

Barriers to effective uptake of cancer screening among black and minority ethnic groups

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Abstract

Aim To describe some of the factors that act as barriers to effective uptake of breast and cervical cancer screening services among black minority ethnic (BME) groups living in Brent and Harrow in the UK.

Design A series of focus groups among African Caribbean, African, Gujarati, Pakistani, Greek and Arabic groups were held to discover their perceptions of cancer screening, the barriers to effective uptake and some strategies for intervention.

Sample This consisted of 135 participants: 85 women and 50 men.

Results Analysis of focus group data has revealed poor knowledge, underlying health and cultural beliefs, attitudes, language and unhelpful attitudes of health professionals to be important barriers. In terms of strategies for effective intervention, the most popular strategy for improving uptake of screening services was community-based cancer awareness education that is sensitive to religious and cultural needs.

Conclusion There is a need to provide community-based education to increase the uptake of screening services among BME groups. It is essential to plan concurrently to educate GPs and other health professionals in cultural beliefs and customs, language needs, racial awareness and communication skills.

the epidemiology, prevalence and service provision relate to 2001 when the study was undertaken.

During the time of the study, cancer was the most important cause of death after coronary heart disease for the whole population in Brent and Harrow. However, because of lack of ethnic data, it had been virtually impossible to get aggregated data for the BME communities component of the deaths, despite the fact that ethnicity coding for hospital episode statistics was introduced nationwide in 1995.

Attention was focused rightly on uptake of cancer screening which appeared to be low: breast screening was 58.3% while cervical screening had an uptake of 78.3% (Northwest London Hospital Strategic Health Authority, 2002). It was suggested that this could, in part, be explained by the ethnic mix within the area and strategies for reaching this group were being explored. In addition, there was some anecdotal evidence from clinicians of late presentation of cancer among BME groups. It is against this background that the question of perception of cancer and potential barriers to cancer screening was sought to be addressed.

Brent and Harrow Health Authority's Health Action Zone (HAZ), which was set up to tackle inequalities, agreed to fund this community-based research. This research was aimed at discovering the reasons for poor uptake of such services by BME groups in Brent and Harrow.

Breast and cervical cancer screening services

In the UK, breast screening using mammograms is offered free to women aged between 50 and 64 years every 3 years. In the USA, guidelines recommend that women aged between 40 and 49 years are screened every 1–2 years, and annually if over 50 years (Acheson, 1998). The age

Cancer-related deaths are common and are on the increase among all groups in developed and developing countries (Acheson, 1998). Epidemiological data points to considerable ethnic differences in mortality from different cancer sites. For example, cancer of the oral cavity, pharynx, liver and gall bladder appear to be higher among those born in the Indian subcontinent, whereas cancer of the cervix, breast and prostate, stomach and liver are high among African Caribbeans (Bhopal and Rankin, 1996).

Brent and Harrow covers boundaries between northwest London and Middlesex in the UK. There is an ethnically diverse population with over 53% from black and minority ethnic (BME) communities in Brent and 38% in Harrow. There are also an estimated 16 000 refugees within the boroughs (Northwest London Hospital Strategic Health Authority, 2002). Data on

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of screening for cervical cancer in the UK is between 20 and 65 years, undertaken at 3 yearly intervals. Women over 65 years are discharged from the recall system if they have had two consecutive negative smear tests in the previous 10 years.

Utilization of cancer screening services among BME groups

Research suggests that there is a lower uptake of cancer screening among BME groups. For example, studies on cervical and breast screening have shown that there have been low rates of uptake in the inner cities among BME groups and lower socio-economic groups (Pilgrim et al, 1993; Hoare, 1996).

There are also inter-ethnic differences in the extent to which BME groups display preventative health behaviours. For example, Baxter (1989) found that, on the whole, African-Caribbean women were more likely to have had cervical smears on their own initiative. They also showed a clearer understanding and were more knowledgeable about breast self-examination and cervical smears.

The systematic review on screening carried out by Jepson et al (2000), considered participants' race or ethnic origin as a predictor of screening uptake in 15 studies with only five of these studies identifying it as a significant predictor of breast screening (Skinner et al, 1994; Sutton et al, 1994; Janz et al, 1997; Margolis et al, 1998; Rimer, 1999). However, the overall conclusion of the review was that the majority of studies did not find a significant association between the uptake of mammograms and ethnicity (Jepson et al, 2000).

Most of this research was conducted in USA and, therefore, it is unclear what

contribution they can make to the present study. What is clear, is that BME groups in Brent and Harrow differ greatly in many ways including cultural attitudes, beliefs and ideas on health care. These differences are under-explored and have yet to be explained. In this research, Baron and Byrne's (1984) definition of attitudes has been used. They define attitudes as relatively lasting clusters of feelings, beliefs, and behaviour tendencies directed towards specific persons, ideas, objects or groups.

In addition to ethnic background, the beliefs, attitudes and knowledge significantly affect how people cope with illness, as well as their health-seeking and health-promotional behaviour (Thomas, 1997; Thomas et al, 2000). This, in turn, influences their ability to access and use health services effectively (Parsons, 1990).

Scanlink, a Department of Health (DH) funded project, undertook a year long community health awareness initiative on breast and cervical screening among BME women in Watford and Newham (Scanlink, 1998a,b). These reports are especially useful in informing the present study about the potential cultural and attitudinal barriers, because the ethnic profile of the communities is similar to that of Brent and Harrow. The women in the Scanlink projects were South Asian, Muslim, Somali refugees and Turkish.

For these BME groups, there was a strong association between cancer and death and this fatalistic attitude considered cancer to mean 'certain death', to be always painful and impossible to treat. In addition, the Scanlink projects identified religious beliefs, language barriers, lack of knowledge, illiteracy and preference for traditional remedies to be large obstacles to the uptake of cancer-screening services (Scanlink, 1998a,b).

Conceptual psychological model informing the research

The Health Belief Model (Rosenstock, 1974) has been the model in health psychology applied most widely. It suggests that an individual's decision to take up cancer screening is determined by a number of psychological factors listed in *Table 1*.

The factors listed in *Table 1* combine to influence a person's view of the threat associated with cancer. In addition, people need cues to put into action, such as health promotion advice, mass-media campaigns, and screening invitation letters. However, the actual likelihood of a person taking up screening depends on

Table 1. The psychological factors that determine an individual's decision to take up cancer screening

The individual's perception of his/her own susceptibility to a particular illness
His/her perception of the severity of the condition
These variables are influenced by three modifying factors:
Demographic characteristics, like age, race and ethnicity and gender
Psychosocial variables such as social class, personality, social pressure
Structure variables such as knowledge and prior contact

Source: Rosenstock (1974)

Table 2. Research objectives

- To determine African Caribbean, African, Gujarati, Pakistani, Greek and Arabic Muslim refugee groups' understanding and perception of cancer and their knowledge of their own susceptibility to particular cancers
- To ascertain these groups' knowledge of the existence of breast, cervical and prostate cancer-screening services
- To describe the factors that act as barriers to the uptake of such services
- To establish what kind of intervention would be acceptable, appropriate and desired by these groups
- To determine healthcare professionals perceptions of the barriers, for black and minority ethnic (BME) groups for whom they care

the perceived benefits minus the perceived costs (Rosenstock, 1974).

Therefore, an individual is likely to take up screening if: he/she is motivated highly about his/her health; believes he/she is susceptible to develop cancer; understands the seriousness of getting cancer; and believes the benefits of the taking time off work to take up screening far outweigh the cost of lost pay. These conditions need to be triggered by an internal (physical symptom) or external (health screening letter) cue to action.

Method

The scope of the study was designed to describe some of the factors that act as barriers to effective uptake of breast and cervical cancer screening services among BME groups in Brent and Harrow. Thus, this study was exploratory in nature and consequently did not lend itself to hypothesis testing but the research objectives identified can be seen in *Table 2*.

The Brent and Harrow medical ethics committee granted approval for the study.

Focus group methodology

The qualitative method chosen for this study was focus groups, which was considered to be the most appropriate method to explore the attitudes and experiences of the BME groups. Focus groups are organized discussion groups where data is generated through interaction and anecdotes. They are especially useful in situations where there is little documented data on BME groups' attitudes and beliefs about cancer and where interaction is linked to storytelling (Kitzinger, 1995; Powell and Single, 1996).

Focus groups have been the prime method utilized in the development of the quality-of-life measure WHOQOL-

100 (World Health Organization Quality of Life (WHOQOL) Group, 1994). Two psychologists facilitated the focus groups.

The role of facilitator

The focus group facilitator had a prime responsibility in terms of: providing clear explanations of the purpose of the group; helping people feel at ease; and facilitating interaction between group members. With regard to promoting debate and discussions, the facilitators asked open questions influenced largely by the individual's perception of his/her own susceptibility to cancer and his/her perception of the severity of the condition as outlined in the health belief model (see *Table 1*). During the discussions, the facilitators asked clarifying questions especially to draw out people's differences, and tease out the diversity in range of meanings about cancer.

The focus groups were conducted:

- In the community between June and October 2001
- Among the professionals between May and July 2001 (this paper does not include the data gleaned from their perspective which is being prepared for a separate analysis and report).

The participants ($n=135$) in the community were aged 20–75 years and were recruited through community centres, GP practices, Brent African Association, Brent and Harrow Refugee Organization, Brent and HAZ and voluntary cancer agencies such as Cancer Black Care and Cancer Voices. They were informed that the researchers wanted to learn their views about cancer services in order that improvements could be made. The groups were asked to speak from their personal experience and their knowledge of others in the family and community. Barbour and Kitzinger (1999) highlight the importance of context, in terms of physical environment, ownership of space, the research relationship and the impact on the type of data generated.

A South Asian bilingual health advocate (fluent in Gujarati, Punjabi and Hindi) explained the nature of the study to Gujarati, Punjabi and Hindi speaking participants. The focus groups varied from 45 to 90 minutes and were conducted after 6pm and on Saturday to accommodate people's working commitments. A few telephone interviews were also conducted with individuals who were unable to attend a focus group.

The 85 women and 50 men recruited belonged to the ethnic groups listed in *Table 3*.

Data analysis

The majority of focus group discussions were tape recorded and the content was transcribed verbatim. Verbatim written records were kept of focus groups that were not tape recorded.

Content analysis was used to search for patterred regularities in the transcribed data (Polkinghorne, 1991). The verbatim transcripts were read and reread by the researchers and two other people in order to gain overall understanding of the themes arising from the patients' accounts and to group them under a number of themes.

A phenomenological approach was used to guide analysis with the objective of looking for 'perceived meaning' behind reports rather than 'objective reality'. In identifying themes, a coding method based on frequency of ideas was used to organize the content into a number of areas (manifest coding). The researchers then utilized information from the background literature to narrow down and refine the themes.

It is recognized that religious beliefs in themselves can influence attitudes but it was difficult to disentangle the affects of religion and culture.

Descriptions are intended to reflect participants' explanations of theirs and others' experience at the time of the focus groups in the form of descriptive themes and verbatim quotes. For simplicity, the results will be presented as a summarized account under the headings of key findings, using illustrative individual quotes.

Discussion

The discussion of the results will be structured around BME communities' responses to the following areas:

- Knowledge of cancers and those that are common in specific BME groups
- Cultural beliefs and attitude to cancer

- Accessing cancer-screening services
- Factors that act as barriers
- Suggestions for improvement.

Knowledge of cancers common in specific BME groups

All of the participants were aware that 'cancer' is a serious illness and most people identified it as a major cause of death; however, few were knowledgeable about common cancers that occurred in their own ethnic communities. The exception was the West African group who identified accurately liver, breast, cervical and prostate cancers as commonly occurring within their community. With regard to the causes of cancer, considerable numbers identified some well-known carcinogenic factors that included genetics, chemicals, radiation and diet. In general, the female participants were more knowledgeable about cancer and screening services, possibly because national cancer screening services target women.

A worrying feature was that the youngest members of the African Caribbean community (18–20 years) were the least knowledgeable about cancer. This reflects perhaps their perceived sense of lack of susceptibility since they considered cancer to be a disease of older people. Those who reported on the source of their cancer knowledge, identified the television, radio and leaflets and posters acquired from GP surgeries as important sources. However, it is likely that these sources of information might have raised more questions than answers, since a significant proportion of the researchers' time was used to provide education about cancer, indicating a clear need.

Many of the participants required explanations about when and how to undertake breast self-examination, the cancers that commonly occur in specific ethnic groups, eligibility and interval for breast, cervical and prostate screening as well as information about new treatment strategies.

Cultural beliefs and attitudes to cancer

All of the BME groups associated cancer with certain death and felt it was not talked about within their communities. There was a superstition that talking about it would enhance its malevolent power:

'...most African people don't like to talk about...that they have got cancer. They just see it as a taboo, in fact, I know a lot of people who do not even mention the word cancer. Before I had

Table 3. Ethnic groups of the participants

Ethnic group	Female	Male
Indian (Gujarati speakers) n=26	14	12
Pakistani Urdu speakers (Muslim) n=16	12	4
Blind Asian group (largely from Indian subcontinent) n=9	5	4
West African n=22	12	10
African Caribbean n=26	18	8
Arabic (Muslim) n=14	8	8
Greek n=20	16	4

'...although approximately one-third of the sample fell within the age range eligible for breast screening, only three females reported actually going for breast screening at regular intervals.'

cancer I wouldn't mention the word, I would just say that "c" thing...'

Some cancers were seen to be more taboo than others as implied in the following quote: 'If it's cancer of the cervix or the uterus it makes it even worse, that is really taboo, nobody wants to talk about it.'

A similar cultural finding was revealed in the Scanlink projects carried out in Newham and Watford (Scanlink, 1998a,b) where South Asian women considered cervical cancer to be caused by promiscuity and was, therefore, considered 'a just punishment from God'.

Box (1984) found that this is not too distinct from the views of the white Caucasian population. In Box's study a significant proportion of the respondents believed cancer to be owing to punishment for wrong doings, loose morals and contagion. Sontag (1989) pointed out that cancer in the modern Western world is often viewed as a disease brought upon oneself through irresponsibility, either by indulging in bad diets, smoking or by suppressing negative thoughts.

Accessing the screening services

The knowledge and uptake of screening services, in general, appeared to be poor across all of the groups. However, Africans, African Caribbean, Gujarati Asians and Greeks seemed to use cervical screening more regularly although there seemed to be a lack of understanding about the recommended frequency for the tests.

Some of the women apparently had not received screening letters and others reported that they would not have the screening procedure repeated because of previous negative experiences.

Other women stated that they did not like to assume responsibility for finding out the cervical screening results and the process was made worse by delays in getting results. The experience of waiting for results was seen to be stressful as this might imply an unfavourable cancerous outcome. Another difficult barrier identified was the possibility that the identification of inconclusive abnormal cells would necessarily lead to further cervical smears. These past experiences influenced their willingness to attend.

Interestingly, although approximately one-third of the sample fell within the age range eligible for breast screening, only three females reported actually going for breast screening at regular intervals.

This is unlikely to be a reflection of shyness, since people spoke freely

about cervical screening. It may, however, be related to views of life-cycle needs. For example, some of the Caribbean, Gujarati and both Arabic and Pakistani Muslim women in the mid-fifty age range stated that screening was important only for younger women. Owing to lack of opportunity to explore reasons more deeply, it is likely that this may be related to the women's own view that the 'sexual part' of their life was over (Scanlink, 1998a,b). It may also be related to cervical and breast screening age limits. BME women might interpret these age limits to mean that they were no longer at risk.

The Asian blind participants reported never having had any form of cancer screening. The bilingual facilitator working with this group suggested that it may be owing to their reliance on others to interpret the invitation. In these situations, cultural values shape the interpretation of the invitation in terms of appropriateness and need. Another problem is that the sighted carer may not be able to read owing either to linguistic or literacy barriers. Explaining the procedure to patients is an important way that the health professional can empower patients and instil trust. The desire to have a trustworthy health professional becomes even more vital when one is not sighted and this was articulated by one of the blind Asian females:

'...being blind or partially sighted you must feel that you are undergoing such intimate procedures with someone trustworthy in the room. You need someone to explain both the geographical layout as well as the procedure in a step-by-step fashion.'

Barriers to screening services

A number of factors were identified as hindering the uptake of specific screening services. In addition to the low level of literacy among some minority ethnic women, which is well recognized barrier (Scanlink 1998a,b), the following barriers can be added: language problems; poor health education; cultural values and beliefs; misconceptions about perceived risk; lack of knowledge about services; lack of local access to services; and poor attitudes of GPs.

Language barrier

Language was the most commonly reported barrier among the Gujarati and Muslim communities. The groups reported that screening information leaflets are not available in all the BME languages and where translations are undertaken, the

'All of the black and minority ethnic (BME) groups involved in the focus group discussion had significant concerns about cancer ...and how and when to undertake breast self-examination.'

translation is not always adequate. While African people speak and understand English, the importance of screening was not conveyed owing to terminology and nuances of the language used.

There appears to be inadequate information about the reasons for screening and, therefore, its importance, which is further compounded by language barriers and ignorance. All of the BME groups involved in the focus group discussion had significant concerns about cancer and its causation, how to recognize the signs and symptoms, and how and when to undertake breast self-examination. Language barriers and illiteracy coexist commonly and this could give rise to large cancer information and health education deficits.

Cultural beliefs

An important culturally shaped belief is the notion that Muslim women can only be seen naked by their husbands, which influenced their preference for female GPs especially for cervical smears. This preference was stated very strongly by Muslim women and men. Interestingly, younger Pakistani women reported a preference for a female GP, but said they would not mind a male GP as it is being done for medical reasons.

An interesting finding emerged among the young women within the cervical screening age range, which might provide one explanation of the low uptake of cervical screening. The need to subscribe to the culturally desired norm of young women entering marriage in the virginal state, and to keep up this appearance, was voiced strongly by the both the Arabic and Pakistani Muslim focus group participants.

A few of the younger Pakistani Muslim women stated that they would go along for a smear test if the doctor was not of the same cultural background for fear of being 'found out'. It became apparent that many young BME women 'bin the screening invitation letters' to prevent suspicion. This was also considered to be a factor among young Greek orthodox females. For example, one of the women attending the Greek focus groups accompanied her daughter and when the daughter was asked whether she had been for cervical screening, the mother replied: 'They send her the letters but she is not at that stage yet.'

Lack of confidence in screening and outcome

The participants identified false negative and false positive screening results as influencing

uptake because people lose confidence in the importance of screening. False negative results naturally have medical and psychological consequences since delay in seeking treatment with a palpable lump in breast cancer may lead to a significantly higher rate of advanced disease (Pettigrew et al, 2000). One of the women from the Arabic Muslim refugee group experienced such a delay:

'I had mastectomy — both my breasts were removed; the tumour was large yet my doctor kept saying oh nothing, go home. He did not bother to look.'

There was agreement among the focus group participants that the mixed messages from GPs and experts can influence their intention to access screening services. However, this potential for confusion may not be recognized by medical staff because the lay and the medical perspective differ.

According to Pettigrew et al (2000), the medical aims of screening are to seek out, diagnose and treat, while the lay person's aim is to be reassured about the present and the future. If people are predisposed to seeking reassurance, then false reassurance may be the outcome of cancer screening. Consequently, patients interpret a negative screening result as a certificate of health. When the true outcome is discovered, people are likely to react with anger, feelings of being treated wrongly and, ultimately, a loss of faith in the medical profession.

If one loses confidence in Western medicine, then this increases the likelihood of turning to traditional remedies. The African and Caribbean groups stated that they turned to self-help or traditional medicines rather than going to their GPs. The reliance on traditional medicines was noted by Nwoga (1994) among Nigerian cancer patients who considered cancer to be an organic disease caused by an evil curse or magic. The tendency for patients to use alternative healthcare services when one medical system has failed transcends all cultures evidenced by its rapid growth.

Relationship with health professionals

Many of the BME focus group members spoke very highly of their GP, with a tendency to treat the GP as a higher authority, to be 'obeyed'. This was especially evident among the older Asian, Gujarati, and Pakistani focus group members. However, it would seem that GPs might not realize the esteem in which they are held, since

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they appeared to be missing important opportunities with respect to screening.

In spite of the reverence that the BME groups have for their GP, all of the participants identified unhelpful GPs' attitudes as a factor that affected their desire to take up screening. Difficult attitudes and having to wait for an appointment (sometimes as long as 1 month) exacerbated the situation. Both the Greek and Caribbean focus group members stated that when they eventually got to see their GP, they were disappointed because they expected to be physically examined, e.g. have their blood pressure taken. In their experience this did not happen. As one of the Caribbean men stated:

'I go to the GP surgery and all he wants to do is to write a prescription, so now I don't bother because what is the point of going.'

The BME patients' focus groups stated that their GPs' communication skills were poor. All the groups felt that GPs sometimes conveyed a sense of not wanting to communicate with them:

'My GP, he sits like he is getting impatient that I am there, I am watching his body language and I am asking "is it okay for me to be here are you sure", he said "No, you go on...I am trying to think what help you really need here" and I'm thinking don't worry about it — I'm just wasting your time.'

They also claimed that non-verbal behaviour discouraged any desire to ask questions or raise queries arising from instructions issued by the GP. Similar experiences were reported by Bengali cancer patients (Thomas et al, 2000).

Attitudinal problems and poor communication skills were not just confined to GPs but also extended to hospital-based staff and GPs' receptionists. The BME groups claimed that the receptionists in the GPs' surgery not only exhibited discriminatory attitudes, but also acted as a gatekeeper further eroding trust in the GP.

Religious beliefs

Overall the majority of BME groups are religious and derived strength from their spiritual beliefs. In times of emotional or physical difficulties, they reported that they turned to their religious belief as a coping strategy. Certainly, many of the

groups stated that if you leave things in God's hands 'he would find solutions'.

With regard to Muslim patients, the Islamic law should be taken into consideration by health professionals. As a group, they feel stigmatized and experience discrimination simply because they are Muslims. They felt that receiving an invitation to attend for screening or an outpatient appointment during the holy month of Ramadan was insensitive. Incorporating a multicultural calendar into the appointment-booking template might be a solution.

Improving uptake of screening

The focus group participants were vocal about strategies for improvement which included community-based cancer awareness education. This should be sensitive to religious and cultural needs. It is essential that workers have a thorough understanding of the issues and where possible place of religious worship should be used as venues for the educational sessions.

They especially identified religious leaders Imam and Pastors as key in delivering the message by identifying aspects of the Qur'an or Bible that endorse health promotion and health-seeking behaviour.

The groups thought that a seminar or questions and answers approach would be useful with separate educational groups for men and women. This would allow for open discussion of cancers that affected sexual body parts. While this is more pertinent for Muslim groups, it is important to create an environment that is free of barriers for all groups. Education should also focus on teaching how to carry out self-examinations.

Cancer-screening services should also be sensitive to religious and cultural needs. For example, one participant stated that: 'there should be more availability of female GPs'.

Mobile screening units are useful for people who do not like going to hospital, particularly if sited within housing estates. They believed that this strategy would encourage the uptake by women. One of the objectives of the primary care trusts is to establish screening centres within the community.

All of the BME groups, as well as the professionals, recommended the education of GPs, health professionals and GPs' receptionists as an important strategy. In particular, they identified education in cultural beliefs and customs, language needs, racial awareness, and communication skills as being essential in helping to address the attitudinal problems. This is particularly important because family GPs and

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community nurses play crucial roles in helping people to reduce the risks of cancer by promoting early detection and fast referral for investigation when necessary.

These suggestions accord with the findings of Jepson et al's (2000) systematic review on cancer screening. This review suggested that interventions targeted at both physicians and individuals should increase uptake significantly. There was also evidence in the review to suggest that combined community-based interventions could be effective in improving uptake (Jepson et al, 2000).

The NHS Cancer Plan (DH, 2000) and *Guidance on Cancer Service: Improving Supportive and Palliative Care* (National Institute for Clinical Excellence, 2004) pledged to widen cancer screening so that effective screening programmes are extended and new programmes commenced. Both the breast and cervical screening programmes have been extended and upgraded to improve outcomes.

Colorectal screening occurs mainly among those with a family history but awareness about it has increased considerably over the past few years.

Limitations

This study has a number of limitations and, therefore, all conclusions should be considered together with the following points:

- This study utilized a community-based sampling approach. A more robust randomized design was considered in which participants would be recruited via attendance to clinics; however, it was felt that patients would be required to be identified and thus introducing bias.
- A variety of BME faith groups and community centres were relied upon to assist in the recruitment of participants to the focus groups. It is possible that this convenience sample was biased towards people attending faith organizations and community centres. Therefore, some caution is needed in generalizing the findings to the wider BME population in Brent and Harrow.
- The project was ambitious in trying to include several BME communities with their own language, culture and religious differences. Focus groups that were not possible to run in English required a translator or a researcher to assist the key researchers. Every attempt was made to standardize the interview schedule and guide the researchers/translators.
- The authors acknowledge that each of the BME groups identified are not

a homogenous group of people with the same language, culture and religion. Therefore, caution is needed in generalizing the findings as typical of each group.

- The authors had considered comparing the BME communities to the indigenous white community but opted not to owing to time and budget constraints. Future study could carry out such a comparison.

Conclusion

'Screening' is fraught with many problems within the general public including cynicism, indifference and fear. These findings suggest that this is compounded by an overlay of the specific issues relating to BME groups. This community-based qualitative study has revealed inadequate knowledge and uptake of cancer-screening services among African Caribbean, African, Gujarati, Pakistani, Greek and Arabic groups.

Important barriers included health and cultural beliefs and attitudes, language and unhelpful attitudes of health professionals. Some of these factors were also identified by the systematic review on cancer screening (Jepson et al, 2000). For example, individuals with a female health provider were more likely to take up screening. GPs are revered by many of the BME groups, but in spite of this reverence, a significant proportion of participants felt that they would not be taken seriously by their GP. This finding is also true for working class members from the wider community (Wells, 2001).

The finding of obstructive health professionals' attitudes coexisting with language and educational deficits is worrying. The purpose of any screening test needs to be explained adequately to those participating, including information on risks and benefits. In this study, the results indicate clearly that not only is there poor uptake in BME groups generally, but also those who do take up screening services are not participating on the basis of informed choice.

The outcome of the focus groups with healthcare professionals is not included here but there was remarkable consensus on the key issues, which makes it puzzling that those strategies have not been implemented.

Finally, the health belief psychological model was utilized to structure the questions and qualitative analysis, which was also used by Jepson et al's (2000) review. Overall, research has shown that having a lower fear barrier is the best predictor of uptake of screening (Murray and McMillan, 1993). It would seem from the present study that fear is the greatest barrier that gets in

the way of the BME groups' view of their susceptibility to cancer. Therefore, directing educational strategies at BME communities and at professionals is likely to be useful. Professionals or trained community workers could set up education sessions located in religious venues and leveraging the influence of the religious leaders.

This study has served just as a diagnostic tool but provides richness of meaning behind the identified barriers of the uptake. However, these findings should be considered together with limitations. Nevertheless, if the findings are used in combination with the essentially quantitative systematic screening review (Jepson et al, 2000), the North West London Hospitals NHS Trust and the Brent and Harrow Primary Care Trusts can really begin to address the needs of the BME communities that it serves.

Although there are high levels of fear in BME groups acting as a barrier to the uptake of screening, it did appear that people seemed to experience real benefit from the focus group discussions on cancer. This kind of forum is essential to allay fears and provide reassurance. These community-based strategies in conjunction with the voluntary sector, are aligned to the public health strategies being suggested by the government.

The research team are encouraged and believe that community-based education that takes account of cultural beliefs, gender, educational level and socio-economic factors are likely to go a long way towards increasing the screening uptake among BME groups. 

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- Acheson D (1998) *Independent Inquiry into Inequalities in Health Report*. HMSO, London
- Barbour RS, Kitzinger J (1999) *Developing Focus Group Research: Politics, Theory and Practice*. Sage, London
- Baron A, Byrne D (1984) *Social Psychology: Understanding Human Interaction*. 4th edn. Allyn and Bacon, Boston
- Baxter C (1989) *Cancer Support and Ethnic Minority and Migrant Worker Community: A Report Commissioned by Cancerlink*. Cancerlink, London
- Bhopal R, Rankin J (1996) Cancer in minority ethnic populations: priorities from epidemiological data. *Br J Cancer Suppl* 74: S22-S32

- Box V (1984) Cancer, myths and misconceptions. *J R Soc Health* 104(5): 160-70
- DH (2000) *The NHS Cancer Plan*. DH, London
- Hoare T (1996) Breast screening and ethnic minorities. *Br J Cancer Suppl* 74: S38-S41
- Janz NK, Schottenfeld D, Doerr KM et al (1997) A two-step intervention of increase mammography among women aged 65 and older. *Am J Public Health* 87(10): 1683-6
- Jepson R, Clegg A, Forbes C, Lewis R, Sowden A, Kleijnen J (2000) The determinants of screening uptake and interventions for increasing uptake: a systematic review. *Health Technol Assess* 4(14): 1-133
- Kitzinger J (1995) Introducing focus groups. *BMJ* 311: 299-302
- Margolis KL, Lurie N, McGovern PG, Tyrrell M, Slater JS (1998) Increasing breast and cervical cancer screening in low-income women. *J Gen Intern Med* 13(8): 515-21
- Murray M, McMillan C (1993) Health beliefs, locus of control, emotional control and women's cancer screening behaviour. *Br J Clin Psychol* 32(1): 87-100
- National Institute for Clinical Excellence (2004) *Guidance on Cancer service: Improving Supportive and Palliative Care for Adults with Cancer*. NICE, London
- Northwest London Hospital Strategic Health Authority (2002) Public Health Profile. (www.nwla.nhs.uk/AboutTheSHA/health_in_nw_london.doc) (accessed 11 November 2005)
- Nwoga IA (1994) Traditional healers and perceptions of the causes and treatment of cancer. *Cancer Nurs* 17(6): 470-78
- Parsons C (1990) Cross-cultural issues in health care. In: Reid J, Trompf P, eds. *The Health of Immigrants in Australia*. Harcourt Brace Jovanovich, Sydney: 108-53
- Pettigrew MP, Sowden AJ, Lister-Sharp D, Wright K (2000) False-negative results in screening programmes: systematic review of impact and implications. *Health Technol Assess* 4(4): 187-9
- Pilgrim S, Fenton S, Hughes T, Hine C, Tibbs N (1993) *The Bristol Black and Ethnic Minorities Health Survey Report*. University of Bristol, Bristol
- Polkinghorne DE (1991) Qualitative procedures for counselling research. In: Watkins CE, Schneider LJ, eds. *Research in Counselling*. Lawrence Erlbaum, Hillsdale: 163-207
- Powell RA, Single HM (1996) Focus groups. *Int J Qual Health Care* 8(5): 499-504
- Rimer B (1999) The impact of tailored interventions on community health center population. *Patient Educ Couns* 37: 125-40
- Rosenstock I (1974) Historical origins of the health belief model. *Health Educ Monogr* 2: 328-35
- Scanlink (1998a) *Scanlink in Newham: Report on Raising Community Health Awareness Around Cervical Cancer and Cervical Screening Among Black and Minority Women*. Cancerlink, London
- Scanlink (1998b) *Scanlink in Watford: Report on Raising Community Health Awareness Around Breast Cancer and Breast Screening Among Black and Minority Women*. Cancerlink, London
- Skinner CS, Strecher VJ, Hospers H (1994) Physicians' recommendations for mammography: do tailored messages make a difference? *Am J Public Health* 84(1): 43-9
- Sontag S (1989) *Illness as a Metaphor*. Penguin Books, Harmondsworth
- Sutton S, Bickler G, Sancho-Aldridge J, Saidi G (1994) Prospective study of predictors of attendance for breast screening in inner London. *J Epidemiol Community Health* 48(1): 65-73
- Thomas VJ (1997) Cancer and minority ethnic groups: factors likely to improve nurse-patient communication and facilitate the delivery of sensitive care. *Journal of Cancer Nursing* 1(3): 134-40
- Thomas VJ, Richardson A, Saleem T (2000) The efficacy of bilingual health advocacy in ethnic minority patients with cancer. *Nurs Stand* 14(2): 32-33
- Wells M (2001) The impact of cancer. In: Corner J, Bailey C, eds. *Cancer Nursing: Care in Context*. Blackwell Science, Oxford: 63-85
- WHOQOL Group (1994) The development of the World Health Organization Quality-of-Life Assessment Instrument. In: Orley J, Kuyken W, eds. *Quality-of-life Assessment: International Perspectives*. Berlin Heidelberg, Springer-Venlay

Key words

- Cultural attitudes and beliefs
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