

## Research paper

# Black and South Asian women's experiences of breast cancer: a qualitative study

Geeta Patel BSc MSc PhD

Research Associate, University of the West of England, Bristol, UK

Diana Harcourt BSc MSc PhD

Co-Director, Centre for Appearance Research, University of the West of England, Bristol, UK

Habib Naqvi BSc MSc DPsych

Senior Equality Manager, Policy Directorate, NHS England

Nichola Rumsey BA MSc PhD

Co-Director, Centre for Appearance Research, University of the West of England, Bristol, UK

### What is known on this subject

- Breast cancer diagnosis and treatment can be challenging and distressing experiences for any individual.
- Little is known about the experiences of breast cancer among British black and minority ethnic (BME) women.
- Previous research has suggested that BME women's experiences of breast cancer are in some respects similar to those of white women, but in other ways different.

### What this paper adds

- It enhances our understanding of black and South Asian women's experiences of breast cancer.
- It highlights the important role of culture in shaping BME women's experiences of cancer.
- It illustrates the importance of providing culturally competent care and support to meet BME women's needs.

## ABSTRACT

Breast cancer is one of the most common forms of cancer in the UK, and affects women of all ethnic groups. The psychosocial impact of breast cancer has been well documented. However, research conducted in this area has been primarily focused on white women. There is very little work within the breast cancer literature that captures the experiences of black and minority ethnic (BME) women. The aim of this qualitative study was to explore the experiences of breast cancer diagnosis and treatment in black and South Asian women living in the UK. Individual semi-structured interviews were conducted with 22 English-speaking breast cancer survivors (11 black and 11 South Asian women).

Thematic analysis of the data revealed five key themes, namely social support, spirituality, body image concerns, healthcare experiences and life after cancer. The findings showed that although the BME women shared similar concerns to white women, their experiences were also influenced by cultural specific concerns. This study has implications for healthcare professionals and recognises the need to provide culturally sensitive care and support to BME women, tailored specifically to their values and beliefs.

**Keywords:** black, breast cancer, ethnicity, psychosocial, qualitative research, South Asian

## Introduction

The estimated lifetime risk of developing breast cancer at any given time is 1 in 8 for women in the UK (Cancer Research UK, 2013). In 2010, a total of 49 564 women in the UK were diagnosed with the disease (Cancer Research UK, 2013), making breast cancer the most common form of cancer in women of all ethnic groups (Breast Cancer Care, 2005).

The UK is a multicultural society, made up of populations from a diverse range of ethnic backgrounds. The most recent figures, based on the 2011 Census, show that there are approximately 9.1 million (12.1%) black and minority ethnic (BME) men and women living in the UK (compared with 6.6 million in 2001). Black (black Caribbean, black African or other black) and South Asian (Indian, Pakistani, Bangladeshi or other South Asian) populations form the largest ethnic minority communities (Office for National Statistics, 2011). Despite this growing BME population, very little is known about their experiences of breast cancer (Thompson *et al*, 2008).

The diagnosis and treatment of breast cancer can be a challenging and distressing experience for any individual. Within the last four decades, a vast amount of research has documented various psychosocial issues associated with this condition, including depression, anxiety, body image issues, varying support networks, social stigma, lowered self-esteem, an increased sense of vulnerability, and fear of death (Fobair *et al*, 2006; Harmer, 2006; Hegel *et al*, 2006; Shapiro *et al*, 2001). The majority of studies have focused on white women. However, researching BME women's breast cancer experiences is important, as their experiences and healthcare needs may differ from those of white women due to varying cultural backgrounds and differences in the epidemiology of breast cancer. For example, UK data (albeit limited) suggest that although black and South Asian women have a lower incidence of breast cancer, they tend to be diagnosed at a younger age, and are more likely to be diagnosed at an advanced stage and with aggressive forms of the disease, than white women (Bowen *et al*, 2008; Farooq and Coleman, 2005; Jack *et al*, 2009; Zaman and Mangtani, 2007). Rates of mastectomy are also higher among South Asian women than among non-South Asian women (Velikova *et al*, 2004). These differences suggest that BME and white women's experiences of breast cancer may differ, especially in groups where mastectomy rates are higher or where cancer is presented at later stages and requires more aggressive forms of treatment. Researching BME women's breast cancer experiences can also help healthcare professionals to gain a better understanding of these women's healthcare needs, and work to provide care and support that is culturally competent. This would

help to reduce health inequalities, which is one of the main goals of the healthcare services (Department of Health, 2011).

The handful of studies that have explored the experiences of BME women with breast cancer have highlighted unique factors which are largely shaped by socio-cultural norms, behaviours and beliefs (Ashing-Giwa *et al*, 2004; Gurm *et al*, 2008; Henderson *et al*, 2003; Howard *et al*, 2007; Wilmoth and Sanders, 2001). For example, Wilmoth and Sanders (2001) conducted two focus group interviews with 16 African American breast cancer survivors (i.e. individuals living with or beyond cancer) (Macmillan Cancer Support, 2008). Analysis of their data revealed that the women mentioned body image issues about hair loss, feeling lop-sided in their clothing, and the lack of prostheses available to match their skin colour. This study also reported variation in the availability of support from different sources, such as family, friends and healthcare professionals, and a desire to educate others and make them breast aware. This has also been reported in other studies (Henderson *et al*, 2003; Moore, 2001).

A growing body of literature has been exploring and comparing black women's breast cancer experiences with those of other BME communities, such as East Asian or South Asian women (Knobf, 2007). Research within South Asian communities has focused predominantly on Canadian Punjabi women (Bottorff *et al*, 2007; Howard *et al*, 2007; Gurm *et al*, 2008). For example, Gurm *et al* (2008) interviewed 20 Canadian Punjabi breast cancer survivors and found that, as the women's experiences were shaped by their cultural background, they felt an obligation to their family to resume daily chores and domestic responsibilities immediately after treatment. Many wanted to seek support from other breast cancer survivors, but felt isolated due to cultural pressures to keep personal issues private. The women's distress was further exacerbated by judgemental and insensitive comments made by uneducated and older-generation community members. Receiving information and talking to others in their own language was important to these women, as were spirituality and religion in helping them to manage the experience.

Although these studies contribute to the limited literature on breast cancer in BME patients, they have mainly been conducted in America and Canada (Banning, 2011). It would be inappropriate to assume that the findings of American- and Canadian-based studies can be generalised to the UK, particularly as the healthcare systems are not directly comparable and people in these countries may differ in cultural and lifestyle patterns (Farooq and Coleman, 2005). To date only one UK-based study has explored BME women's breast cancer experiences (Blows *et al*, 2009). Blows *et al* (2009) conducted four focus group

interviews with 20 black and South Asian women. The women in this study raised concerns about communication issues. They expressed a preference for communicating in their mother-tongue, and described the varying availability of support from family and friends, together with cultural taboos and stigma surrounding cancer. They also experienced negative effects of breast cancer on their body image and femininity, and reported concerns about skin and hair care, and the use of prostheses and lymphoedema sleeves. Further UK-based research is needed in order to gain a better understanding of BME women's breast cancer experiences which can inform healthcare professionals about the delivery of culturally competent care. The need for such research in order to reduce health inequalities and improve BME patients' cancer experiences has also been highlighted in the Cancer Reform Strategy (Department of Health, 2007). This study aimed to obtain an in-depth understanding of black and South Asian women's experiences of breast cancer diagnosis and treatment in the UK.

## Method

### Study design

A qualitative approach, adopting a constructivist epistemology, was undertaken to gain an in-depth understanding of women's breast cancer experiences. Within the constructivist approach, the individual's reality, that is, their meanings and experiences, are socially produced within a given context, and are ever changing (Dures *et al*, 2010). Qualitative methods based on a constructivist approach have been found to be a valid method, allowing for exploration in areas where little is known (Liamputtong and Ezzy, 2005). Specifically, individual semi-structured interviews

were conducted. This process allows 'the emergence of the individual experience and the creation of a combined understanding of the phenomenon' (Darlaston-Jones, 2007, p. 24), and is particularly beneficial when exploring sensitive topics (Reid *et al*, 2005). A semi-structured interview schedule was developed using the current breast cancer literature as a guide. Topic guides were broad to allow women to share their experiences (see Table 1).

### Recruitment strategy

Participants were recruited via snowball and chain referral (recruitment of participants via multiple social networks) sampling. These have been found to be successful strategies when recruiting 'hard-to-reach' populations (Penrod *et al*, 2003). Various cancer support groups in areas that have the highest ethnic minority populations in the UK (London, Cardiff and Birmingham) were approached, via telephone calls and emails, to see if they would be willing to help with recruitment. Previous research has tended to concentrate on areas with the largest BME populations, such as London, Bradford and the West Midlands (Stirland *et al*, 2011).

The majority of the participants ( $n = 20$ ) were recruited via cancer-specific support groups. Group facilitators approached members of their support group on behalf of the researcher to see if they would be interested in participating. With the potential participants' permission, the support group facilitators forwarded their contact details to the researcher (GP). She then contacted each potential participant to explain the study in detail and to arrange a suitable time and place to conduct the interview. Two participants were recruited via snowball sampling.

**Table 1** Extract from interview guide

Topic	Exemplar questions
Diagnosis and treatment	How did you feel when you were told you had breast cancer? What kind of treatment(s) did you receive? How did your [family/partner/friends] react to your diagnosis/treatment?
Experiences of breast cancer in relation to ethnicity	How does your culture (or people in your community) deal with illnesses such as breast cancer? Is it openly talked about?
Overall thoughts	What has been the hardest thing for you to deal with since you were diagnosed with breast cancer? Do you have any concerns or feelings about the future?

## Sample

A total of 22 breast cancer survivors took part in this study, consisting of 11 black women (nine Caribbean, one African and one mixed white and black Caribbean) and 11 South Asian women (10 Indian and one Pakistani), who were residing in major cities in the UK, namely Cardiff ( $n = 1$ ), the outer areas of London ( $n = 20$ ), and Birmingham ( $n = 1$ ). All of the South Asian women were first-generation immigrants and had been living in the UK for an average of 32 years (range 9–42 years). Two of the black women had been born in the UK. The remaining nine were first-generation immigrants and had been living in the UK for an average of 30 years (range 9–50 years). The age range of the participants was 43–75 years (mean age, 54 years). The women's age at initial diagnosis was in the range 42–60 years (mean age, 48 years), and the time since initial diagnosis was in the range 1–15 years (mean time, 5 years). Table 2 provides a summary of the participants' demographic and breast cancer data, and Table 3 provides a list of definitions of medical terms.

## Procedure

Ethical approval was obtained from the School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol.

Interviews took place over a 6-month period in 2009. Participants were allowed to choose the language in which they wanted to share their experiences. All of the participants preferred to be interviewed in English, although there were times when some South Asian participants shared aspects of their experiences in their own language, namely Gujarati and Hindi. The interviewer (GP) has a fluent understanding of both these languages. At the beginning of each interview, the participant was given an information sheet to read. This sheet outlined in detail the purpose of the research and the nature of participation. They were then given the opportunity to ask questions and were reminded of both the confidentiality of their responses and their right to withdraw. They then read and signed the consent form. Demographic details were collected and the researcher commenced the interview.

On completion of the interview the participants were thanked for their time and given a £20 gift voucher in appreciation of their willingness to share their experiences. Offering incentives and subsidising costs such as travel have been found to be successful strategies for increasing participation rates among BME communities (Stirland *et al*, 2011). Recruitment of participants was difficult, and the researchers were advised by one of the support group facilitators that offering such an incentive might increase the number of participants from her group. Therefore this incen-

tive was offered to all of the participants, regardless of how they had been recruited. However, only the participants who were recruited from the support group whose facilitator made this suggestion were aware that they would receive this incentive before they expressed an interest in taking part (see Patel (2013) for a detailed account of the difficulties of recruiting hard-to-reach populations). The majority of the interviews took place in the participants' homes. All of the interviews were audio-taped and lasted for 37–135 minutes (mean duration, 79 minutes). The interview duration was very much dependent on how much each participant wanted to share. However, detailed responses were obtained by further careful probing during some of the shorter interviews.

## Data analysis

The interviews were conducted and transcribed verbatim by the first author. Comments made in Gujarati or Hindi were translated into English and transcribed. A qualitative software program, QSR NVivo (version 9), was used to analyse and manage the data in an organised manner.

The data set was analysed via inductive thematic analysis, which has been defined as a 'method for identifying, analysing and reporting patterns (themes) within data' (Braun and Clarke, 2006, p. 79). Braun and Clarke's step-by-step guide provided a bottom-up approach in which themes were closely related to the data. First, each transcript was read thoroughly several times, and notes were made where appropriate. A list of codes was produced and grouped into potential themes by creating a map of the codes and themes and generating themes and sub-themes. This was then reviewed in detail and further refined to ensure that the codes were relevant to each theme. Each transcript was re-read to check for additional coding and to ensure that nothing had been missed out in the earlier phases. Finally, the themes and sub-themes were checked to make sure that they told a clear story and captured the depth and breadth of the data.

The findings were verified by an independent qualitative researcher experienced in thematic analysis, who analysed 12 randomly selected transcripts as a means of validating the accuracy of the interpretations (Mays and Pope, 1995). Meetings with the researcher were arranged to talk through the data set and to resolve any disputes.

## Findings

Thematic analysis revealed five main themes, with sub-themes emerging within each of them. The

**Table 2** Participants' demographic and breast cancer data (*n* = 22)

Pseudo-nym	Age (years)	Ethnicity	Language(s) spoken	Religious affiliation	Country of origin	Time in the UK (years)	Marital status	Employment status	Age at diagnosis (years)	Time since diagnosis (years)	Treatment	Primary/secondary cancer
Anna	51	African	English	Christian	Kenya	11	Single	Unemployed	49	2	M, IR	Primary
Jean	47	Caribbean	English	Christian	Jamaica	10	In a relationship	Employed	43	4	L, C, R, M	Secondary
Corinne	50	Caribbean	English	Christian	Jamaica	21	Married	Employed	46	4	M, T	Primary
Amanda	43	Caribbean	English	Christian	Jamaica	25	Single	Employed	42	1	C, O, R, T	Primary
Isabelle	49	Caribbean	English	Christian	Jamaica	9	Divorced	Employed	48	1	C, M, R, T	Primary
Julia	51	Caribbean	English	Christian	UK	51	Single	Employed	43	8	L, C, R, T, A	Primary
Alexandra	57	Caribbean	English	Christian	Granada	44	Married	Employed	46	11	C, L, T	Primary
Rachel	43	Mixed white and Caribbean	English	Christian	UK	43	In a relationship	Employed	42	1	L, C, R, T, H	Primary
Angie	65	Caribbean	English	Christian	Jamaica	48	Widowed	Retired	58	7	L, R, T	Primary
Denise	75	Caribbean	English	Christian	West Indies	50	Widowed	Retired	60	15	L, C, R, T	Primary
Lauren	71	Caribbean	English	Christian	Jamaica	48	Widowed	Retired	56	15	M, T	Primary
Vanita	63	Indian	Gujarati, English	Hindu	Kenya	27	Widowed	Retired	55	8	M, R, T	Primary
Sanjani	57	Indian	Gujarati, English	Hindu	Kenya	9	Married	Employed	56	1	L, C, R	Primary
Anu	51	Indian	Gujarati, English	Hindu	Tanzania	36	Married	Employed	47	4	L, M	Primary

Table 2 Continued

Pseudo-nym	Age (years)	Ethnicity	Language(s) spoken	Religious affiliation	Country of origin	Time in the UK (years)	Marital status	Employment status	Age at diagnosis (years)	Time since diagnosis (years)	Treatment	Primary/secondary cancer
Fahima	62	Indian	Hindi, English	Hindu	India	39	Widowed	Retired	47	15	L, R, M, C, T	Secondary
Savita	48	Indian	Gujarati, English	Hindu	India	39	Married	Employed	45	3	L, C, R	Primary
Tanuja	50	Indian	Gujarati, English	Hindu	Tanzania	32	Married	Retired	46	4	Bilateral M, T, A	Primary
Nashida	50	Pakistani	Urdu, Hindi, English	Muslim	Kenya	24	Divorced	Unemployed	47	3	L, C, R, A	Primary
Raaksha	47	Indian	Gujarati, English	Hindu	Uganda	37	Married	Employed	44	3	C, L, R, H	Primary
Kaveeta	53	Indian	Gujarati, English	Hindu	Kenya	41	Married	Employed	50	3	L, R, T	Primary
Hema	50	Indian	Gujarati, English	Hindu	India	25	Married	Employed	49	1	L, C, R, A	Primary

**Table 3** Glossary of medical terms

Arimidex (also known as Anastrozole)	Type of hormonal therapy that reduces the levels of oestrogen in the body by blocking aromatase, an enzyme which helps to form oestrogen from other steroids
Breast reconstruction	The formation of a breast shape after a total mastectomy, using a synthetic implant or tissue from the woman's body
Chemotherapy	The use of anti-cancer drugs to destroy cancer cells
Herceptin (also known as Trastuzumab)	A type of biological therapy that is used to reduce the risk of breast cancer recurring in women with HER2-positive breast cancer
Lumpectomy (also known as breast-conserving surgery or wide local excision)	Surgical removal of a lump from the breast
Lymphoedema	Swelling of the arm or breast due to a build-up of lymphatic fluid
Mastectomy	Surgical removal of the breast
Primary breast cancer	Breast cancer that is confined to the breast and/or the surrounding area, such as lymph nodes
Radiotherapy	A type of treatment that uses high-energy X-rays to destroy cancer cells
Secondary breast cancer (also known as metastasis)	The spread of cancer to other organs in the body
Tamoxifen	A type of hormonal therapy that uses an anti-oestrogen drug to prevent oestrogen in the body from attaching to breast cancer cells

**Table 4** Themes and sub-themes

Themes	Sub-themes
Social support	Unlimited support Support from other breast cancer survivors
Spirituality	Spiritual faith and beliefs Fatalistic beliefs Punishment
Body image concerns	Altered appearance Use of appearance-related products Femininity issues
Healthcare experiences	Satisfaction with healthcare Gender of the healthcare professionals
Life after cancer	Changes to quality of life Thankful to be alive Altruistic tendencies

themes were social support, spirituality, body image concerns, healthcare experiences and life after cancer (see Table 4). Each theme is described below and

illustrated with extracts from the data. All of the names are pseudonyms.

## Social support

Being well supported was imperative in the women's experience. They talked about the amount of support they received from various sources and how this helped them to deal with their diagnosis and treatments.

### *Unlimited support*

The majority of the women spoke of receiving unlimited support from their family members, friends, work colleagues and support groups. They described this in terms of invaluable practical help with household chores (such as shopping, cooking and cleaning), emotional support (such as listening, and giving words of encouragement and positivity), moral support (such as visiting them in hospital and/or at home and going to hospital appointments with them) and informational support (through advice and/or leaflets about breast cancer):

I can't grumble ... I really can't grumble. I was supported at church, I was supported at home, I was supported.

(Julia)

Only the black women spoke of receiving support from community church members, who offered comfort by praying for and/or with them. Many South Asian women found that members of their community were unsupportive and would often make inappropriate remarks, which resulted in the women wanting to keep their cancer private and avoiding such negativity:

Somehow I thought I don't want to move towards that person, she's going to ask me something and she did. 'I thought you had it [her breast] chopped off and you're just running around like normal.' I said 'What's wrong with that? They haven't chopped my leg off.'

(Anu)

Although sources of support varied, family members and partners played a key role in supporting the majority of the women. Some women's family members, their sisters, mother or in-laws, moved in to support and care for them. Yet although the majority of the women were very well supported, a few described their support network as very limited, and they had to be proactive in finding appropriate care and support elsewhere:

I had no family to support me. I went to the library and just picked up a lot of books and self-trained you can say.

(Mina)

### *Support from other breast cancer survivors*

Attending support groups was described as a great source of help for the majority of the women. The

emphasis was on being around other breast cancer survivors who could understand what they were going through, particularly from a cultural perspective:

They [support group] gave us things and they catered for our colour.

(Julia)

Women often compared their own cancer experiences with those of other people. This made many of them feel better about their situation, particularly when they compared themselves with people who were worse off. Others felt better about their cancer when they compared themselves to women who were living positively with the disease and not allowing it to dominate their lives:

The Macmillan nurse would suggest you know 'Oh we have this group and would you like to come?' and that was very very encouraging. And I went along and there was this air hostess, very glamorous and you know sort of looking where was it [cancer]? And that gave me a lot of hope.

(Alexandra)

## Spirituality

This theme focuses on the varied spiritual attitudes that influenced women's experiences and facilitated acceptance and understanding of their cancer.

### *Spiritual faith and beliefs*

The majority of the women already held strong religious beliefs which strengthened after their diagnosis. As a result, they were praying more, reciting mantras, reading holy books, and listening to and singing religious hymns. They felt that this was instrumental in helping them to understand and deal with their cancer:

I'm a Christian and I believe in God and I know it was my faith that kept me going.

(Amanda)

### *Fatalistic beliefs*

From a religious perspective, some women believed that their cancer was predetermined by forces beyond their control, such as God. They believed that it was meant to happen, and this view consequently helped many of them to accept the cancer:

I've never questioned why me you know, it's God's wish.

(Lauren)

### *Punishment*

Other women questioned why they had developed cancer, and thought of it as a punishment from God.

They felt that they had done something wrong in life and were being punished for their bad deeds. This belief was further encouraged by members of their community who would insinuate that they must have done something to deserve it:

I used to think oh why God has done this to me. Look he chose me, what crime have I committed? What crime have I done that he chose me to give me this?

(Nashida)

Some spoke of their cancer in terms of *karma*, as being a consequence of having done something bad in their present or previous life. Going through the cancer journey was a way of repenting for their past mistakes:

You might have gone through something in life which you have to pay for now so it was part of payment to go through torture that I had probably created to somebody else.

(Raaksha)

## Body image concerns

This theme highlights the impact that treatment had on the women's thoughts and feelings about their appearance.

### *Altered appearance*

Women who underwent a mastectomy, chemotherapy and/or radiotherapy spoke of the devastating impact of losing their breast and/or hair, and of changes to their skin, such as tightening or discoloration. The side effects of hormonal therapy resulted in many of them gaining weight. The women described feelings of depression, distress, shame, embarrassment, and loss of self-esteem and positive body image:

I lost ALL my hair, I had long nice straight hair, they were ALL gone. ALL bald. And I never went out for two years! Two years I stayed home. I was too shy, too nervous to go out, tell people, apart from my appointments. Eyebrows, eyelashes all [gone] ... I was looking horrible.

(Nashida)

Some of the single and divorced women voiced their concerns about starting a new intimate relationship:

Well for one I'm very conscious of the fact that I have had the mastectomy so you know the thought of meeting somebody new scares me because then I have to tell them I've had a mastectomy and then they have to see the difference so you know I'm conscious of that.

(Anna)

Although changes to their appearance had an impact on them, some women tried to manage the situation and their feelings by seeking control. This included getting appropriate information from

others, maintaining their appearance regardless of the changes, and being proactive in managing the side effects of treatment (e.g. exercising to control weight gain, and shaving their head rather than waiting for their hair to fall out):

I felt good. I said I'm in charge here. It [hair]'s going to fall out and I'm going to get used to seeing myself in the mirror with a bald head.

(Sanjani)

### *Use of appearance-related products*

Women also attempted to manage both their own reactions to their altered appearance and the reactions of other people by equipping themselves with products such as wigs, scarves, prostheses and make-up. They described how this had helped to boost their confidence, and had enabled them to carry on as normal and to avoid the taboos and stigma associated with cancer. Yet although products were available to help women deal with their altered appearance, many expressed their dissatisfaction with the limited range of items such as wigs, prostheses and lymphoedema sleeves, and felt that culturally these did not meet their needs. Wigs designed specifically for South Asian and black women were limited and not readily available through the NHS, and these women found that they had to go elsewhere to buy a suitable wig. They also complained that they had problems getting breast prostheses and lymphoedema sleeves that matched their skin colour:

They [the wigs] were horrible. I think they [the NHS] need to look at the wigs because as a black person, I feel that those wigs don't suit black people. They're more of European type and we're the Caribbean people. I'm speaking from Caribbean side of people, them type of hair is not for us.

(Amanda)

### *Femininity issues*

Changes to the body raised issues of femininity which, for many of the women, had an adverse effect on their self-confidence. They explained how things that they believed defined them as women had been negatively affected by treatment. The onset of early menopause, surgery and hair loss made them feel less feminine:

Prosthesis or not ... when you undress fully, you are not a full woman.

(Mina)

However, a minority of the mastectomy patients did not feel that loss of a breast equated to loss of their femininity, and they continued to see themselves as whole women:

I'm still a complete woman. I still see myself as totally feminine.

(Anu)

## Healthcare experiences

This theme outlines how healthcare experiences were central to the women's stories about their cancer.

### *Satisfaction with healthcare*

The majority of the women were extremely satisfied with the healthcare that they had received. Healthcare professionals, particularly breast care nurses, were described as caring, sympathetic and very supportive. Consultants and nurses clearly explained the breast cancer process, including treatment side effects. The women felt reassured at each stage of their illness, and described the nurses as invaluable providers of informational, practical and emotional support. Being well supported, and particularly the aftercare that was received, was crucial in boosting the women's self-esteem and body image, and helped them to understand and accept their illness:

I was scared at looking in the mirror. For a week I didn't even look at myself in the mirror after surgery. It was horrible but then slowly and gradually the breast care nurse helped me.

(Tanuja)

However, not all of the women were satisfied with the care that they had received. Some felt that their healthcare team were not always empathetic or attentive to their needs, and that information about treatment was not always clearly explained. These women found their breast cancer experience to be very challenging, and felt they had to be proactive in obtaining emotional and informational support, for example, about support groups, treatment options and lymphoedema sleeves:

The consultants were very aloof ... you just don't feel comfortable talking about anything. Not empathetic, very aloof, very dismissive of any concerns you bring up and very detached from the patients. They just don't show any human feelings.

(Anna)

### *Gender of the healthcare professionals*

Culturally specific experiences of healthcare were also evident, in that South Asian women described being treated by male nurses as uncomfortable and embarrassing. This was something they could not avoid, since there were no female consultants or doctors available. They were also aware that reluctance to be examined by male healthcare professionals was common within their culture, which often resulted in

women avoiding examinations, and sometimes even avoiding treatment:

Radio[therapy], there are times when there are only men there and you know ... us Indians are a shy race and when it comes to sort of exposing your body in front of men it's a bit ... it's not very pleasant.

(Sanjani)

Thank God there were ladies over there because you have to take your top off.

(Nashida)

The need to be treated by female healthcare professionals was not mentioned by any of the black women in this study.

## Life after cancer

This theme outlines how the women viewed their life and reflected on it once their treatment was over.

### *Changes to quality of life*

For many women, the side effects of their treatment had a negative impact on their quality of life, and thoughts of their mortality were ongoing:

People don't realise it but half of your life is gone after this treatment. Your self-confidence, your mentality, your thoughts, you're in pain constantly and you always worry that you're going to die.

(Mina)

Some women spoke of additional chronic illnesses they had developed during and/or after their cancer treatment, such as arthritis, weak bones and lymphoedema, which further increased their feelings of depression, anger and frustration. For example, women with lymphoedema were worried about being in public places such as busy shopping malls or on buses because they would get pushed and knocked. However, many women remained positive, carried on with their lives and made practical adjustments to improve their quality of life. The women emphasised the need to look after and be more attentive to their body, by engaging in healthy behaviours.

### *Thankful to be alive*

Some women also sought to explain the cause of their cancer. A commonly held belief that breast cancer was a result of being stressed led many women to try to avoid undue worry. They had all taken time to reflect on this life-threatening experience, and described having a new-found appreciation of life. Many viewed life as too short for them to worry about trivial things, and although it was second nature to them to think of family before themselves, they learned that it was also important to prioritise their own well-being:

I'm quite happy cos I go out dancing, go on holidays and things like that and enjoy my life while I can.

(Lauren)

### *Altruistic tendencies*

The women described how they now felt very motivated to help to support other cancer patients by providing moral, practical and emotional support. Furthermore, they acknowledged the cultural taboos and stigma attached to illnesses such as cancer, which led women to be very private about their illness and sometimes reluctant to seek medical help because of shame, embarrassment and fear. This motivated them to try to overcome these barriers and raise awareness of breast cancer. This was done voluntarily. Feeling that they were making a difference to others made them feel good about themselves:

I am an Asian voice for Macmillan. I've given talks about my experiences and I feel good. I feel like I'm making a difference.

(Kaveeta)

## Discussion

This study has explored black and South Asian women's experiences of breast cancer. The findings add to the previously limited literature on breast cancer in BME women, and have provided an understanding of how psychological, social and cultural influences shaped the participants' experiences. The role of support, body image concerns, healthcare experiences and positive aspects of the experience (such as a new-found appreciation of life) have previously been documented in the mainstream breast cancer literature, which has predominantly captured white women's experiences (Knobf, 2007; Helms *et al*, 2008; Landmark *et al*, 2008; Shapiro *et al*, 2001). The findings of the present study show that although BME women's experiences of breast cancer are similar to those of white women, there are also aspects that are unique and shaped by socio-cultural norms, behaviours and beliefs.

As in previous research, family members, support groups and belief in God were regarded as important sources of support (Knobf, 2007; Koffman *et al*, 2008), but these varied. First, regardless of ethnicity, religion acts as a support mechanism for those who have a belief in a God (Levine *et al*, 2007; Swinton *et al*, 2011). However, previous research shows that BME groups are more likely to turn to religion for support, and often hold stronger beliefs in and affiliations associated with their religion, compared with white populations (Bourjolly and Hirschman, 2001; Koffman

*et al*, 2008). Religion and spirituality have been observed to play an integral role in the process of coping among BME breast cancer survivors (Banning *et al*, 2009; Gurm *et al*, 2008; Simon *et al*, 2007). The role of religion, evidenced through references to God as a source of support and internalising religious beliefs, shaped the experiences of women in the present study, thus adding to the current breast cancer literature and emphasising the varying role that religion can play among different ethnic groups.

As well as being a support mechanism, religious beliefs are beneficial in helping people to make sense of their illnesses. Religious beliefs based around fatalism and/or karma are widely held among South Asian communities, and reinforce the notion that God is in control of cancer and so will guide and protect them. These beliefs may help women to understand why they developed cancer in the first instance, and could help them to cope in a positive manner. However, it is also possible that such beliefs can result in passive acceptance. For example, women who accept the diagnosis as God's will may choose to do nothing about it, possibly avoiding treatment (Gurm *et al*, 2008).

Survivors also value support from other cancer patients whom they can relate to and with whom they can share information. Previous research has reported the benefits of support groups in increasing a sense of belonging, reducing isolation, increasing psychological well-being and improving quality of life (Coreil *et al*, 2004; Lydon, 2009). Although support groups for breast cancer survivors are widely available across the UK, they are more commonly made up of white English-speaking middle-class women (Avis *et al*, 2008). The women in the present study also found that the support they received from other breast cancer survivors was useful. In addition to receiving support from their peers, they described the importance of and their preference for gaining support from other breast cancer survivors whom they could relate to from a cultural perspective. This was important, as many of the women felt limited in their ability to seek information that was tailored to their cultural needs, for example, how to obtain culturally appropriate wigs and breast prostheses. This is something that support groups consisting predominantly of white women may not be able to offer, and as a result BME women are highly under-represented in such settings (Avis *et al*, 2008). However, support groups are not suitable for everyone. Although hearing positive cancer stories can be inspirational, some women avoid support groups because they do not want to be reminded of their cancer identity or risk feeling worse about their situation (Buunk and Gibbons, 2007).

The findings of the present study provide a more detailed view of the cultural beliefs about and attitudes towards cancer in black and South Asian communities, emphasising how such beliefs are particularly

fixed in first-generation immigrants who, despite having lived in the UK for most of their lives, continue to maintain strong cultural beliefs and practices from their country of origin (Meneses and Yarbrow, 2007). Similarities in beliefs about and attitudes towards cancer among the white and BME populations have been reported (Dein, 2004). These are often based around fatalism, stigmatisation, the perception of cancer as a death sentence, and misconceptions that cancer is contagious. The similarity of beliefs suggests that variables such as educational background, rather than ethnicity, can influence attitudes. BME communities have specific cultural beliefs about cancer. For example, particularly in the South Asian communities, modesty and honour are highly valued, and great emphasis is placed on women maintaining the family's honour and reputation (Bottorff *et al*, 1998). Therefore it is not considered appropriate to talk openly about an illness which can compromise the family's honour and bring shame upon them. It is also not considered appropriate for women to talk about or show their private body parts to others, especially men (Howard *et al*, 2007). This was evident among many of the South Asian participants who felt uncomfortable being treated by male healthcare professionals. These cultural beliefs have been reported in previous studies (Ashing-Giwa *et al*, 2004; Banning, 2011; Deepak, 2004; Gurm *et al*, 2008; Howard *et al*, 2007). It is important to note that cultural beliefs are not just present in black and South Asian communities but also in other ethnic groups, such as East Asian (e.g. Korean) and Middle Eastern Asian (e.g. Israeli) cultures (Ashing-Giwa *et al*, 2004; Baron-Epel *et al*, 2004; Harandy *et al*, 2010).

The findings of the present study with regard to concerns about appearance are supported by previous research which has identified similar body image issues among breast cancer survivors, regardless of ethnicity (Ashing-Giwa *et al*, 2004; Helms *et al*, 2008; Russell *et al*, 2008). Appearance-related products, such as breast prostheses or wigs, have been reported to help women to camouflage their loss, thus allowing them to carry on with their daily lives. However, studies rarely mention women's experiences of the suitability of such products. Some studies have reported problems with the use of products; for example, prostheses and wigs can be uncomfortable to wear (Gallagher *et al*, 2009; Roberts *et al*, 2003; Williams *et al*, 1999). However, the physical aspects of such products (e.g. colour, texture) are rarely mentioned (Frith *et al*, 2007; Rosman, 2004; Gallagher *et al*, 2009). It is possible that the study participants did not attach any importance to this and were generally satisfied with their products, or alternatively this aspect may not have been explored in great detail. The suitability or unsuitability of appearance-related products has been mentioned among BME breast cancer survivors,

and was particularly evident in the present study. From a cultural perspective, many women in the present study felt that their needs were not met due to the limited choice of suitable appearance-related products. This view was voiced particularly strongly by black women, especially when they talked about wigs. It is possible that black women report greater dissatisfaction with wigs because their hair texture is very different to that of other ethnic minority or majority populations. The lack of appropriate coloured prostheses, wigs and lymphoedema sleeves has been reported in previous studies of breast cancer in BME patients (Blows *et al*, 2009; Nelson and Macias, 2008; Wilmoth and Sanders, 2001), and the present study has highlighted the worry and distress that this can cause.

## Limitations of the study

All of the women who took part in the present study chose to be interviewed in English. They were able to clearly articulate their experiences, even though at times some of them chose to use their own language, particularly when repeating cultural sayings. The interviewer's understanding of Gujarati and Hindi enabled these women to speak in their mother tongue during the interviews in order to share their experiences in words that best expressed how they felt and allowed a natural conversation to flow. However, a limitation of this study is that it did not capture the experiences of women who were not fluent in the English language. It is possible that this group faces additional barriers compared with women who speak English fluently. The majority of the women were recruited through support groups, which suggests that they were actively seeking support or wanting to offer it to others. The support group facilitators announced the research at their meetings and made personal phone calls to members who might not attend the meetings. Consideration therefore needs to be given to the likelihood that the women who agreed to participate were self-motivated and comfortable talking about their experiences (Rees and Bath, 2000; Shelby *et al*, 2008). In this respect they may differ from the non-support group users; therefore the findings cannot be generalised. The women were predominantly black Caribbean or Indian, so they were not representative of the black and South Asian population as a whole. It is possible that women from other BME communities may have different experiences, particularly those with limited proficiency in English.

## Clinical and research implications

This study has demonstrated how BME women's cultural values, norms and beliefs contribute to their experiences of breast cancer. The findings have implications for healthcare professionals looking to provide patients with culturally appropriate care and support. Healthcare professionals may benefit from training and education that includes cultural awareness skills and diversity issues, especially in areas with large BME populations. Healthcare professionals who have taken part in cultural diversity training programmes have reported an increased awareness, confidence and ability to care for BME populations (Chevannes, 2002).

More research is needed to further enhance understanding in this area. Future studies should continue to explore the psychosocial impact of breast cancer in BME women, with particular attention to non-English-speaking groups. Further work is also needed to develop effective interventions, for example, workshops based on cognitive-behavioural therapy (CBT), since there is currently a dearth of evidence relating to the effectiveness of psychosocial interventions to address BME women's informational and support needs (National Cancer Equality Initiative, 2010). Although the participants were probed about the impact that cancer had on their relationship with their husband or partner, the majority of the women chose not to respond in great detail. It is possible that they did not feel comfortable talking about this subject. Future research may need to examine this issue in detail and consider alternative and sensitive methods that can be used to explore such issues.

In conclusion, this study adds to the existing small body of literature focusing on the psychosocial impact of breast cancer among black and South Asian women. The study highlights how in some respects their experiences are similar to those of white women, but also emphasises that certain aspects of their experiences are unique to black and South Asian breast cancer survivors, and are influenced by their socio-cultural norms.

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#### CONFLICTS OF INTEREST

None.

#### ADDRESS FOR CORRESPONDENCE

Dr Geeta Patel (Research Associate), University of the West of England, Glenside Campus, Blackberry Hill, Bristol BS16 1DD, UK. Email: [Geeta2.Patel@gmail.com](mailto:Geeta2.Patel@gmail.com)

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