The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature

R. ELKAN, BA [HONS], RESEARCH FELLOW, M. AVIS, MA, PROFESSOR, K. COX, PHD, PROFESSOR IN CANCER AND PALLIATIVE CARE, E. WILSON, BA [HONS], RESEARCH FELLOW, S. PATEL, BSC, RESEARCH FELLOW, SCHOOL OF NURSING, POSTGRADUATE DIVISION, MEDICAL SCHOOL, UNIVERSITY OF NOTTINGHAM, NOTTINGHAM, S. MILLER, MSC, INDEPENDENT CONSULTANT, N. DEEPAK, FREELANCE CONSULTANT, C. EDWARDS, PHD, RESEARCH FELLOW, S. STANISZEWSKA, BSC [HONS], DPHIL, SENIOR RESEARCH FELLOW & LEAD, PATIENT EVALUATION AND INVOLVEMENT PROGRAMME, ROYAL COLLEGE OF NURSING INSTITUTE, RADCLIFFE INFIRMARY, OXFORD, & J. KAI, MB, BS, FRCP, PROFESSOR AND CHAIR OF PRIMARY CARE, UNIVERSITY OF NOTTINGHAM GRADUATE MEDICAL SCHOOL, UNIVERSITY OF NOTTINGHAM, NOTTINGHAM, UK


The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature

There is growing evidence of inequalities in access to high-quality cancer services between minority and majority ethnic groups. However, little research has been carried out from the perspective of users from minority ethnic groups themselves. This paper reports a review of the British literature exploring the views and experiences of cancer service users from minority ethnic groups. We reviewed 25 qualitative studies that reported the experiences of people from minority ethnic groups. The studies highlighted significant issues and challenges, including comprehension and communication barriers, a lack of awareness of the existence of services and a perceived failure by providers to accommodate religious and cultural diversity. This paper critically discusses some of the explanations commonly invoked for ethnic inequalities in access to high-quality care, such as the belief that the lack of use of services reflects a lack of need. Despite positive initiatives to respond better to the needs of minority groups, we suggest the impact of these remains highly variable. Institutional racism within services is still much in evidence.

Keywords: minority ethnic groups, cancer service users, qualitative research.

Failure to make specific consideration of minority ethnic issues risks increasing ethnic inequalities by unintentionally favouring policies that benefit the ethnic majority. (ACHESON 1998)

INTRODUCTION

The epidemiology of cancer

Information about the epidemiology of cancer in different ethnic groups is difficult to obtain. This is partly because of the difficulty of defining and classifying people into ethnic groups, and partly because of the inconsistent and incomplete way in which data about patients are monitored and collected in the National Health Service [NHS] [Aspinall 2000]. Problems also arise because people from minority ethnic groups are more likely than
others to be of lower socio-economic status, so that it is not easy to separate the effects of ethnicity from those of socio-economic status (Family Resources Survey Department for Work and Pensions 2005). Despite these difficulties, the literature suggests that while the incidence of most common cancers appears lower among minority ethnic groups than the rest of the population, rates of cancer among minority ethnic groups are rising to equal, or possibly, exceed the general population rates in the UK [Winter et al. 1999; Harding 2003; Smith et al. 2003].

Uptake of services

Evidence concerning disparities in the uptake or use of services is also difficult to obtain and interpret. As with the relevant epidemiological data, there are problems with inadequate data collection, as well as difficulties in assessing the relative importance of ethnicity and social class. However, the available national evidence suggests that minority ethnic groups, with the exception of the Chinese who have lower rates of service use, have similar rates of general practitioner consultation, and hospital inpatient use, to the general population [Erens et al. 2001; Sproston et al. 2001].

With regard specifically to cancer services, a number of small, local studies have reported lower uptake of screening services, particularly among some South Asian groups, notably Bangladeshi women [Botha et al. 1993; Naish et al. 1994; Rudat 1994; Kernohan 1996; UK Colorectal Cancer Screening Pilot Evaluation Team 2003], although the evidence for lower uptake is not conclusive [Hoare 1996; Chiu 1998; Chiu 2003]. Small-scale, local studies have also found that hospice and other palliative care services are under-used by some minority ethnic groups [Hill & Penso 1995; Fountain 1999; Spruyt 1999; Karim et al. 2000; Johnson 2001]. The very small UK literature about minority ethnic groups and cancer clinical trials also suggests that minority ethnic groups are under-represented [Mason et al. 2003].

While there is a growing UK literature documenting inequalities in access to health services between minority and majority ethnic groups, few qualitative studies have been carried out which consider the process of accessing care, and the quality of care received, from the perspective of users from minority ethnic groups themselves [Szczerpura 2005].

This review synthesizes the available UK literature based on the reported views and experiences of people from minority ethnic groups using cancer services, in order to inform service providers’ attempts to respond better to patients’ needs. Although we focus on cancer services, many of the issues raised are likely to be applicable across other health and care contexts.

AIM

The aim of this study was to draw together published and unpublished studies that reported experiences of cancer services among people from minority ethnic groups.

METHODS

We searched relevant electronic databases for studies undertaken between 1990 and March 2005 which reported the views and experiences of cancer services of people from minority ethnic groups.

The following databases were searched:

- BIDS
- British Nursing Index
- CancerLit
- Cochrane Library (CENTRAL, CDSR, DARE)
- Cumulative Index to Nursing and Allied Health Literature – CINAHL
- Embase
- Medline
- Ovid Online
- PsychInfo
- ScholarGoogle
- Science Direct
- Web of Science

In addition, we checked the bibliographies of included papers, and searched on cancer sites on the Internet. Key individuals and organizations were also contacted.

For the purposes of our review, ‘cancer services’ included screening services, hospices and other palliative care services, cancer clinical trials, hospital inpatient and outpatient cancer care, cancer information provision, and support for cancer patients and families from linkworkers, interpreters and advocates.

Inclusion criteria

We included UK studies which reported the views and experiences of cancer services of people from minority ethnic groups. We excluded international studies, studies concerning the ethnic mix of the workforce, studies reporting only the views of service providers (rather than patients or their families) and studies about services other than cancer services. However, some studies which were not about cancer services were discussed, although not formally reviewed.
Study populations

The majority of studies were of South Asian patients and carers, that is, people from India, Pakistan and Bangladesh, who comprise about half of the total minority ethnic population of the UK (Census 2001). Together, study respondents represented a wide range of ethnic and language groups, although some minority groups, notably the Irish, the gypsy traveller population and recent migrants and asylum seekers, were not represented in most of the studies meeting our inclusion criteria.

Ethnic classifications

We report ethnic classifications as used by study authors, while recognizing the limitations of an uncritical reliance on crude ethnic classifications (see ‘Discussion’ section later).

The reviewed studies

The studies we reviewed are summarized in Table 1, ordered alphabetically by first author. We reviewed a total of 25 studies. [Some studies were reported in more than one paper.]

Nine studies focused on screening services (Hoare 1992; Botha et al. 1993; Hoare et al. 1994; Naish et al. 1994; Rudat 1994; Kernohan 1996; Box 1998; Chiu 1998; Bell et al. 1999; Chiu 1999; Chiu 2004; Pfeffer 2004). Eleven studies were of palliative care (Iqbal 1994; Hill & Penso 1995; Iqbal et al. 1995a,b; Spruyt 1999; Young et al. 2000; Koffman & Higginson 2001; Simmonds 2001; Sommerville 2001; Chattoo et al. 2002; Randhawa et al. 2003; Randhawa & Owens 2004), one was of clinical trials (Hussain-Gambles 2004a), three looked at information and support needs [Cancerlink 1999; National Cancer Alliance 2002; Muthu Kumar et al. 2004] and one was concerned with advocacy services [Fazil & Kai 2004].

The majority of reviewed studies involved interviews with people from minority ethnic groups [see Table 1]. One study used interviews as part of a randomized controlled trial [Hoare 1992, Hoare et al. 1994]

RESULTS

Available large-scale studies on service uptake have been quantitative, relying largely on secondary analysis of routinely collected data. They provide little insight into quality of care, or experiences of disparities in the quality of care received by different ethnic groups. The studies included in this review focus on the views and experiences of people from minority ethnic groups themselves. Their principal findings are summarized in Table 1, and the principal issues and challenges they highlight are considered as follows.

Comprehension and communication barriers

Many studies highlighted that some people, notably members of South Asian and Chinese groups, experienced comprehension and communication difficulties:

If you don’t know English then their [hospital staff’s] understanding is that you are completely mad. [A 60-year-old man of Pakistani origin, quoted in Chattoo et al. (2002), p. 42]

There are nurses in the other place [district general hospital] who do not speak my language and sometimes when I tried to express my feelings staff just smiled and backed away. You feel like you are deaf and dumb because people don’t respond to you and you cannot communicate. [South Asian patient, quoted in Clegg (2003), p. 283]

These communication difficulties were often exacerbated by a lack of appropriate translation and interpreting facilities, and advocacy schemes:

I sit there all day watching but I cannot ask for anything or express how I feel. I have to wait for my daughter to come so she could tell the nurse or doctor. There were no interpreters. I did not think you could ask for interpreters. I feel terrible that I could not speak to the nurses, so lonely. There are so many people there but for me, it was like being alone in a crowd. [Female Hindu patient, quoted in Vydelingum (2000), p. 104]

One gets tired by radiotherapy. Nobody explained to me in Gujarati what radiotherapy was. . . . They sent me a letter in English and I can’t understand the English language. . . . Nobody was with me to explain. [Female breast cancer patient, translated from Gujarati, quoted in National Cancer Alliance (2002), sec. 3.4]

In the absence of interpreters, patients frequently had to rely on family members. This raised a number of issues, such as the extent to which family members censor information, and the inappropriateness of using a child or other close relative to interpret:

Understanding about cancer is difficult when you speak English, but even more difficult when you
<table>
<thead>
<tr>
<th>Table 1. Reviewed studies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Author(s)/year</strong></td>
</tr>
<tr>
<td>Bell et al. (1999)</td>
</tr>
<tr>
<td>Botha et al. (1993)</td>
</tr>
<tr>
<td>Box (1998)</td>
</tr>
<tr>
<td>Cancerlink (1999)</td>
</tr>
<tr>
<td>Chattoo et al. (2002)</td>
</tr>
<tr>
<td>Chiu 1998, 1999 and 2004</td>
</tr>
<tr>
<td>Diver et al. (2003)</td>
</tr>
<tr>
<td>Fazil &amp; Kai (2004)</td>
</tr>
</tbody>
</table>
Table 1. Continued

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Aim, design, methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hill &amp; Penso</td>
<td>1995</td>
<td>To identify the reasons for low uptake of palliative care services by minority ethnic groups through interviews with staff (n = 110). No patient or carer interviews.</td>
<td>Black and Asian patients were said to prefer day-care facilities. Barriers to access were said by staff to include: fear of hospital, lack of knowledge and culture. There was also said to be a lack of appropriate accessible information in suitable languages. There were reported communication problems, and interpreting services were said to be inadequate. Black and Asian patients were said to prefer day-care facilities.</td>
</tr>
<tr>
<td>Hoare &amp; Hoare</td>
<td>1992</td>
<td>To assess, to develop and evaluate a health education strategy to encourage breast screening in Asian women.</td>
<td>Barriers to access were said by staff to include: fear and stigma of cancer, preventing people seeking services; a view of hospices as Christian, not religious, and lack of knowledge of available services. An RCT to investigate the effectiveness of linkworker visits on subsequent attendance for breast screening by Asian women. (145 Pakistani and Bangladeshi women in the intervention group, 251 Pakistani and Bangladeshi women in the control group). There was no difference in uptake between intervention and control groups (47% and 46% respectively). The authors suggested that contamination of the control group occurred, i.e., information about screening was spread from members of the intervention group to the controls.</td>
</tr>
<tr>
<td>Hoare et al.</td>
<td>1994</td>
<td>To explore South Asian patients' views and experiences of clinical trial participation through interviews with 15 South Asian patients who had participated in 6 trials.</td>
<td>South Asian women had the lowest levels of knowledge, and also showed the most significant improvement. Of South Asian women who had not participated, 28% reported a difference in attitude because of the sex of the doctor. Some women reported that attitudinal barriers, such as fear of cancer, were not deterrents. Women were enthusiastic about breast screening once the purpose and procedure were understood. Administrative and cultural barriers were also important. The Chinese, Bengali and Punjabi groups preferred a female doctor and to be accompanied by a female, English-speaking health advocate.</td>
</tr>
<tr>
<td>Hussain-Gambles</td>
<td>2004a</td>
<td>To assess access to, and appropriateness of, palliative care services, and identify barriers to increased uptake. Interviews with 15 patients and 18 carers (total n = 33) from White, Black Caribbean, South Asian, and Middle Eastern backgrounds.</td>
<td>Barriers were said to include: poor communication, lack of information in an appropriate language, and absence of information networks for BME groups.</td>
</tr>
<tr>
<td>Iqbal</td>
<td>1994</td>
<td>To assess the impact of a community health education strategy on breast and cervical screening uptake among Asian women.</td>
<td>Barriers were said to include: lack of information in an appropriate language, and absence of information networks for BME groups.</td>
</tr>
<tr>
<td>Iqbal et al.</td>
<td>1995a,b</td>
<td>To assess satisfaction of carers with services received by them and deceased patients they had cared for. Interviews with 50 Black Caribbean carers.</td>
<td>Negative satisfaction ratings of health care were recorded among a larger proportion of respondents representing Black Caribbean patients than White patients. Few Black Caribbean patients accessed specialist palliative care units or hospices.</td>
</tr>
<tr>
<td>Kernohan</td>
<td>1996</td>
<td>To provide information about breast and cervical screening to minority ethnic women through the development and evaluation of a health education strategy.</td>
<td>Barriers were said to include: fear and stigma of cancer, preventing people seeking services; a view of hospices as Christian, not religious, and lack of knowledge of available services. An RCT to investigate the effectiveness of linkworker visits on subsequent attendance for breast screening by Asian women. (145 Pakistani and Bangladeshi women in the intervention group, 251 Pakistani and Bangladeshi women in the control group). There was no difference in uptake between intervention and control groups (47% and 46% respectively). The authors suggested that contamination of the control group occurred, i.e., information about screening was spread from members of the intervention group to the controls.</td>
</tr>
<tr>
<td>Muthu Kumar et al.</td>
<td>2004</td>
<td>To find out the information needs of British Asian cancer patients and White British control patients. Interviews with 82 Asian patients and 220 White British control patients.</td>
<td>Barriers were said to include: lack of information in an appropriate language, and absence of information networks for BME groups.</td>
</tr>
<tr>
<td>Naish et al.</td>
<td>1994</td>
<td>To determine the factors that deter ethnic minority women from attending their GP for cervical screening. 11 focus groups, 33 patients and carers.</td>
<td>Barriers were said to include: lack of information in an appropriate language, and absence of information networks for BME groups.</td>
</tr>
<tr>
<td>National Cancer Alliance</td>
<td>2002</td>
<td>To find out the information needs of South Asian patients and carers about cancer. Focus groups and interviews with 33 patients and carers.</td>
<td>Barriers were said to include: lack of information in an appropriate language, and absence of information networks for BME groups. There was a demand for quality face-to-face communication.</td>
</tr>
</tbody>
</table>
Table 1. Continued

<table>
<thead>
<tr>
<th>Author(s)/year</th>
<th>Aim, design, methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pleffer (2004)</td>
<td>To explore women's assessment of their own risk of breast cancer, and their explanations for accepting or refusing an invitation to attend for mammography. 20 focus groups with speakers of English, Cantonese, Gujarati, Punjabi, Somali, Sylheti and Turkish.</td>
<td>Explanations of the causes of breast cancer ranged through smoking, drinking and dietary habits, to reproductive behaviour, and God's will. There was no neat 'fit' between on the one hand, the explanation of cancer offered and the assessment of self-risk, and on the other, ethnicity/language/religion. Women's explanations for accepting or refusing an invitation to attend for mammography could not be 'read off' from their ethnicity/language/religion or from their beliefs about the causes of cancer.</td>
</tr>
<tr>
<td>Randhawa &amp; Owens (2004)</td>
<td>To explore perceptions of cancer and cancer services. Focus groups with 48 people from South Asian groups.</td>
<td>Almost all had some knowledge of cancer and its causes, but awareness of specialist local cancer services was low.</td>
</tr>
<tr>
<td>Randhawa et al. (2003)</td>
<td>To explore the experiences of palliative care of South Asians through interviews with 12 South Asian patients and carers [5 families].</td>
<td>Communication was a problem for some. Many felt that not enough palliative care staff were recruited from 'their community'. Respondents were only partially aware of the services available to them.</td>
</tr>
<tr>
<td>Rudat (1994)</td>
<td>To explore the extent to which different groups have used cancer screening services. Interviews with African-Caribbean (n = 432), Indian (n = 527), Pakistani (n = 471) and Bangladeshi (n = 350) women.</td>
<td>Those who stated they did not know what a smear test was constituted, 1% of African-Caribbeans, 13% of Indians, 15% of Pakistanis and 34% of Bangladeshis.</td>
</tr>
<tr>
<td>Simmonds (2001)</td>
<td>To explore palliative care issues with members of Black and minority ethnic communities. 12 semi-focused interviews with professionals, users, non-users and 'key members' of minority ethnic groups; 6 focus groups.</td>
<td>Patients from minority ethnic groups were three times less likely to be aware of the existence of the Hospice. Once they know of the Hospice's existence, many older Asian women desired to see the Hospice for themselves. Strong beliefs were expressed about caring for the sick by the family. It was recognized that younger generations were moving away from traditional caring practices. There were anxieties about food preparation. Fears were expressed that people from BME groups might feel vulnerable and out of place in a hospice setting, and that other patients and staff might be racist.</td>
</tr>
<tr>
<td>Sommerville (2001)</td>
<td>To explore the experiences of carers of deceased cancer patients from the Bangladeshi community. Interviews with 7 carers from 5 families.</td>
<td>Responsibility, duty and love were motivations for caring, but were also cited as reasons to decline hospice services. Participants were uncomplaining about the level of help they received, but the researcher felt some were needy of professional support. Not all had the support of family or friends. Participants gained most professional support from district nurses and the Community Palliative Care Team. However, there was minimal contact with the GP and a lack of childcare provision for those with large families. Carers experienced communication barriers, isolation and anxieties regarding wider problems related to visas and housing.</td>
</tr>
<tr>
<td>Spruyt (1999)</td>
<td>To describe the palliative care experience of Bangladeshi patients and carers. Interviews carried out in Sylheti with bereaved primary carers of 18 Bangladeshi patients.</td>
<td>Communication difficulties were common. Patients' fluency in English was low. There was a lack of bereavement follow-up.</td>
</tr>
<tr>
<td>Young et al. (2000)</td>
<td>To assess the accessibility and acceptability of palliative care services among BME groups. Three focus groups with members of the BME community. Interviews with a further 27 patients/carers and service providers.</td>
<td>There was a lack of information for BME communities about palliative care. Communication barriers were evident. There were difficulties accessing professional interpreters. Cultural and religious factors hindered access.</td>
</tr>
</tbody>
</table>

BME, black and minority ethnic; GP, general practitioner; RCT, randomized controlled trial.
don't, and a member of your family has to act as an interpreter. You don't really know whether they are telling you what you need to know or what they think you should know. [Member of a breast cancer self-help group for Asian women, quoted in Cancer Support Centre (2000), p. 19]

I have two sons, their wives, eight nephews and a neighbour's daughter who interpreted for me on many occasions. Now I can realise that on many occasions, whatever the palliative care team said, it was not translated to me at all. [Carer of Bangladeshi patient, quoted in Spruyt (1999), p. 122]

It is difficult to talk frankly about details of your bodily function through an interpreter, especially if it is a male member of your family. [Member of a breast cancer self-help group for Asian women, quoted in Cancer Support Centre (2000), p. 19]

I went there for a check-up. I was not told anything, but my daughter, who accompanied me, was told by the doctor 'Your mummy has cancer. Do you want her to be informed?' My daughter replied in the affirmative, and then the doctor came to me. [Female breast cancer patient quoted in National Cancer Alliance (2002), sec. 4.2]

Some studies suggested that written materials in their own language were appreciated by those whose preferred written language was not English. Other studies suggested that the provision of written information in appropriate languages was effective in increasing knowledge or uptake of services, although the evidence of small-scale, qualitative studies cannot be viewed as conclusive (Botha et al. 1993; Iqbal 1994; Hill & Penso 1995; Iqbal et al. 1995a,b; Kernohan 1996; Box 1998; Chiu 1998; Bell et al. 1999; Young et al. 2000; National Cancer Alliance 2002; Muthu Kumar et al. 2004; Randhawa & Owens 2004). It was noted that not all spoken languages are written and not everyone can read a language they speak [Iqbal 1994, Iqbal et al. 1995a,b; Box 1998]:

The leaflets, I cannot read English, I cannot read at all. I have to tell someone else to read this one for me. They might explain it properly or not. [Male bowel cancer patient, quoted in National Cancer Alliance (2002), sec. 4.3]

Several studies suggested that face-to-face communication, rather than written information, was preferred by patients and carers [Box 1998; National Cancer Alliance 2002; Muthu Kumar et al. 2004].

I would want to be told about the [cervical screening] test in my own language. ['Woman', quoted in Box (1998), p. 8]

Hence, poor communication appeared to be central and was often implicated in poor experiences of care (Iqbal 1994; Hill & Penso 1995; Iqbal et al. 1995a,b; Kernohan 1996; Spruyt 1999; Young et al. 2000; Chiu et al. 2002; National Cancer Alliance 2002; Randhawa et al. 2003; Chiu 2004; Fazil & Kai 2004, Hussain-Gambles 2004a).

Lack of awareness of services

Studies of palliative care highlighted significant gaps in the knowledge of some minority ethnic groups of local services (Iqbal 1994; Hill & Penso 1995; Iqbal et al. 1995a,b; Cancerlink 1999; Koffman & Higginson 2001; Simmonds 2001; Randhawa et al. 2003; Randhawa & Owens 2004). Some study respondents did not know of the existence of hospices (Simmonds 2001; Chiu et al. 2002; Randhawa & Owens 2004), and others did not know the meaning of terms such as 'hospice' and 'palliative care' (Randhawa & Owens 2004).

There don't seem to be many [South Asian patients] attending there [local hospice] and I've just spoken to one and she's got no idea what it's about, that's why she wouldn't go. But when we actually got her to go, she starting attending and she really likes it . . . . I don't think they realise that the service is available and the fact of what it does. [Health professional, quoted in Randhawa & Owens (2004), p. 66]

A lack of understanding of the concept of screening and a lack of awareness of screening services were also reported (Hoare 1992; Kernohan 1996; Box 1998). However, as with palliative care services, some respondents expressed a desire to learn about screening services:

Contrary to . . . assumptions . . . minority ethnic women were keen to receive information about the purpose and the procedure of the smear test. [Chiu 1999, p. 18]

US studies of clinical trials suggest that members of minority ethnic groups may be unaware of the existence of trials (Roberson 1994; Harris et al. 1996; Shavers-Hornaday et al. 1997). We were unable to ascertain whether this was also the case in this country, since there is very little UK literature on this topic (Mason et al. 2003; Hussain-Gambles 2004a,b).
Lack of cultural competence from providers

Several studies highlighted that people do not always feel that provision is made for religious or dietary needs, or other needs surrounding death and bereavement [Iqbal 1994; Hill & Penso 1995; Iqbal et al. 1995a,b; Young et al. 2000; Simmonds 2001]:

I think generally, nurses did not seem to know about our religion or culture. Nobody asked much about any specific religious needs. They knew I was a Muslim as they asked me that when I first came on the ward. That was the end of that. I think they just ask because they have to fill in the forms. [Male Muslim patient, quoted in Vydelingum (2000)]

We had the family praying by her side in hospital. The doctors were very insensitive to this. [Black Caribbean family member, quoted in Koffman & Higginson (2001), p. 343]

I had a bad experience in the hospital. I stayed with my husband there and I wanted to do religious duties in the hospital but, because of the doctors and nurses, I was not able to do the necessary things I had to do. [Carer of Bangladeshi patient, quoted in Spruyt (1999), p. 125]

However, there were examples in the literature which suggest that staff made efforts to cater for specific needs:

My wife was in the hospital. The nurse used to come to my wife and tell her, ‘Now is your prayer time’. They facilitated everything for her and I am very happy with them and I can trust them. [Carer of Bangladeshi patient, quoted in Spruyt (1999), p. 125]

A number of studies drew attention to the inappropriateness of male professionals delivering services:

There’s purdah at home. You talk about culture, let me tell you about culture. It’s embarrassing to be in front of a strange man. [Sylheti speaker, quoted in Pfeffer (2004), p. 15]

The following female client of an advocacy service was unhappy with her male advocate, and would have preferred a woman:

. . . If I get a lady advocate then that would be great because then I can openly say things that I want. With a man you can get shy and think, ‘I mustn’t say this, it might not be appropriate to say’. [Female client of advocacy service, quoted in Fazil and Kai (2004), p. 27, box 10]

A few studies highlighted a perception by respondents of racist attitudes on the part of service-providers [Iqbal 1994; Iqbal et al. 1995a,b; Simmonds 2001; Chiu 2004].

After all I am a human being and I felt that they were insulting me. [Elderly patient of Indian origin, quoted in Chattoo et al. (2002)]

They wouldn’t have said all those things if I had been white. [Female patient, quoted in Iqbal et al. (1995b)]

Health beliefs

Fear and stigma associated with cancer were said to prevent some minority ethnic patients from accessing services. Some from minority ethnic groups believed cancer to be a punishment from God, others associated it with promiscuity and others thought it was contagious [Naish et al. 1994; Hill & Penso 1995; Box 1998; Cancerlink 1999].

I questioned whether I had done something wrong to Allah. Why is He punishing me like this? . . . [Carer of Bangladeshi patient, quoted in Spruyt (1999), p. 124]

Cancer, yes it happens here, but not to us . . . we stay with our men. [‘Woman’, quoted in Box (1998), p. 7]

. . . The cancer might be there [in the clinic] . . . you never know . . . they need to cover it with water, wash it all away . . . I’ve never seen them do that. [‘Woman’, quoted in Box (1998), p. 9]

Diversity of views and experiences

The issues and challenges for minority ethnic groups described above were not shared by every member of every minority ethnic group. Chattoo et al.’s (2002) work, in particular, highlights that other factors were often more important in shaping experiences than ethnicity:

We observed more variations within each group than between groups, pointing to the significance of biographical features of gender, age, family history and class. [Chattoo et al. 2002, p. 11]

Similarly, Pfeffer (2004) found no neat fit between respondents’ views and their ethnicity, language or religion.
Our own findings suggested a great deal of variation within ethnic groups. For example, many of the communication problems encountered by those who did not share a common language with providers were not an issue for those from ethnic minorities whose first language was English (Chattoo et al. 2002; National Cancer Alliance 2002). Some members of minority ethnic groups had a good understanding of screening services (Chiu 1999), and there were reports of satisfactory experiences of services, which suggested that health providers’ attempts to deliver culturally sensitive services had had some success [Spruyt 1999; Koffman & Higginson 2001; Chattoo et al. 2002].

There were also many similarities between minority and majority ethnic groups. For example, Hussain-Gambles (2004a) suggested that the motivations of his South Asian respondents to participate in clinical trials were similar to those of the White majority population. Similarly, in studies of information needs, a desire of ‘not to know’ was found, particularly in older respondents, among members of both minority and White majority ethnic groups, as was a failure to disclose information to family members (Chattoo et al. 2002; National Cancer Alliance 2002; Muthu Kumar et al. 2004).

LIMITATIONS OF THE REVIEW AND METHODOLOGICAL CONSIDERATIONS

Our review was not exhaustive of every ethnic group. Much of the literature is about South Asian groups, and this is reflected in our review.

It should be recognized that a focus on the views of people from minority ethnic groups can falsely create the appearance of ‘issues’ for particular ethnic groups when often there are similar issues and challenges for people from all ethnic groups. Moreover, by selectively reporting key findings it is easy to give the impression that a particular experience is common to an entire ethnic group, when in fact there is considerable variation between and within every ethnic group. The majority of the studies we reviewed did not include respondents from White majority groups, making it difficult for us to compare majority and minority ethnic groups. The aim of most studies was to report problems and issues for particular groups, making it difficult for us to know how common or widespread such problems were within these groups.

DISCUSSION

Similarity and difference

In attempting to define ethnicity, some early theorists used fixed or categorical definitions. For example, Thoe-

rnstrom et al. (1980) listed 14 characteristics of ethnic groups, including common geographical origins, migratory status, language, religion, values and food. More recently, it is increasingly argued that cultural or ethnic ‘attributes’ are not fixed or immutable, that ethnic groups are not homogeneous, and that a person’s identity or behaviour cannot be simply inferred from their ethnic origins. Modood, for example, notes:

[Many are critical of the assumptions that] cultures are discrete, frozen in time, impervious to external influences, homogeneous and without internal dissent; [and] that people of certain family, ethnic or geographical origins are always to be defined by them and indeed are supposed to be behaviourally determined by them. (Modood 1998, p. 378)

We would concur that the concept of a homogenous ethnic group, with a shared identity or shared experiences, does not accord with the reality of far greater diversity and complexity. As Chattoo et al.’s (2002) study concludes:

South Asian participants’ . . . identities and experiences are not determined solely by some notion of a static and stale ‘culture’ or ‘ethnicity’ . . . . The findings show both similarities and differences between participants’ experiences, where social class, gender or other aspects of personal biography can be every bit as important as religion, culture or country of origin . . . . These findings demonstrate the connectedness of human experience across, and diversity within, ethnic, religious and social groups. (Chattoo et al. 2002, p. 54)

Several of the studies we reviewed pointed to the danger of reducing people from minority ethnic groups to the status of a representative of an ‘ethnic category’ (Young et al. 2000; Chattoo et al. 2002; Chiu 2004; Pfeffer 2004). On the basis of the findings of their study of palliative care, Young et al. caution against generalizing from a patient’s ethnicity, stressing the fundamental principle of palliative care of treating each person and family as unique, irrespective of their ethnicity:

What is important is that the uniqueness of every family and situation is appreciated. Each palliative patient merits an individually tailored approach to care and assumptions must not be made about needs based crudely on ethnicity or religion. Individual histories, personalities and choices make generalization unacceptable. [Young et al. 2000]

Some studies further disputed the assumption that those from minority ethnic groups have different needs.
to ‘everyone else’ [Kai 2003a]. One of our reviewed studies in particular stressed the universality of health needs [Diver et al. 2003]. Two further studies [which were discussed but not formally included in the studies we reviewed] emphasized that the needs of all patients for humane treatment, respect, dignity, to understand and be understood, are universal human needs which are not confined to particular ethnic groups [Vydelingum 2000; Clegg 2003]. Hence, attempts to improve quality of care for minority ethnic groups should involve recognition that meeting the language, cultural and religious needs of patients is a means of meeting more universal human needs which all patient share, irrespective of their ethnicity.

Beliefs about cancer

The notion that fears and misconceptions about cancer affect uptake and experiences of services is widespread [Lodge 2001]. However, as Pfeffer [2004] points out, an analysis which focuses only on the cultural or religious beliefs of a particular minority ethnic group may exaggerate differences between ethnic groups, or fail to identify similar beliefs between minority and majority ethnic groups. It appeared, from the small number of studies we reviewed that contained both White majority and minority ethnic groups in their samples (see Table 1), that many beliefs were shared across ethnic groups, for example that cancer is a death sentence:

Cancer still has connotation of death, not only in the Asian community, but most communities. [Female breast cancer patient, quoted in National Cancer Alliance [2002], sec. 3.1]

Pfeffer [2004] cites a study of White groups by Bahl which found that a third of respondents believed that cancer was either inherited, due to punishment for not taking care of family members, loose living or contagion [Pfeffer 2004]. Similar findings were reported among minority ethnic groups in Box’s [1998] study of cervical screening. Hence, although fears and misconceptions about cancer may provide some of the explanation for lower uptake of some cancer services, lack of knowledge and elements of guilt or taboo appear to be in evidence among all ethnic groups.

Myths about low service utilization

Ebrahim [1996] has questioned the belief that ‘No use of services equals no need for services’. Our findings contradict this belief, identifying lack of awareness, or the inappropriateness of services rather than lack of need, as the main reasons for low use of some services. Simmonds’ [2001] and Randhawa & Owens’ [2004] studies of palliative care showed that once South Asian women had been told about hospices and had been shown around the local hospice, they were enthusiastic about the service. Other studies drew attention to the inappropriateness of a screening service providing no female doctors to Muslim women [Naish et al. 1994], or an advocacy service providing advocates of a different ethnicity and gender to clients (Fazil & Kai 2004).

Some commentators have cited extended family care, the notion that ‘they look after their own’, as a reason why some minorities, notably South Asian groups, do not use palliative care services [Ebrahim 1996]. Although it was noteworthy that some study participants expressed strong feelings about family obligations [Simmonds 2001; Sommerville 2001; Chattoo et al. 2002], the studies we reviewed suggested that the lack of knowledge about services, or the inappropriateness of the services offered, rather than the lack of needs for a professional input was key to explaining poor uptake.

There is widespread reference in the literature to minority ethnic communities [our italics]. This constant reference to communities may have helped to foster the myth that ‘they look after their own’. ‘Community’ is a notoriously overworked term, conjuring up a picture of a close network of relatives and friends. As Chattoo et al. note, while some members of minority ethnic groups are part of a ‘community’ in this sense, others are not (Chattoo et al. 2002; Jewson et al. 2003; Kathamna et al. 2004). Deepak’s case history of a Vietnamese patient, who lived in ‘lonely isolated conditions’, and whose ‘family and children did not want to know him’, illustrates graphically that a close community of family or friends cannot be taken for granted (Deepak 2004, chap. 3, case history 2). There is increasing evidence that, as with other populations, older people from minority groups may lack social support networks. Some Chinese elders, for example, are distanced from their children and grandchildren, with many lacking even contact details for their offspring [Kam Yu 2000]. Similarly, many African-Caribbean elderly people are on their own, with no ‘community’ to support them (Blakemore 2000). Such findings make clear that not all members of minority ethnic groups are members of a close-knit community which is able or willing to ‘look after their own’.

Finally, people from minority ethnic groups are often described as ‘hard to reach’. The ‘hard to reach’ stereotype has been challenged by Gay, who argues that to subscribe
to this notion is to place blame on people from minority ethnic groups themselves for being inaccessible (Gay 2005). As Gay, and Campbell and McLean have argued, there needs to be an appreciation of the circumstances and perspective of users or patients, an understanding of why they might find it difficult, or be reluctant, to be reached. This should replace blaming minority ethnic groups for being ‘hard to reach’, and may reflect shortcomings in the way in which information and services are delivered to them (Campbell & McLean 2002, 2003).

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

This review found that some people from minority ethnic groups felt there was a poor understanding of their needs, some lacked information, and some were unaware of the support available to them. A number of factors appeared to increase the likelihood of experiencing a poorer service. These included the low socio-economic status of a high proportion of people from minority ethnic groups, in particular those of Pakastani and Bangladeshi origin, a limited command of the English language of some older members of some minority groups, and the apparent failure of some service provision to accommodate religious and cultural diversity.

Such findings underscore growing recognition that minority ethnic groups are experiencing institutional, or unwitting, racism in the NHS (Macpherson Report 1999, Molassiotis 2004). That is to say that much discrimination faced by minority ethnic groups arises from practices that may not be deliberately racist in their intent but are racist in their effect (Acheson 1998, McKenzie 1999). Although direct or overt racism was identified as a problem in some studies, the greatest challenges appeared to result from institutional racism, from a failure of the NHS to respond adequately to the information, language, religious and other cultural needs of people from minority ethnic groups. Much good work has been carried out in this country to develop initiatives to better respond to the needs of minority groups (Deepak 2004). However, this review suggests that such initiatives represent pockets of good practice rather than being embedded throughout services and their organization (Hancock 1999).

Our review has implications for education, practice and research. We suggest that the traditional focus in health professional education upon the cultural attributes of different ethnic groups is misguided. Although this may help health workers to become more sensitive to cultural differences, a reliance on checklists or ‘fact-files’ of ethnic attributes can encourage the very stereotyping and token-ism they are designed to combat. There needs to be a move away from ‘formulaic models’ (Pfeffer 2004) which fail to predict health behaviour and attitudes, and which can militate against individualized patient care. Instead, practitioners should be empowered to respond to individuals, and develop a generic approach using principles of good practice for all patients, for example, facilitating access to care, achieving effective communication, and developing sensitivity to stereotyping and racism. (Kai et al. 1999, 2001; Cortis 2003; Kai 2003b, 2005).

For research, Pfeffer and others urge a move away from a focus on static categories, such as ‘ethnic group’ or ‘Muslim’, towards a study of dynamic social processes (Gunaratnam 1997, 2001; Chiu 2004; Pfeffer 2004). It remains a priority for cancer services to seek ways to understand the views, experiences and expectations of people who feel their needs are not adequately met. Direct methods of user involvement to listen to, and act upon, users’ experiences must be prioritized.

ACKNOWLEDGEMENT

This literature review was supported by a grant from Macmillan Cancer Relief.

REFERENCES


Hussain-Gambles M. (2004b) Why ethnic minority groups are under-represented in clinical trials: a review of the literature. Health Social Care in the Community 12, 382–388.

Iqbal H. (1994) Palliative Care Service Use by Black and Minority Ethnic Groups in Leicester. Leicestershire Health Authority, Leicester, UK.


