al*, 2004; Gerrish *et al*, 2004), and palliative care services (Randhawa and Owens, 2004).

The literature review: aims and methods

The aims of the project reported here were comprehensively to review research literature on health, published in the UK between 2000 and 2005, that addressed ethnicity, 'race' and health, identifying commonality and differences between and within ethnic groups in the UK. The review proposal and protocol were developed following extensive consultations with two information scientists employed in an international centre of excellence in respect of critical appraisal and systematic review – the School of Health and Related Research, the University of Sheffield. Both information scientists were review team members. The methodology and choice of a critical rather than systematic review were informed by this expertise.

The project was funded for six months, from December 2005 until June 2006, with a small grant (£1938) from the Carer, Ageing and Rehabilitation

(CARER) Department of the School of Nursing and Midwifery at the University of Sheffield, UK, and members of the project team contributed on a part-time basis during the lifetime of the project. Major organisational changes in the School of Nursing and Midwifery at the University of Sheffield meant that there was no possibility to extend the project. Time, resource and organisational constraints thus did not permit a full systematic review of the literature, nor was it practicable to consider literature published later than 2005 because of the limited resources available.

While the scope of the review was to be comprehensive, and to encompass all literature on UK research into 'race', ethnicity and health published between 2000 and 2005, the principles of systematic review methodology (Centre for Reviews and Dissemination, 2001) informed the search strategy. During the early stages of the project, the project team identified databases to be searched (Medline; EMBASE; NHS HTA; Cochrane; HMIC; CINAHL; Amed; Psycinfo; British Nursing Index; Web of Science; ASSIA; Sociological Abstracts; International Bibliography of the Social Sciences; and Caredata). Search terms to be used relating to 'race' and ethnicity (ethnic minority; refugee; black; black and minority ethnic groups; BME; migrant; race; asylum seeker), the larger of the discrete, black and minority ethnic population groups identified by the UK census in 2001 (Asian; South Asian; Jamaican; Irish; and African Caribbean), and health state (well-being; ill health; illness; sickness; wellness; health; disease; and dysfunction), and inclusion and exclusion criteria for the retrieval of articles were then identified. Articles to be included would address the health and illness of the UK's BME communities and comprise research papers published in the English language between 2000 and 2005. Articles addressing the health and illness of the general UK population or of non-UK BME communities, or that were not research reports, were published before 2000 or after 2005 or were published in languages other than English were excluded. All articles meeting the inclusion criteria relating to research studies into 'race', ethnicity and health in the UK conducted between 2000 and 2005 were retrieved, either from local library sources or from the British Library Document Supply service, for appraisal. It was determined that article quality should be assessed using Critical Appraisal Skills Programme (CASP) checklists (National Health Service (NHS) Public Health Resource Unit, 2005). The rationale for so doing was that only articles that met quality criteria should be included in the written review.

This paper reviews research published on cancer and palliative care, which was identified as one discrete element among several identified from the literature on 'race', ethnicity and health that was retrieved during the project. It should be noted that the literature relating to cancer and palliative care reviewed here was not

identified as a result of a focused review of cancer and palliative care pertaining to people from the UK's BME communities. This would have been a different project and would probably have identified a related, but distinct, body of literature.

As this was not a systematic review, and as the nature of the studies identified was not appropriate to so doing, meta-analysis of the findings of the studies reviewed here was not conducted by the authors. Instead, key themes have been identified for analysis, and a methodological review section addresses the overall strengths and limitations of the studies reviewed. The following sections summarise the main themes and findings identified from the articles reviewed under four main subheadings: epidemiology of cancer in BME communities in the UK; risks and awareness; screening; and palliative and end-of-life care. In total, 31 research reports are reviewed.

Epidemiology of cancer in BME communities in the UK

Eleven studies are considered here (Table 1), all of which were limited in relation to geographical region of the UK, ethnicity of the study population, or both. None of the papers retrieved during our review of UK literature focused on genetic factors relating to cancer, though the genetics of cancer is increasingly recognised within the literature and in the most recent government policy document on cancer services in the UK (Department of Health, 2007).

Only one study included in the present review considered the incidence of all cancers within the UK's BME population, although the authors noted the lack of empirical evidence available (Smith *et al*, 2003a). However, this study focused on South Asian people living in Leicestershire. It concluded that the incidence rate, especially for breast, colorectal and prostate cancer and disease in children, was increasing for Leicestershire's younger South Asians, contemporary with decreasing incidence for the general population.

Breast cancer is the commonest cancer affecting women of all ethnic groups in the UK, and was the focus of four papers. Two studies reported that first-generation South Asian women were at up to 29% lower risk of developing breast cancer (Dos Santos Silva *et al*, 2002; McCormack *et al*, 2004), and have better survival rates at five years post-diagnosis (Farooq and Coleman, 2005) than the general female population. McCormack *et al* (2004) analysed the associations between diverse cultural and religious norms and risks for the development of breast cancer for women of Pakistani Muslim, Indian Muslim, Gujerati Hindu,

Table 1 Epidemiology and risk

Author/date	Risk and risk factors	Risk awareness and response	Survival
Muthu Kumar <i>et al</i> , 2004		The majority of Asian patients, like white patients, wanted to know about their cancer; the views of those who do not want to know should be respected and permission sought before disclosure of confidential information to relatives.	
Papadopoulos, 2004		Effective, culturally competent communication with health professionals is of prime importance	
Randhawa <i>et al</i> , 2004		Lack of awareness of cancer and cancer services; eagerness to learn; cultural sensitivity needed to address health inequalities of BME communities	
Scanlon <i>et al</i> , 2005		Breast cancer. BME women have lower awareness of risk factors and practice breast awareness less than majority population	
Stiller <i>et al</i> , 2000			Childhood. Survival rates for childhood cancers in UK similar for all ethnic groups except ALL
Vora <i>et al</i> , 2000		Oral cancers. Alcohol, tobacco, paan use and knowledge of risks varies among south Asian community	
Dos Santos <i>et al</i> , 2003			Breast cancer. Survival rates better for south Asians than majority population
Farooq <i>et al</i> , 2005			Breast cancer. Five year survival from breast cancer in England and Wales higher for south Asian women

Table 1 Continued

McCormack <i>et al</i> , 2004	Breast cancer. Breast cancer rate lower for south Asians than majority population
Dos Santos <i>et al</i> , 2002	Breast cancer. South Asian vegetarians had lower risk of breast cancer than meat eaters
Fischbacher <i>et al</i> , 2003	Gastric cancer. <i>Helicobacter pylori</i> infection rates similar in south Asian and Europeans; Gastric cancer incidence and mortality lower in south Asians
Tham <i>et al</i> , 2003	Gestational trophoblastic disease. Women of Asian origin appear to be at greater risk
Flavell <i>et al</i> , 2005	Hodgkins disease. Epstein Barr virus, Hodgkins disease, material deprivation and south Asian ethnicity associated
Ades <i>et al</i> , 2000	HTLV and T cell lymphoma. Prevalence of HTLV highest in pregnant women born in endemic area
Smith <i>et al</i> , 2003a	All cancers. Incidence lower in south Asians than in non-south Asians but is rising among younger south Asians although falling among non-south Asians health promotion programmes should recognise this
Smith <i>et al</i> , 2003b	Lung cancer. Incidence lower in south Asians than non-south Asians; smoking rates higher in younger south Asians risk should be recognised
Khan <i>et al</i> , 2000	Oral cancer. Use of tobacco, alcohol and paan varies within and between BME groups

Punjabi Hindu, and Punjabi Sikh origin, and identified heterogeneity of risk. Muslim women, particularly of Pakistani origin, were at greater risk of developing breast cancer than other women of South Asian descent. McCormack and colleagues suggested a possible association with diet and body size but noted the need for further research. A limitation of this case-control study is that the South Asian women included as 'cases' were all first-generation migrants to the UK, while increasing proportions of people of South Asian background living in the UK are second- and later-generation residents.

An earlier study found that lifelong vegetarians experienced a lower – though not statistically significant – incidence of breast cancer than women who included meat in their diet, although it was unclear whether abstinence from meat or a greater intake of vegetables and pulses in the diet was protective (Dos Santos Silva *et al*, 2002). Dos Santos Silva *et al* (2003) and Farooq and Coleman (2005) found that South Asian women were more likely than white women to survive breast cancer. In Dos Santos Silva and colleagues' study of 1037 South Asian and 50 201 non-South Asian women, ten-year survival rates for breast cancer were 72.6% for South Asian women, compared to 65.2% for non-South Asian women. Farooq and Coleman's (2005) study of 115 712 women diagnosed with breast cancer between 1986 and 1990 found that South Asian women were between 3% and 8% more likely to have survived to five years post-diagnosis than were other women. The data available did not suggest why this population should enjoy such an advantage.

While lower for South Asian people than for the general UK population, between 1990 and 1999, contrary to the decreasing trend for the general UK male population, lung cancer incidence rose among South Asian men in Leicester (Smith *et al*, 2003b). Lung cancer incidence increased for women of all ethnic groups over this period, though more quickly among South Asian women. The report noted a common assumption that South Asian people are at low risk for lung cancer and other smoking-related diseases. Yet smoking rates are higher among younger South Asian males than in older age groups (Smith *et al*, 2003b).

Data from two studies (Stiller *et al*, 2000; Flavell *et al*, 2001) indicate that survival rates for most childhood cancers diagnosed between 1991 and 1996 were similar for children from all ethnic backgrounds. However, BME children – especially children of South Asian background – had poorer five-year survival rates than did white children for acute lymphoblastic leukaemia (ALL), with South Asian children 25% more likely to die following diagnosis than white children. Flavell *et al* (2001) reported a strong association between South Asian ethnicity and Epstein–Barr virus seropositivity in Hodgkin's disease in childhood, which persisted after adjusting for material deprivation.

Conversely, while the prevalence of *Helicobacter pylori* infection is high among South Asians living in the Indian subcontinent, for British South Asians the prevalence is close to that found in the general population (Fischbacher *et al*, 2004). Yet, the authors noted, there is a lower incidence of gastric cancer in the UK South Asian population than in the general population – though the size of this incidence is not noted in the paper. The authors recommend further research, especially in view of the association between *H. pylori* infection and both gastric cancer and coronary heart disease (Fischbacher *et al*, 2004).

An association between infection and cancer has also been considered in relation to the prevalence of human T cell leukaemia/lymphoma virus (HTLV), associated with the development of T cell lymphoma in adults, among pregnant women resident in the UK (Ades *et al*, 2000). Seroprevalence rates among women born in endemic areas were higher than for those born in non-endemic countries. The highest HTLV rate was found in women born in the Caribbean, whose seroprevalence rate was 16.9 per 1000, compared with 0.36 per 1000 among women born in Europe. The authors recommended consideration of screening either all women during pregnancy or those from high-risk groups, in order that strategies for the reduction of risk of transmission from mother to child might be considered.

A prospective observational study of women in Northern England and North Wales identified that, compared with the general population, Asian women are at 1.95 times the risk of gestational trophoblastic disease (GTD), a spectrum of very rare malignancies. In this study, based on registration of women with GTD at Weston Park Hospital in Sheffield, 'Asian' was defined as including women whose origins lay anywhere in the continent of Asia. However, the study suggests that the rarity of the conditions may lead to misclassification and the authors recommend that regional or national registration centres may help to improve the accuracy of epidemiological data which could assist in identification of risk factors (Tham *et al*, 2003).

Risks and awareness

South Asians are often considered at high risk for the development of head and neck cancers, although the pattern was changing during the 1990s (Smith *et al*, 2003a). Two studies considered the use of tobacco, alcohol and paan by members of UK BME communities. These are recognised risk factors for the development of oral cancer (Khan *et al*, 2000; Vora *et al*, 2000). Questionnaire surveys in England's South Thames region (Khan *et al*, 2000) and Leicester (Vora *et al*,

2000) sought information about use of alcohol and tobacco and of alcohol, tobacco and paan, respectively. The South Thames study surveyed members of all BME communities, male and female, while that conducted in Leicester targeted Asian men. Both studies described considerable differences, especially inter-generational ones, in substance use within and between BME communities. The researchers urged the development of health promotion programmes that recognised the heterogeneity within BME communities, as well as research into rapidly changing patterns of cancer.

Scanlon and Wood (2005) identified lower awareness of breast cancer and of breast self-examination among BME than white women in the UK. Yet a critical review of research published the previous year had suggested that BME women lacked appropriate information about breast health (Watts *et al*, 2004). Similarly, a pilot study of testicular cancer awareness and testicular self-examination (Khadra and Oakeshott, 2002) identified that 'non-white' men were less likely to have correct knowledge of the condition, and less likely to be carrying out self-examination than were white men. Although the researchers had identified the ethnicity of subjects, they did not use these data in their analysis of the results of their study.

Other studies considered the attitudes of people from BME communities towards cancer. Papadopoulos and Lees (2004) conducted 'in-depth, semi-structured' interviews with six men with cancer and their 'significant other', each dyad representing a distinct ethnic background, during a pilot study conducted in order to identify experiences of cancer and its meanings for people of different ethnic backgrounds. The paper reported only the 'communication aspects' of the subjects' experiences, and neither the meanings of cancer nor the experiences of the men's wives as carers and supporters of someone with cancer were explored. A common theme identified by the men interviewed for the study was that, regardless of ethnicity, effective communication was important for those interviewed. The authors recommended the education of health professionals in culturally competent communication.

This was also highlighted in a study by Randhawa and Owens (2004), which found low levels of awareness about cancer and cancer services among South Asian people in Luton, England, although people were eager to receive information about both. 'Cultural insensitivity' was identified as contributing to health inequalities in the experience of South Asians with cancer. This study and that by Muthu Kumar *et al* (2004) claimed that it is sometimes assumed that South Asian people will not want to be told if they have 'cancer', because it is stigmatising. A corollary of this is that South Asian families may filter information between health professionals and patients (Karim, 2002). However, Muthu Kumar and colleagues (2004) found that

92.6% of South Asians surveyed wanted to know, although 88.9% wanted family members to be present when they received their diagnosis.

Screening

Variability in screening uptake has been identified in relation to specific subgroups within the overall UK population, including women from BME backgrounds (Table 2). However, a systematic review noted a paucity of evidence from UK studies to establish either contributory factors or solutions (Jepson *et al*, 2000). In addition, published studies consider 'culture', 'ethnicity' and 'socio-economic status' uncritically, and the quality and quantity of information are further undermined by the limited availability of ethnicity data in the UK (Chiu, 2003).

Sutton and colleagues (2001) identified that South Asian women living in Wakefield, England, were more likely than non-South Asians to be overdue for both cervical and breast screening, though 'conspicuously' overdue for breast screening. Webb *et al* (2004a,b) found similar patterns in relation to cervical screening uptake in Manchester, England. However, women from other minority ethnic backgrounds were also less likely to have attended for screening, and women born overseas were more likely never to have been screened. South Asian women attending a general practice where 20% or more patients were of South Asian origin were more likely than the general population of women to attend for cervical screening.

Seeking the views of service users, Pfeffer's study of candidacy and compliance in relation to breast cancer screening in Hackney, a socio-economically deprived London borough, found that an individual woman's perception of her susceptibility to developing breast cancer ('candidacy') and her ethnic self-identity could influence her response to a screening invitation, but suggested that the relationship between these two constructs and compliance was not predictable (Pfeffer, 2004). Other influences, including social norms, religious faith and the sex of the healthcare professional providing the service, might also influence an individual's response to a screening invitation.

By contrast, Thomas *et al* (2005), exploring knowledge about and attitudes towards cancer among BME women in two London boroughs, found that many lacked knowledge, and sought explanations about cancer from the research team. While all cancer was feared and taboo, some cancers were especially stigmatised, and some women did not attend for screening because they feared the revelation of fatal disease. Others considered themselves not to be 'at risk' and therefore not in need of screening. Yet others did not attend simply because they were not sent an invitation.

Table 2 Screening

Author/date	HTLV	Breast	Cervix
McCormack <i>et al</i> , 2004		Breast cancer incidence rates for south Asians 'mask great heterogeneity'; may be of use when considering screening for breast cancer.	
Pfeffer, 2004		Response to invitation to breast screening is socially patterned; candidacy and ethnicity interpreted by women to explain risk of breast cancer; compliance with invitations may not be for medical reasons.	
Sutton, 2001		South Asians more likely to be overdue to attend for screening (breast, cervical) than are non-south Asians; both south Asians and non-south Asians are more likely to be overdue to attend breast screening than cervical screening.	
Thomas <i>et al</i> , 2005		Limitations in knowledge and desire for information identified; education of BME communities and health professionals required to increase screening uptake	
Webb <i>et al</i> , 2004a			Strongest predictors of not attending cervical screening identified as: overseas place-of-birth; being registered with a large inner-city general medical practice; south Asian women - being registered with non-south Asian GP.
Webb <i>et al</i> , 2004b			Routine collection of accurate and specific ethnicity for all patients is required in primary care to allow development of evidence based health promotion and planning of cervical screening programmes.
Chiu, 2004			Divergence of perceptions of screening between lay people and professionals led to dysfunctional clinical communication;

Table 2 Continued

Ades <i>et al</i> , 2000	<p>Women born in regions where HTLV endemic are at increased risk of being seropositive</p> <p>General or targeted antenatal screening may be indicated more research needed.</p>	<p>most women did not understand purpose of test; action research led to solutions being generated by women and professionals; improved uptake of screening by up to 66%; overall satisfaction with clinical encounters increased,</p>
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Lack of knowledge about cervical screening was also identified by Chiu (2004), whose action research study found that misperceptions on the part of both lay women and health professionals undermined the quality of the care experience, and contributed to low screening uptake. The action research process permitted improvements in communication, screening uptake and happiness with service provision in primary care settings in the localities in South Yorkshire, England, where the research was conducted, as well as improvements in job satisfaction for professionals.

One study identified that the potential for requests for prostate-specific antigen (PSA) testing to increase has implications for NHS workload and costs (Melia *et al*, 2004). This study provided limited information about the rates of PSA testing for men from BME communities, although regression analyses of general practitioners' (GPs') PSA testing rates suggested that black and Asian men were less likely to be tested for the presence of PSA than were white males.

The geographically specific studies reported here suggest that further research into screening uptake among people of all ethnic backgrounds, ages and socio-economic groups and living in the different regions of the UK is warranted, in order to establish the extent and pattern of inequalities. In addition, the findings of Webb *et al* (2004a,b), Pfeffer (2004) and Chiu (2004) indicate that the reasons why some BME people in the UK take up screening opportunities while others do not should also be subject to further investigation.

Palliative and end-of-life care

A systematic review of research into specialist palliative care services reported between 1997 and 2003 concluded that people from BME backgrounds were among a number of groups experiencing limited access to 'timely referrals' to specialist palliative care services (Table 3). Referrals depended on both the potential service user and the health professional being knowledgeable about the nature and availability of services, and their potential to meet individual needs (Ahmed *et al*, 2004). In this section of the review, studies that were identified and that considered access to palliative and end-of-life care are considered.

GPs and hospital consultants are less likely to refer people of BME backgrounds than white patients to hospice inpatient and day-patient care. One study in Birmingham, England, reported that health professionals assumed that people from BME communities would prefer to be at home during the terminal stages of disease (Karim *et al*, 2000). Specialist palliative care nurses advised medical staff to refer clients for home care support rather than to hospice inpatient and day-patient care, because family members would be loath to reveal a diagnosis of terminal illness to their relative. An unintended consequence was that BME people with life-limiting illness were more likely to experience terminal care in general hospital settings than to receive specialist palliative care services, because when their condition deteriorated and family carers' ability to meet their needs was compromised, hospital rather than hospice admission was more likely to result.

Table 3 Palliative and end-of-life care

Author/date	Referral and service uptake	Carers	Cultural competence
Karim <i>et al</i> , 2000	GPs and hospital consultants less likely to refer BME than white patients to hospice in-patient and day-patient services; as likely to refer to home care services; BME patients lack awareness of services; culturally sensitive palliative care needed		
Karim, 2002			Professionals perceive BME clients to prefer non-disclosure or cancer diagnosis, with family acting as information gate-keepers.
Koffman and Higginson, 2001	Patients of African-Caribbean background have lower access to hospice care; African-Caribbean people are more dissatisfied with services provided in final year of life		
Koffman and Higginson, 2002			Religion important for African-Caribbean and European patients; Role and meanings more 'pronounced' for African-Caribbean people
Koffman and Higginson 2003a		Overall similarities between African-Caribbean and white carers' experience of caring roles during last year of dependant's life; African-Caribbean carers more likely to experience hardship	
Koffman and Higginson, 2003b	African-Caribbean people less likely to be admitted to hospice than were Europeans during final year of life; More qualitative research recommended to explore why African-Caribbean		

Table 3 Continued

	people report greater distress than Europeans with some symptoms	
Owens <i>et al</i> , 2004		Communication problems identified for south Asians needing palliative care
Randhawa <i>et al</i> , 2003		Delivery of culturally competent care hindered by ineffective communication

The lower rate of referral of people from BME communities for hospice care was also identified by Koffman and Higginson (2001), who found that first-generation Londoners of black Caribbean heritage were less likely than white people to have had access to specialist palliative care services, despite their availability in the locality where the study took place. Koffman and Higginson also found that caregivers from the black Caribbean community were more likely to report finding the role of caregiver during the final year of the patient's life to be problematic (Koffman and Higginson, 2003). In addition, they reported more distress associated with symptoms on the part of the person for whom they were caring, which led them to suggest that service providers should develop greater cultural awareness and improved cancer symptom assessment and management (Koffman *et al*, 2003).

A common theme in the literature on palliative care services is that health professionals require education in cultural sensitivity and the development of cultural competence in order to meet the needs of people from the UK's BME communities (Koffman and Higginson, 2002; Randhawa *et al*, 2003). This could also give health professionals greater job satisfaction (Jack *et al*, 2001; Randhawa *et al*, 2003; Owens and Randhawa, 2004).

Methodological review

While people from BME communities have enjoyed a lower incidence of cancers than the general UK population, this appears to be changing. The need for detailed, comprehensive information about changing trends and their implications thus exists (Department of Health, 2007). Most studies reviewed focused on a narrow range of cancers affecting the UK's BME population and dealt primarily with two ethnic groups – people of South Asian and, to a far lesser extent, African-Caribbean origin – and/or considered people

living in small areas. There were further limitations. The terms 'South Asian' and 'African Caribbean' refer to people of varied cultural, linguistic, and religious origins, and of diverse socio-economic status – variables that few studies acknowledged.

In the absence of comprehensive ethnicity data linked to mortality, morbidity and service use data, the development of computer algorithms (Nam Pehchan, SANGRA) with high specificity and sensitivity allows researchers to identify members of South Asian more than people of other BME communities. There is thus a bias towards studies of people apparently belonging to easily 'identifiable' groups. Furthermore, first-generation migrants were well represented in epidemiological studies, whereas the UK population includes a growing proportion of people of second and subsequent generations, and people of dual heritage. The limitations of ethnicity data were a factor here, as place of birth could be used only to identify first-generation migrants. Moreover, the studies reviewed paid little or no attention to possible effects of acculturation on attitudes towards cancer and its meanings for individuals. Nor were intergenerational differences in risk factors, or experiences of cancer and its significance, addressed robustly.

The focus of the studies ranged from regional epidemiological studies to very small-scale interview studies conducted in one locality. Studies that sought insider views of the causes and meanings of cancer were generally limited to very small numbers of people and to narrowly defined geographical areas. Koffman and Higginson's (2001) study provides insights to the experiences of people of African-Caribbean origin, but dealt with people living in London, and the findings cannot be generalised to people living elsewhere in the UK. There is generally only limited information about cancers in relation to minority ethnic communities in the UK other than people of South Asian or African-Caribbean background. The challenges that this imposes, as the profile of the BME population changes, have been acknowledged by the

English Department of Health's *Cancer Reform Strategy* (2007), which notes that inequalities in cancer can have multifaceted deleterious impacts on 'incidence, survival, mortality, patient experience or quality of life', but that the evidence about the extent of inequalities is inadequate in scope and in depth.

Discussion and conclusions

It is notable that the risk of cancer morbidity and mortality rates are rising among the UK's BME population, possibly as a consequence of acculturation and integration into British society. It is therefore of increasing importance that the needs and health service experiences of the several BME communities in the UK are explored in order to ensure that people's needs for and access to healthcare are assessed accurately and met effectively and appropriately. Improving ethnicity data capture would contribute to enhanced accuracy of information about emerging patterns of disease, and associated risk factors (Kingsland, 2006). Yet, the increased surveillance of individuals in the contemporary UK makes it a highly political and personally sensitive issue.

The relationship between 'ethnicity' and 'health' is complex (Karlsen and Nazroo, 2002b), with socio-economic factors identified as possible confounders. Unconscious and structural racism in the delivery of health services also need to be addressed (Chiu, 2004). This review indicates that the unintended consequences of limited cultural awareness on the part of health professionals include poor communication and well-intentioned but culturally insensitive patterns of care provision. While there are examples of good practice (Jack *et al*, 2001), evaluation studies should be conducted in order that the strengths and limitations of provision may be identified and future developments based on the needs of service users. Moreover, there appears to be as strong a need for research strategies that focus on service users' perspectives. These should seek users' views of current services, from health promotion through to screening and cancer treatments and palliative care. They should also facilitate service user involvement in setting the research agenda.

This review has identified that while some very useful research has been conducted, the range and quality of studies of the health and wellbeing of people of BME origin in the UK, with respect to cancer and palliative care, are patchy. While this review has considered only papers published between 2000 and 2005, which reported on research that commenced as early as 1986, a recent policy document (Department of Health, 2007, p. 85) suggests that the lack of comprehensive, detailed evidence on the '... extent to which

inequalities exist, what causes them and what interventions will be most effective in addressing them' persists. There are clear opportunities for further research, with people from BME communities central to the negotiation of the research agenda, to identify risk factors and service user perspectives. There is also a strong indication that health professionals need to ensure the sensitive and appropriate capture of ethnicity data in order to support a body of research that addresses the needs of all the UK's BME people. Without such developments, the intention of contemporary cancer and palliative care policy in the UK to provide for the needs of all people with cancer and palliative care support needs cannot be achieved.

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CONFLICTS OF INTEREST

None.

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