

RESEARCH COMMUNICATION

Culture, Attitude and Knowledge about Breast Cancer and Preventive Measures: a Qualitative Study of South Asian Breast Cancer Patients in the UK

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Abstract

Background: Little is known about the influence of culture and beliefs about breast cancer, and its implications on preventive health behaviour among South Asian people in the UK. **Methods:** Using a qualitative approach, 24 South Asian breast cancer patients and their significant others were interviewed. **Results:** Most patients were unfamiliar with the subject of cancer; they expressed lack of knowledge of cancer as a disease and its symptoms. They identified a painless lump in the breast as sign of abnormality, but not cancer. They also did not know any non-lump breast symptoms. Over half participated in breast screening after encouragement from daughters or relatives. Most did not practise breast self-examination. Perceptions of cancer and health behaviour were influenced by cultural beliefs. Common themes were cancer is a taboo subject and cancer is a stigma. Patients also expressed misunderstandings about the cause of cancer. Cancer in the family had ramifications on children's marriage prospects and may cause marital breakdown. Terminology used also caused communication problems with healthcare professionals and within the family: the use of 'chest' to substitute 'breast' changed the meaning of the message conveyed. **Conclusions:** Cultural beliefs and practices accentuate difficulties in understanding breast cancer, breast screening and breast self-examination, and can prevent South Asian women from adopting preventive health practices.

Keywords: Breast cancer - culture, beliefs, attitudes - South Asians - UK

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Introduction

Studies of cancer epidemiology in the UK continue to show ethnic differences in cancer incidence and mortality (Bhopal & Rankin, 1996; Bahl, 1996; Moller, 2008; Ben-Shlomo, 2008). Although cancer incidence is somewhat lower among minority ethnic people than the majority white population, cancer mortality is consistently higher among minority ethnic people. Biomedical and socio-economic factors are strong influences but cannot fully explain these differences (Lannin et al., 1998).

Breast cancer is a major cause of death in South Asian women (Bhopal & Rankin 1996). Poor survival rate in this group of women, when compared to white women can be explained by low uptake rate in breast screening (Rudiman et al., 1995; Hoare, 1996; Sutton et al., 2001); delayed diagnosis; and late presentation of disease (Ramirez et al, 1999; Richards et al.,1999). The reasons for these ethnic differences are not clear, although recent evidence suggested that tumour size and type could be an attribute (Bowen et al, 2008). Reasons

for poor participation in breast screening practices have been reviewed (Szczepura, 2005), but little is known about the factors influencing presentation and late-stage presentation in South Asian women. Dixon Woods (2005) argued that presentation could be explained by 'candidacy' or in other words, the ability of individuals to identify that they are candidates for medical attention and intervention, and initiate action. Failure to candidacy thus may lead to delayed presentation to healthcare. Cultural beliefs may also offer an explanation as these, together with socio-economic variables, were found to have the most important effect leading to delayed presentation once a woman had developed a palpable breast abnormality (Lannin et al., 1998). There are then the difficulties of gaining access to appropriate provision, which is culturally sensitive (see Ahmad & Bradby, 2007) as well as the more general difficulties raised by institutional racism (Atkin & Chattoo, 2007).

Culture refers to the conventional patterns of thought and behaviour, including value beliefs, and rules of conduct, which distinguish a particular social group

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(Helman, 1994) and which are transmitted through the most fundamental dimensions of culture: faith, ethnicity, heritage, food, language and kinship relationship (Bhopal, 2007). All ethnic groups, including the ethnic majority, use culture norms and values to make sense of health and illness (Chattoo & Ahmad, 2004). Culture, however, might assume particular meaning in multi-cultural societies, where default values of the majority white population, might not apply equally to all ethnic groups (Kymlicka, 2001).

Evidence from North America showed that culture influences individuals' perceptions of health, expectations for care, treatment choices, advance healthcare planning, and other aspects of care (Baxter, 1983; Pachter, 1994; Chavez et al., 1995; Morgan et al., 1995; Uba, 1992; Gregg & Curry, 1994; Rajaram & Rashidi, 2003). One study explored South Asian women's views on the causes of breast cancer, and this study found that South Asian women's beliefs and explanations about cancer are culturally patterned, and these beliefs informed their perceptions of risk and the type of action taken to minimize risk for breast cancer (Johnson et al., 1999).

Few studies explore cultural beliefs about cancer in the UK (Randhawa and Owen, 2004): participation in breast and cervical screenings (Naish et al., 1994; Hoare, 1996; McCaffery et al., 2003), and treatment for breast and ovarian cancer (Bhopal, 1986; Rider, 1997). One study had specifically explored the meanings of cancer and perceptions of cancer services by South Asian people in Luton (Randhawa & Owen, 2004).

The paper reports the findings of a study exploring attitudes, knowledge and understanding of breast cancer and preventive measures amongst South Asian breast cancer patients. This study is part of a larger project to explore South Asian and White breast cancer patients' knowledge about preventive measures (breast self examination and breast screening), experience and barriers in accessing healthcare and treatments for breast cancer, disclosure of information within family and communication with healthcare professionals.

Materials and Methods

Qualitative individual face-to-face interviews
Qualitative methodology was used because it allows for a deeper, richer understanding of patient's experience of disease and service access via open dialogue between the researcher and participants (Strauss and Corbin, 1990). Individual face-to-face interview was chosen as the method for data collection because it offers participants privacy and opportunities to engage in story telling that was prompted by a topic list. Sensitive and supportive probing to encourage openness and elaboration into unanticipated leads were used. For example, cultural taboos and superstitions amongst patients in the present study meant that questions on personal susceptibility had to be asked indirectly to avoid bringing bad luck by saying the word 'cancer'. A multi-lingual researcher (GK) who was proficient in all South Asian languages was available to conduct the interviews.

A topic list was used to guide the interviews and it included themes such as lay understanding and beliefs about breast cancer, knowledge and attitudes towards breast screening and breast self-examination, experience of breast cancer and treatment process, interaction with healthcare professionals and continuity of care and service, barriers in accessing treatment and breast cancer care, and communication within family.

Participants

For inclusion into this study, participants must be of South Asian origin and had had breast cancer. Only breast cancer patients were included because we were interested in the socio-cultural factors influencing attitudes, knowledge and experience about the disease, preventive measures (breast self-examination and breast screening) and access to healthcare.

After gaining approval from local research ethics committees, South Asian breast cancer patients were contacted by the staff at the breast cancer unit in 3 hospitals in West Yorkshire to ask whether they would like to participate in this study. Twenty-four South Asian breast cancer patients agreed to be interviewed and a researcher later contacted these patients to arrange a time and place most convenient to conduct the interview. Information on 'non-response', however, was unavailable as staff at the breast cancer units did not collect this data.

Before the interview, patients were fully informed about the study and were asked to sign a written consent form for participation and were assured of confidentiality and anonymity.

Fifteen significant others were also interviewed. These were individuals who were chosen by participants as being important in their cancer journey. Four were interviewed in the presence of the patients whilst 11 were interviewed individually. Daughters were identified by Muslim cancer patients as the significant other or main carer while the main carers for Sikh patients were their spouses. A few of the women also named their son, niece, sister-in-law and daughter-in-law as their main carers. Most of the significant others could converse in English.

Analysis

Framework analysis which is a matrix-based approach to qualitative data analysis was used to analyse the data (Richie & Spencer, 1994). The transcripts were examined for emergent themes and a framework analytic structure was then developed and refined. Recurring and important themes were identified based on a combination of a priori issues, emergent issues and recurring attitudes or experiences. Once the first themes were identified, they were applied to further transcripts to encapsulate other cultural practices and beliefs, and experiences of participants.

Results

We interviewed a total of 24 South Asian breast cancer women. Our immediate problem in defining a sample was how to capture the experience of a diverse community, of various faiths, cultures, languages and dialects, which

become 'imagined' in the policy literature as 'South Asian'. Practical responses – which inform this study – tend to classify people according to their ethnic origin and religious identification. There is some theoretical justification for this, as for people of South Asian origin, ethnicity and religious identity often reinforce each other (Modood et al., 1997). Beyond this, our sample reflected the demographic profile of the fieldwork sites. Our sample included: 12 Pakistani Muslims, 2 Bangladeshi Muslims, 2 Indian-Hindus and 8 Indian-Sikhs. The majority of patients (17) were 50 to 69 years old; the remaining 7 participants fell in the age group of 39 to 49 years old. The mean age of this group of patients was 58 years old. Their length of residence in the UK ranged from 12 to 46 years.

Most of the women (17) preferred to be interviewed at home, while 7 were interviewed at the breast cancer support centre because they felt restricted talking about their illness at home. Seven interviews were conducted in English while the remaining 17 were conducted in the participant's spoken language: Punjabi, Gujarati, Urdu, Sikh and Bengali as appropriate. All interviews were tape-recorded, translated and transcribed into English by the interviewer.

Awareness and knowledge of breast self-examination and breast screening

When asked about breast self examination, most of these women said they did not practise breast self examination and they acknowledged poor knowledge and understanding of the technique. A few who knew about breast self-examination said they did not think it was necessary, and if this was needed, it should be done by a healthcare professional.

Over half of the female cancer patients took up breast screening only after they were encouraged by their daughters or relatives, and these patients also reported having poor awareness and knowledge of the breast screening programme. A few women reported that they threw the breast screening invitation letter in the bin, while some said they did not bother reading the letter because they "cannot read English". This is not surprising as over 70% of the participants (17) could not speak fluent English.

Knowledge of breast cancer as a disease and symptoms

Cancer patients were asked about their knowledge of 'cancer' and 'breast cancer' before they were diagnosed with the illness. Most of South Asian women were unfamiliar with the subject of cancer. They expressed lack of knowledge of cancer as a disease and its symptoms. Although the male patient heard about cancer before his diagnosis, he never knew that men could suffer from breast cancer as well. He was shocked when told of the diagnosis and had difficulty telling his family and others about his illness.

Expressions such as "never knew anything about cancer before." "I never knew." "I didn't know what is cancer" were common. Lack of knowledge of cancer could have contributed to the absence of personal experience of cancer: none of the patients in the present

study knew someone personally who had cancer.

Many women in the present study recognised a lump in the breast or under the arm as a sign of 'illness', but they did not know that this could signify breast cancer. One woman was referred to the hospital when the doctor found a lump in her breast. However, she did not realise the urgency of the matter and went to Pakistan for a few months.

"I had a little lump in my breast ..for a while. I used cream to rub it, thought it will go away. (I) thought nothing of it. Then after 3 or 4 days, I had a lot of pain and I was awake all night" "I was perfectly alright, except I had a lump that was not causing any problem."

This group of South Asian patients also did not know about other symptoms of breast cancer such as nipple dryness, dimpling of the breast skin, or nipple retraction. The following quotes reflected poor knowledge about breast cancer symptoms that subsequently delayed a visit to the doctor.

"It all started about 2, 3 months I noticed the skin was just filling out over and over and then I went to see the doctor" "I could not tell anyone or I didn't know the difference but it was always painful. There was no lump. Just one breast is bigger than the other...I didn't see the doctor until many years later ... when it became so painful" "I was reading my prayer, my breast side was really swollen up. I didn't know it was cancer. I didn't know anything about cancer. I did not see doctor soon" "I was washing ...and there was lot of fluid coming out of my breast. My pillow was soaked.... I was shocked when my nephew told me it was cancer. We don't have it in the family. I never hear about any relatives having it."

Cultural practices and beliefs about cancer

Culture mediates the different ways that individuals understand cancer, the ways they explain it and their attitudes toward it (Dein, 2004). For this group of South Asian people, the main themes that emerged were: cancer was a taboo subject, cancer was contagious, cancer was a stigma and cancer in the family had ramifications on children's marriage prospect. Some of these beliefs were shared by white women (Dein, 2004). Box (1984) found that white women perceived the causes of cancer to range from moral wrongdoing to contagious factors. These beliefs and cultural practices about cancer could be a potential key barrier to healthcare access and adoption of preventive measures.

(i) This group of patients confirmed the findings in Luton (Randhawa and Owen, 2004) that the word 'cancer' is not to be talked about. Cancer is considered a taboo in the family, among relatives and in the community.

"I never talked about it" "I suffered in silence" "...my mum, even though she's been here so long, you'd think she understands English. But she doesn't. Cancer is not discussed by South Asians" "we were all terrified because we don't hear much about breast cancer or any other forms"

of cancer in the community” “It’s a very hidden thing” “every time I mentioned about it to my husband he said that one should not talk about this thing so I didn’t talk to anyone else. I wasn’t allowed to go out to talk to anyone else.”

(ii) Many women claimed that simply talking about cancer, or using careless words, could put one at risk. Some women also said that using the word cancer precipitated ‘bad luck’ which in turn would lead to breast cancer in themselves and their family.

“we don’t even talk loudly about cancer; we whisper when cancer is mentioned or discussed. ... might catch it” “knowing about it is bad luck. Therefore we don’t talk about it.”

(iii) Some South Asian women believed that cancer is caused by being in close proximity or sharing personal items with an individual who has cancer. Individuals diagnosed with cancer were people to stay away from. Women purposefully avoided visiting and sitting next to friends or relatives with cancer in order to protect themselves and their families. Underlying these explanations might have been sense of cancer as a contagious disease. These accounts however might also reflect the more symbolic meaning of cancer, reflecting issues of taboo and stigma.

“when my sister-in-law’s mother visited my mother in the hospital after her mastectomy, she told my sister-in-law not to let her son near the lady opposite my mother’s bed or he might catch something. Little did she know that my mother also got the same illness as that lady” “when it bursts, it will infect others nearby. So we have to keep my mother away from anyone”

For one woman, the concern about catching cancer focused on sharing personal items and she attributed the spread to ‘cancer germs’ on the personal items used by the cancer sufferer. “Keep everything separate, all the food, plate, cup, blanket, clothes,”

(iv) The fear surrounding cancer was also implicit in the warnings against revealing to others that one has cancer. Such revelations could lead to isolation from relatives and friends.

“...and even when families do discover they suffer from some form of cancer, they don’t like to let anybody else know. No one will visit them” “We are very honest family. Dad said not to let anybody else outside the family know that mum has this disease... cancer” “Everyone in the community will look down on me. No one in the community has this illness” “My daughter does not tell her in-laws when she takes me to the hospital...”

A few patients also expressed loneliness because they could not share their emotional problems with their loved ones.

“I have to be brave and strong. I cannot show the children I am sick. They need their mother to be well. They are still young” “I tried to do all the things I used to do. If my daughter-in-law said, come, let’s go shopping, I go with her. I don’t want pity from my children, friends...I showed them I am happy”

(v) Some South Asian women worried about the ramification on their children’s marriage prospects.

“I hope I don’t give this illness to anyone- especially to my children” “if they know, no one will want to marry my daughters” “this will affect their future marriage prospects...”

(vi) Participants also expressed difficulty in communication within their family and to healthcare professionals, particularly to male doctors about health issues related to their body (feminine problems).

One woman patient said that she suffered for over 10 years because she was not allowed to talk about the pain in her breast.

“every time I mentioned about it to my husband he said that one should not talk about this thing so I didn’t talk to anyone else. I wasn’t allowed to go out to talk to anyone else.”

The male cancer patient only told his son about his diagnosis, and he did not tell his wife or his daughter. He said that everyone in family were concerned for him to get well and as a family they “don’t speak about it... or openly discuss the illness”.

When consulting with a male doctor, these women said they would not use the word ‘breast’ but instead substituted it with ‘chest’. Some said they pointed to their chest to avoid saying the word ‘breast’. One woman also said that she did not consult her doctor because the doctor originated from the same community.

“We can’t talk to doctors like that (asked the doctor about lump in the breast)...” “we don’t say ‘breast’ to the doctor. We say ‘chest’ pain. It is more difficult talking about women pain with male doctor” “when I went to see the doctor, I knew him and I did not want him to examine me, especially when he asked to look at my breasts – that did not feel right for him to examine me.”

Social support

Spirituality was highlighted as a fundamental element of the healing process and comfort for family members. Although many participants acknowledged initial fear upon hearing the cancer diagnosis, spirituality served a source of comfort, enhanced confidence, and lessened fears. Muslim women stressed the significance of prayer for the recovery from cancer; God is an important source of support.

“everyone ... really really prayed for me. Someone went for a Haj in Mecca and prayed especially for me and it’s so encouraging when you think people pray for you and

that really helped, God will make me better.

"I did not tell anyone outside the family about this illness. I rather sit down and talked to God in my prayer. Talking to God relieves all the pain."

"God helped me, and our faith helped us... we got to be confident and got to carry on. The prayer, we used to sit together, asked for forgiveness, we used to feel that we have to pray together – mum, brothers, sisters, in-laws – we have to be close to each other. God gives us the understanding that we have feeling for each other."

Immediate family (children and/or spouse) was the main source of support for these patients, and these also included daughters-and sons-in-law. The roles of immediate family included accompanying the women to medical visits.

"we're a funny family. They don't all clamour round (to) hold my hand and say well, don't worry, we'll support you. I mean I expect them to be there when I need them. Everybody knows his or her position."

"he (husband) was very upset, he looks after me, he says to rest, not to do work, not to e with children because they make noise... he feels that as long as my life is there, it's better..."

However, one woman expressed lack of support from her husband and said that he found her 'unattractive' after her operation.

"I didn't get the support from my husband. He was never there to help me. He left me and my children after my breast was taken out. I think he found me not womanly."

A few of the women attended a breast cancer self help support group and found that this group gave them emotional support. They could share their anxiety and problems with other Asian women like them. Because of cultural practices and beliefs, these women felt encouraged by other patients. Support group also provided a means of obtaining valuable information regarding treatment and recovery which they said they did not get from the hospital or understand.

"I am a voluntary worker in the cancer support group. I go there. Everytime I help other people and talk about it in same language. And teach other people and learn from them and that helps. Help each other. It's very rewarding" "mum was recommended to go the breast cancer self-support group (Umeed). She did not know what to expect... I went with her... We saw many Asian women and it was a lovely family atmosphere... we never had anyone with cancer in our family or friends that we heard that had cancer... we asked 'why us?'. When we saw so many Asian women at the meeting, it relaxed us... I am not the only sick one. Mum talked to all these women and she felt much happier."

Discussion

Poor knowledge and awareness of breast cancer

preventive measures (BSE & BS) remain a common feature among the South Asian communities in the UK; as reported by the South Asian breast cancer patients in the present study in the UK. These findings had also been reported elsewhere (Gunaratnam, 2005).

Knowledge of 'what was cancer' and experiences of cancer however cannot be generalised across the wider South Asian population. None of the women in the present study knew or had heard about 'cancer' or had any experience with cancer. However, 96% of the 48 healthy South Asian participants in Luton, South of England, had heard of cancer and many knew of someone in the community who had cancer, although some men were also found not to have heard or knew of cancer (Randhawa & Owen, 2004). The difference in knowledge about cancer in these studies may be methodological. Randhawa and Owen (2004) used focus group discussions while individual interviews were used in the present study.

Most of the breast cancer patients in the present study did not recognise a painless lump in the breast or underarm as symptoms of breast cancer; even though they knew that the lump represented abnormality. They also did not know about other non-lump symptoms. Lack of knowledge about breast cancer symptoms and the illness can lead to delayed presentation (Burgess et al. 1998) and can also serve as a barrier to access (Atkinson et al., 2001). The patients in the present study sought help when their cancer was in a late stage. Therefore, it is not surprising that when South Asians knew of someone who had cancer, they encountered this illness only at a late stage or incurable and that it had resulted in death (Randhawa & Owen, 2004).

Explanations of the causes of disease by ethnic minority people have been extensively studied in America (Shuval, 1983; Kleinman, 1988, Gregg & Curry, 1994; Rhoads et al., 2000; Choudury) and in the UK (Goddard & Smith, 1998; Greenhalgh et al., 1998; Chan, 2000; Davies & Webb, 2000). Ethnic differences as well as similarities in beliefs and attitudes about cancer between white majority and ethnic minority were identified. These studies also support the claim that these explanations are culturally patterned, have a high degree of logical coherence and bear complex, and at times contradictory, relationships to medical causes. These properties were apparent in the present study and were reflected in the way cancer is perceived and treated by the participants. Their practices and beliefs contributed to their lack of knowledge and understanding of breast cancer, and the action they did not take immediately. They were unaware of the seriousness of the disease and urgency to seek immediate medical help. These findings also suggest the importance of addressing the cultural aspect of disease presentation and health access because of its perpetuating effects. On the other hand, variables such as level of education (Jepson et al, 1991) and socio-economic factors (Madan et al., 2000), not ethnicity, have also been found to influence attitudes towards cancer. The level of differences in perceptions, beliefs and attitudes toward cancer between minority ethnic and majority white need to be systematically explored in future research.

Cultural beliefs and practices also act as a potential key

barrier to health access, early consultation with the doctors (Johnson et al., 1999; Lannin et al., 1998, Chapple, 2001). For example, women who believed that breast cancer can be brought upon themselves by speaking the word will inevitably avoid any discussions related to cancer with friends or relatives as well as healthcare professionals. Unfortunately this avoidance may hinder early detection and treatment of breast cancer.

Like previous studies (Mitchell et al., 2002; Ashing-Giwa, 2004), our findings also suggest that a strong faith in God provides a valid and important additional component to a health care system devoid of symbolic meaning. Given its central place in patients' lives, this avenue should be explored for its potential role in health education. This role will be most successful if it is informed by both biomedical understanding of disease and by informants' understanding of cancer, and can thus mediate between the two.

Support groups are a valuable resource for some women, particularly in sharing their emotional problems and information about treatments. However, constraints due to culture, religion as well as physical restricted the participation of South Asian women. Further research is needed to explore the benefits of self support groups in the South Asian community and address barriers to regular participation. Moreover, the essentialising view of ethnicity has been repeatedly challenged (Atkin and Chattoo, 2007). It has been pointed out that not every aspect of a person's identity and experience - and not every aspect of their health and encounters with the health care system - can be explained by his or her ethnic background. As among the 'white' population, a person's identity, like their health experiences and health care encounters, will be influenced by their age, gender and socioeconomic position, as well as by how others respond to these different dimensions of identity. Because these multiple influences on identity can be hard to capture in quantitative studies of health, researchers have looked to qualitative approaches to enable people to talk about when and how ethnicity makes a difference - and when it does not. For example, in cases where inequity of access to health and healthcare was due to structural factors rather than by ethnicity.

Since the completion of the present study (Karbani et al., 2002), the National Cancer Screening Directorate had commissioned a number of studies aiming to improve health access for South Asian people in England. For examples, Szczepura et al. (2005) investigated barriers to uptake of bowel cancer screening; Chiu et al. conducted an intervention using community health workers to promote breast and cervical screenings in 2008; an on-going study to evaluate effective strategies/intervention to improve uptake to cancer screening (Centre for Ethnic, Health and Diversity, University of Warwick) and other health promotion initiatives to produce cancer awareness and screening information in South Asian languages. However, none of these studies or initiatives aimed to improve our knowledge and understanding of the effects of ethnicity and culture on health decisions in cancer prevention and delayed access to healthcare. In addition, health care provision for ethnically diverse populations occurs against a backdrop of socio-economic disadvantage,

institutional racism and social exclusion (Parekh, 2000). Despite increasing awareness about the nature of culturally sensitive provision, various discriminatory practices - revealed in professional assumptions and organisational practices - either ignore or misrepresent the needs of ethnically diverse populations (Karslen, 2007). Practitioners, for example, still lack confidence, when discussing cultural competent practice (Peckover and Chidlaw, 2007), often reverting to simplified generalisations, which they believe enable them to 'manage' ethnic diversity (Atkin and Chattoo, 2007). All these issues need to be further explored and addressed.

In conclusion, there was significant delay in the presentation of South Asian women with breast cancer leading to more advanced disease at diagnosis in this study. Only a small proportion of South Asian breast cancer patients presented through national breast screening programme, even though majority of the patients were in the screening age group. Even after its introduction more than two decades ago, the national breast screening programme seems to have not been embraced by some of the ethnic minorities. Further qualitative research is needed to identify the route cause for this to better target this population in whom the breast cancer incidence is on the rise.

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