

## Research papers

# Exploring the lived experience of breast cancer diagnosis and treatment amongst Gujarati-speaking Indian women

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### ABSTRACT

Breast cancer is the most commonly diagnosed cancer in females, affecting women of all ethnic groups. Until now, very little research has captured the psychosocial impact of the disease amongst Black and Minority Ethnic (BME) women, and that which has been conducted has been restricted to English-speaking participants. The aim of this qualitative study was to explore the experiences of five Gujarati-speaking Indian women with regard to their breast cancer diagnosis and treatment; all five had Limited English Proficiency (LEP) and lived in the UK. Individual semi-structured interviews were conducted in Gujarati, with the assistance of an interpreter.

Interpretative Phenomenological Analysis (IPA) of the data revealed 3 key themes: making sense of the cancer, importance of support and body image concerns. The findings show that these women's experiences were influenced by culturally specific concerns, especially in relation to knowledge of breast cancer and language barriers. This study has implications for healthcare professionals in terms of providing culturally competent care and support to BME women with LEP.

**Keywords:** Breast cancer, South Asian, Psychosocial, Indian, Gujarati, Non-English speaking

### What is known about this subject?

- Breast cancer is one of the most common forms of cancer in all ethnic groups.
- Black and Minority Ethnic groups are under-represented in the psychosocial breast cancer literature.
- Potential participants who are not fluent in the English language are often excluded from research studies because of language barriers.

### What this paper adds

- An in-depth understanding of the experience of breast cancer diagnosis and treatment amongst Gujarati-speaking Indian women with Limited English Proficiency (LEP).
- Qualitative evidence that highlights the importance of providing information in patients' preferred language in order to provide the best possible care and support for those with LEP.
- Support for previous research and policy calling for healthcare professionals to be aware of patients' cultural and language needs in order to provide them with culturally competent care and support.

### Introduction

Breast cancer is the most common form of cancer in women of all ethnic groups (Breast Cancer Care, 2005). In 2011, 49,936 women in the United Kingdom (UK) were diagnosed with the disease (Cancer Research UK, 2014). UK data, albeit limited, suggest that South Asian women have a lower incidence of breast cancer than non-South Asian women (Farooq and Coleman, 2005; Zaman and Mangtani, 2007, Box 1). However, incidence rates are higher amongst South Asian women living in the UK

than those living in the Indian sub-continent (Jain, Mills and Parikh-Patel, 2005). The incidence is expected to rise further as Black and Minority Ethnic (BME) groups become more acculturated and adopt Western lifestyles (Velikova et al, 2004). Furthermore, data within the UK suggests that South Asian women tend to be diagnosed at a younger age, at an advanced stage of disease and with larger tumours than White women (Farooq and Coleman, 2005; Velikova et al, 2004), and rates of mastectomy are higher amongst South Asian women (Velikova et al, 2004). These differences suggest that South Asian and

White women's breast cancer experiences may differ. However, research into the psychosocial impact of breast cancer has predominantly been conducted on White women and very little attention has been paid to those from BME groups, particularly South Asian women (Knobf, 2007; Thompson et al, 2008).

The existing, but limited, research conducted with South Asian breast cancer survivors has found that their experiences are influenced by socio-cultural norms, behaviours and beliefs (Balneaves et al, 2007; Banning et al, 2009; Bottorff et al, 2007; Howard, Bottorff, Balneaves and Grewal, 2007; Gurm et al, 2008). For example, Howard et al (2007) explored the experiences of 12 Canadian Punjabi women and highlighted their emotional reactions to their diagnosis, the impact the diagnosis had on their families, the importance of family support, the challenges associated with the stigma of the disease and the importance of religion in terms of beliefs and as a support mechanism. Another qualitative study with 20 Canadian Punjabi breast cancer survivors also found that participants' experiences were shaped by their cultural background (Gurm et al, 2008). Many women wanted support from other breast cancer survivors but felt isolated because of cultural pressures to keep personal issues, such as ill-health, private. Their distress was further exacerbated by the judgemental and insensitive comments they often received from other community members, particularly those described as uneducated and older. Receiving information and talking to others in their own language was important to these women, as was spirituality and religion in helping them to manage their feelings about the situation.

Whilst these two studies contribute to the limited literature about BME women with breast cancer, both were conducted in Canada. It would be inappropriate to assume that the findings can be generalised to the UK, particularly as the healthcare systems in the two countries are not directly comparable; there may also be differences in culture and lifestyle (Farooq and Coleman, 2005). In addition, although Howard et al (2007) and Gurm et al (2008) provide valuable insight into the experiences of one specific BME sub-group their findings are not necessarily representative of other South Asian groups. There is considerable diversity between South Asian groups, for example, in terms of religion, language, cultural beliefs and traditions, even though they share similar ancestry (Ahmed and Lemkau, 2000).

Breast cancer research amongst the BME population in the UK is scarce (Banning, 2011). To date, only two UK-based studies have explored this phenomenon (Blows et al, 2009; Patel

et al, 2014). Patel et al (2014) interviewed 22 Black and South Asian breast cancer survivors and highlighted the importance of social support, spirituality and body image concerns resulting from treatment. Women's experiences were also influenced by socio-cultural norms and beliefs. Similarly, Blows et al (2009) conducted focus group interviews with 20 Black and South Asian women, and also described how social support, body image, and cultural influences, such as taboos about cancer, affected the women's experiences. Furthermore, women expressed a preference for wanting to communicate with healthcare professionals and other breast cancer survivors in their mother-tongue. However a limitation of both these studies, and of most other research with BME groups, is that they excluded potential participants who were not proficient in the English language. These people are often excluded from research due to language barriers and practical reasons, such as the cost of and difficulty in using interpreters or validating questionnaires in other languages (Blows et al, 2009; Stirland et al, 2011). This is unfortunate as women with Limited English Proficiency (LEP) may encounter barriers to accessing healthcare services which can hinder their ability to communicate their concerns and health problems clearly, or lead them to avoid seeking medical advice entirely (Deepak, 2004).

Some American and Canadian studies have recognised this limitation and included women with LEP (Ashing et al, 2003; Bottorff et al, 2007; Howard et al, 2007; Gurm et al, 2008) but, to date, no UK based research has explored the experiences of breast cancer in women with LEP. It is important that groups with LEP are included in research so that their experiences are understood in order to guide healthcare professionals in providing culturally competent care and to help reduce inequalities in healthcare. The present study builds from the limitations of our previous study (Patel et al, 2014), and therefore aims to explore the experiences of one specific group of women with LEP, namely Gujarati-speaking Indian women, who had previously been diagnosed and treated for breast cancer (Box 2).

## Method

### Design

A qualitative approach based on phenomenological epistemology was used as this allows researchers to explore participants' lived experiences in detail. Individual interviews were conducted, using a semi-structured interview schedule which was developed based on the existing breast cancer

**Table 1:** Extract of Interview guide.

Topic	Exemplar questions
Diagnosis and treatment	<ul style="list-style-type: none"> <li>• How did you feel when you were told you had breast cancer?</li> <li>• What kind of treatment(s) did you receive?</li> <li>• How did your [family/partner/friends] react to your diagnosis/ treatment?</li> </ul>
Experiences of breast cancer in relation to ethnicity	<ul style="list-style-type: none"> <li>• How does your culture (or people in your community) deal with illnesses, such as breast cancer?</li> <li>• Is it openly talked about?</li> </ul>
Overall thoughts	<ul style="list-style-type: none"> <li>• What has been the hardest thing for you to deal with since you were diagnosed with breast cancer?</li> <li>• Do you have any concerns or feelings about the future?</li> </ul>

**Box 1:** The term South Asian refers to people originating from the Indian sub-continent, including countries such as India, Pakistan, Bangladesh, Sri Lanka, Nepal and Bhutan (Bhopal, 2007).

**Box 2:** Gujarat is a state in the Western part of India, where the principle language spoken is Gujarati.

literature. Broad topics were used to encourage women to share their experiences (table 1).

The study focused on Gujarati speaking Indian women with LEP as this language is the lead researcher's (GP-K) mother-tongue. However, her understanding of Gujarati is better than her verbal skills and so she was assisted by a professional interpreter who asked some of the questions during the interviews.

### Interpreter

A professional female interpreter, with over 22 years' experience, who was fluent in Gujarati and its various dialects was employed to assist in this study. She also had an understanding of health terminology and experience in dealing with sensitive health issues. Before the interviews began, the lead researcher (GP-K) met with the interpreter to discuss the aims of the study and their respective roles during the interview process. The interpreter's role was to translate the researcher's questions to the participants, if necessary, since the researcher's understanding of Gujarati meant she was able to ask most questions and understand participants' replies. The interpreter was also required to sign a confidentiality agreement form, which stated she would not divulge any information to third parties and would respect the confidentiality of the study at all times.

### Recruitment

All the women were recruited from the London region. Two were recruited via the Asian Women's Breast Cancer Group (AWBCG). Support group facilitators announced recruitment of participants for this study in their monthly meetings. Two women expressed an interest and gave permission to the group facilitators to forward their contact details to the researcher. Another 3 participants were recruited via snowball sampling (introduced to the researcher through Indian community events, such as annual social gatherings). The researcher telephoned each potential participant to explain the study in detail and to arrange a suitable time and place to meet. These conversations took place in Gujarati.

### Sample

Five women agreed to take part. They were all first generation immigrants and had been living in the UK for an average of 36 years. Three were from India and two from Kenya. Their ages at the time of interview ranged from 55 to 76 years (mean 66 years). Age at initial diagnosis ranged from 29 to 69 years (mean 51 years) and time since initial diagnosis ranged from 4 to 32 years (mean 15 years). All the women had a diagnosis of primary breast cancer. Three had undergone a mastectomy

and 2 had had a lumpectomy. Four had also undergone one or more adjuvant therapies (chemotherapy (n = 1), radiotherapy (n = 3), Tamoxifen (n = 2) and Arimidex (n = 1). See table 2 for a summary of the participants' demographic and disease/treatment-related information.

### Procedure

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

At the beginning of each interview, participants were given an information sheet to read and the consent form to complete. The information sheet outlined the purpose of the research and nature of participation in detail. Both the information sheet and consent form were prepared in English. As many of the women were unable to read in English or Gujarati, the interpreter verbally went through the information sheet with them. It was for this reason, that the information sheet was not translated into Gujarati (and also due to the variation in dialects). On understanding the information sheet, participants were given the opportunity to ask any questions. They were reminded of the rationale of the study and their right to withdraw. The confidentiality of their responses was also emphasised. Once satisfied with the information provided, participants were required to sign the consent form before the interview commenced.

All the interviews were conducted in Gujarati, predominately by the researcher, with assistance from the interpreter to relay the interview questions, if necessary. Four interviews took place in participants' homes in London. The final interview took place at the participant's local library, in a private room. All the interviews were audio-recorded and lasted between 55 and 74 minutes (mean = 67 minutes). On completion of the interview, participants received a £20 gift card to thank them for sharing their experiences.

### Data Analysis

The interviews were translated and transcribed into English by the researcher (GP-K) and checked for accuracy by the interpreter. Any discrepancies in the translations were discussed and amended accordingly.

Interpretative Phenomenological Analysis (IPA) was used to analyse the data, using Smith and Osborn's (2003) step-by-step approach. IPA is 'concerned with the detailed examination of individual lived experience and how individuals make sense of that experience' (Eatough and Smith (2008) p179). This method of analysis has become an established analytic method within the realms of health psychology; particularly when exploring

**Table 2:** Participant demographic and breast cancer information (n = 5).

Pseudonym	Age (years)	Ethnicity	Spoken language	Religious affiliation	Country of Birth	Time in the UK (years)	Marital status	Occupation	Age at Diagnosis (years)	Time since diagnosis (years)	Treatment (in order)	Primary/secondary cancer
Hansa	60	Indian	Gujarati	Hindu	India	34	Widow	Retired	56	4	M, C	Primary
Alpa	55	Indian	Gujarati	Hindu	India	36	Widow	Retired	29	26	M, R	Primary
Manjula	76	Indian	Gujarati	Hindu	Kenya	32	Married	Housewife	44	32	M	Primary
Raksha	76	Indian	Gujarati	Hindu	Kenya	38	Widow	Retired	69	7	L, R, T, A	Primary
Deepa	61	Indian	Gujarati	Hindu	India	40	Widow	Retired	55	6	L, R, T	Primary

Treatment: M = Mastectomy; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; T = Tamoxifen; A = Arimidex

illness experiences such as cancer, chronic pain and heart disease (Smith, 2011) and is appropriate for use with a small sample size, ranging between 3 and 6 participants (Smith and Osborn, 2003).

A qualitative software programme, QSR NVivo (version 9), was used to analyse and manage the data. Each transcript was read several times, noting interesting points in the left-hand margin. The right hand margin was then used to document emergent theme titles. This was then studied in detail, modified and further developed until a master list of themes was created. A final table consisting of themes and sub-themes was constructed. The interpretations were verified by an independent researcher (PV), who is familiar with researching populations drawn from BME groups and experienced in conducting IPA, to ensure the validity of the data (Reid et al, 2005). At this stage, the independent researcher was presented with three of the five transcripts (chosen at random) to study and check that the themes provided a clear and accurate account of the participants' experiences. Any concerns were discussed but on the whole, the independent researcher was in full agreement of the initial interpretations.

## Findings

IPA of the dataset captured the women's experiences of breast cancer diagnosis and treatment through three main themes (with sub-themes emerging within each theme): 1) 'Making sense of the cancer', 2) 'Importance of support' and 3) 'Body image concerns'. Each theme is described in detail below with extracts from the data and using pseudonyms throughout.

### Making sense of the cancer

All the women described their experiences of breast cancer as being very difficult and distressing. For some, this was the first time they had heard the word 'cancer', which prompted feelings of shock and confusion. It was important for them to be able to understand the concept of cancer and make sense of it in order to accept and manage their experiences.

#### ● Limited understanding

At the time of diagnosis, the women's understanding and awareness of breast cancer was very limited. They were unaware that a lump can be serious and potentially related to cancer or that cancer symptoms can be asymptomatic. Ignoring symptoms resulted in a delayed diagnosis for Deepa and Raksha:

'I found a lump. I just ignored it thinking it happens, you know.' (Deepa)

'This [points below her armpit] became very hard and would hurt but I just thought it's nothing so I didn't do anything about it.' (Raksha)

Some also stated that they were unaware of an illness such as cancer which can vary in type and affect different parts of the body. Throughout the diagnosis and treatment period, the women's knowledge and understanding of breast cancer, and cancer in general, was increasing.

'When I went for my treatment, that's when I saw that SO MANY people get cancer. You see that some don't have a right [breast], some don't have a left [breast] and then you can get

cancer anywhere can't you? And there was purple marks on a man there. So I asked someone. I said "why does he have purple marks there", and she said "because he has cancer there". I was shocked seeing that, that day. Before that I thought I was the only one.' (Alpa)

While Alpa's understanding of her illness was increasing, she also felt that her limited ability to communicate in English hindered her ability to find out more or ask questions. This was a commonly held view amongst all the women.

'At times you do want to know more but because you don't know how to and can't speak [in English], you just sit there quietly.' (Alpa)

However, many of the women acknowledged that over time, this has become less of a problem as information in their mother-tongue is now readily available, prompting them to understand their illness more.

#### ● Searching for answers

The unexpected diagnosis led the women to want to understand why and how they had developed cancer. For example, Deepa believed that breastfeeding reduces one's risk of developing breast cancer and therefore was confused as to why she had developed the disease.

'I felt like why has it happened? I don't know. I have breastfed all my children and I still got it so I don't know.' (Deepa)

However, Manjula did not want to understand the cause and believed her diagnosis was out of her control. She accepted her diagnosis as part of her fate and attributed it to being God's will. Some women also discussed their diagnosis in relation to karma, fate, and believed they had to endure the illness to make amends for bad deeds from their past lives. However, there were times when the treatments would get too much to bear, leaving some women temporarily feeling like the cancer was an act of punishment from God.

'I just thought it was written for me, it was my fate.' (Manjula)

'What we have done in our past life will happen to us. It's not God's fault, it's our doing.' (Deepa)

'At the beginning when I found out, I thought why me? Why did God choose me?' (Alpa)

### Importance of support

As the women told their stories, it became evident that support, particularly from their family members, was very important in helping them get through their experiences of diagnosis and treatment.

#### ● Sources of support

Family members, particularly immediate family, were described as providing practical support such as taking participants to hospital appointments, helping with household chores, assisting with tasks such as bathing or brushing their hair, which the women found difficult after surgery, and caring for other family members.

'He [husband] would do all the house work. And when I had

my operation, my son had an operation on the tonsils. So he was in hospital, I was in hospital and my eldest son would go to school. And my husband would go work, drop him to school, then come to see me and then go see the other son. So my husband was very supportive. He would cook for me too' (Alpa)

Hansa had very little family around to support her, yet still felt well supported as she reached out to her friends and community members.

'I didn't feel alone. [Friend] was always with me. She used to visit me every day.' (Hansa)

Participants described how faith in God was an important source of support and engaging in religious activities, such as praying, helped them. While some women accepted their illness as being God's will, they also believed that God would give them strength and help them to overcome it.

'Even though God gave me this cancer but along with that he sent me very good treatment and support and gave me strength that I needed to get over it.' (Manjula)

Healthcare professionals were also described as supportive, with nurses providing women with emotional support, reassurance and encouragement throughout the cancer journey.

'I was shattered and the nurse came and gave me encouragement and consoled me.' (Manjula)

#### ● Being dependent on others

All of the women who took part in this study were very limited in their ability to understand and communicate in English. For this reason, they relied heavily on others (typically family members) to accompany them to hospital appointments and act as interpreters. This often meant that healthcare professionals would communicate with the family members instead of talking directly to the patient, expecting the family member to pass the information on.

'They would explain everything to [niece], not me. But they did explain things to her.' (Hansa)

To some extent this enabled some women to feel involved in consultations and informed at each stage but others acknowledged that relying on family members to translate information meant they might not always get a detailed understanding and that information could be lost in translation if, for example, family members or children were unable to fully understand all the information themselves. Nonetheless, women preferred to rely on family members or close friends who they knew and felt comfortable with, rather than relying on professional interpreters.

'I can't understand English well or read it and when you ask them [children], they read it once and tell you the main things but kids don't explain everything in detail do they?' (Deepa)

While Raksha, Deepa and Manjula relied on fluent English-speaking family members to interpret information, Alpa and Hansa depended on people who did not speak the language very well. This did not concern Alpa or Hansa because, even though their interpreters spoke only basic English, they still felt that they still understood the main information.

'I wouldn't understand much but my husband would. His English wasn't good but it was better than mine.' (Alpa)

Although the women in this study had had to rely on others to help them overcome language barriers, some voiced their concerns about burdening others with their problems as it often meant family members would need to take time off from work in order to be present.

'Someone would always be with me but I did think that it would be nice if I knew it [English] then it's better, then you wouldn't have to waste her [daughter-in-law] time but I can't communicate everything' (Raksha)

While some women felt they had no choice but to rely on their family members, others tried to avoid inconveniencing them by attending hospital appointments alone and 'getting by' with their limited grasp of English. This limited their understanding of the information they received and also prohibited them from asking for further advice and information. For example, when asking Deepa if the hospital staff had given her information about financial support that she might be eligible to receive, she replied by saying:

'They may have but I don't understand English too well.'

'I would just guess what they are saying. Even now I go to the hospital on my own and some things I don't understand but I guess as to what they may be saying.' (Deepa)

Relying on family members and other people to act as interpreters also meant that treatment decisions were often made as a family. In these circumstances the family helped the women to make decisions about the best treatment for them. In many cases, the women were satisfied with this format as they felt they had been informed and involved in the decision making process and ultimately placed greater trust in literate and educated family members.

'They [daughter] would still understand that little bit more than me as they have grown up here [UK]. So she said to me "Mummy what's the point in taking it all out". They [consultant] did say that it will take a couple of years for it to fill but after that it will be normal whereas if you do the other [mastectomy], then you could get an artificial one [reconstruction]. So my daughter said rather than do the artificial thing, it's better to have some of your breast. So I said okay we'll do it that way.' (Deepa)

### Body image concerns

#### ● Effects of treatment

The extent and nature of appearance-related concerns were dependent on the type of treatments that women underwent and the side effects they had experienced. Three had undergone a mastectomy and these women spoke of the impact this had on their body image. For example, Manjula felt that she had lost an important part of her body, and no longer felt balanced or 'whole', which resulted in not feeling feminine enough. Some women also expressed feeling body conscious, especially when going out in public and, as a result, limited their social activities. Women felt that wearing a breast prosthesis helped them to overcome their body image concerns and helped them to regain their body shape. Such feelings were more prominent during the time the women underwent their treatments. However, over

time and as the women accepted their altered appearance, these feelings became less of an issue.

'Initially I did feel like less of a woman but now it's all forgotten, it's in the past.' (Manjula)

'At the beginning it was all new but now I go swimming, sauna, everywhere. I don't even put a pad [prosthesis] in either. I don't feel like I will be embarrassed or anything like that.' (Alpa)

Hansa was the only participant who received chemotherapy treatment and concerns about losing her hair were evident as she took measures to avoid hair loss by wearing a cold cap to cool the scalp in order to prevent or minimise hair loss. She also dealt with this issue positively by reassuring herself that the hair loss would be temporary.

'There's no use in worrying. If they [hair] go they go, if they stay they stay [laughs].' (Hansa)

#### ● Importance on being alive

All the women underwent changes to their appearance of some kind or another as a result of treatment, but Deepa and Raksha were not particularly concerned by the changes they experienced. Instead, they placed greater emphasis on their health and being alive. They also felt that due to their age, appearance issues were not so important. They believed they were less bothered by the changes than younger women would be, as these women likely to be more invested in their appearance.

'I'm not ...into my body...yeah I am into my body as in it should work properly, or walk or get you to places.' (Deepa)

'I'm not too bothered. Younger people would feel it more.' (Raksha)

## Discussion

This study has offered an insight into the experiences of Gujarati-speaking Indian breast cancer survivors living in the UK. The findings of the study show the importance of social support, body image concerns, cultural beliefs and the need for an awareness and understanding of breast cancer. These findings support previous studies that have explored the experiences of South Asian women (both English speaking and those with LEP) who have been diagnosed and treated for the disease (Bottorff et al, 2007; Howard et al, 2007; Gurm et al, 2008; Blows et al, 2009; Patel et al, 2014). The findings also concur with the results of research involving breast cancer survivors from other BME groups (Ashing-giwa et al, 2004; Blows et al, 2009; Patel et al, 2014). Furthermore, the present study particularly captures women's experiences from a cultural perspective, specifically in relation to language.

The women in this study had very little knowledge of cancer before receiving their own diagnosis. There is evidence of a lack of knowledge and awareness about breast cancer amongst White and other BME populations (Dein, 2004) but women with LEP are even less likely to know about this disease (Bottorff et al, 2007; Howard et al, 2007). An additional factor is that, despite living in the UK for most of their lives, first generation immigrants maintain strong cultural beliefs and practices from

their country of origin, and do not socialise with members outside of their community (Meneses and Yarbro, 2007). This can be especially true for those with LEP and can result in people associating with other people whose knowledge about cancer is inaccurate or limited. This can possibly explain why the women in the present study had very little knowledge of breast cancer. Lack of knowledge about cancer may also be linked to cultural taboos and stigma which result in an avoidance of open discussion about the disease (Scanlon and Wood, 2005). It is also possible that the limited availability of information and educational materials about breast health and cancer in languages other than English contributed to the women's limited knowledge and understanding of breast cancer, particularly at the time when the women in this study were diagnosed.

Our study also emphasises the impact that language barriers can have on women's experiences of breast cancer. Their inability or lack of confidence in communicating in English appears to have contributed to a limited understanding of their condition and resulted in them being unable to gain the full extent of information and emotional support potentially available from healthcare professionals. Language barriers appear to have resulted in many women adopting a passive role in consultations. Other studies have reported that patients with LEP value the importance of shared language in communicating with health professionals. They also benefit from receiving printed information in their own language to aid their understanding of their condition (Kumar et al, 2004; Gurm et al, 2008; Blows et al, 2009).

The present study highlights the importance of family, both as a source of support and to help overcome language barriers, with family members acting as interpreters during health consultations. It is interesting to note that only one woman in our study was aware that professional interpreters could be requested, and she discovered this after she had been diagnosed and treated. It could be that professional interpreter services were less readily available at the time the women in our study were treated. Alternatively, health professionals may not have been aware of the need for interpreters or how to access such services. The provision of interpreter services has improved in recent times; guidelines and policy documents now explicitly recommend the use of interpreters in addressing the healthcare needs of patients with LEP, and also provide information on how to access interpreters (Department of Health, 2004; NICE, 2004; NHS Health Scotland, 2008; Pankhania, 2011). While patients often prefer to use family members as interpreters (Grewal et al, 2005) and healthcare professionals also rely on family members to take on this role (Gerrish, Chau, Sobowale and Birks, 2004), there is a danger that family members may not always relay information accurately between patients and health professionals. This is especially true for family members who themselves are not entirely fluent in English but who may be the only ones available to translate the information.

The breast cancer literature has consistently reported the negative impact of treatment on women's body image, regardless of ethnicity (Ashing-Giwa et al, 2004; Helms et al, 2008; Russell et al, 2008; Patel et al, 2014). Whilst the women in the current study expressed appearance-related concerns, an emphasis on being alive and regaining health was also embedded in their

stories. Factors such as age may help to explain this finding as some women expressed the view that younger women may be affected more than they had been themselves. Previous research has reported that while breast cancer is distressing for women at any age, it tends to have a greater adverse impact on younger women (Avis, Crawford and Manuel, 2004; Baucom et al, 2006; Bloom et al, 2012).

### Methodological considerations

All the participants in this study were Gujarati-speaking Indian women, which allowed the researcher to personally conduct the interviews with support from an interpreter; this facilitated a detailed and natural conversation. Previous research has highlighted the potential complications of a heavy reliance on an interpreter, including the level of accuracy in relaying questions and responses (Farooq and Fear, 2003; Flores et al, 2003; Pitchforth and van Teijlingen, 2005; Flores, 2005). This issue of accuracy was also evident in the current study but was detected due to the researcher's understanding of Gujarati. For example, in the first interview, one of the questions to be translated to the participant was "How were you told about the cancer". The interpreter reworded the question and added a question of her own, saying "How did they [healthcare professionals] tell you? Did they tell you straightaway?" This resulted in the participant responding to the latter question and replied by saying "Yes they told me straightaway". It was due to the researcher's (GP-K) understanding of the language that allowed her to detect such inaccuracies. This happened on a few occasions during the first interview. These errors were discussed with the interpreter after the first interview and it was stressed that the researcher's questions be translated as accurately as possible for subsequent interviews.

Members of South Asian and other BME communities are often excluded in research, especially if they have LEP (Stirland et al, 2011). The researcher's South Asian background and ability to speak in Gujarati may have helped recruit participants for this study. Other non-Gujarati speaking South Asian communities were excluded from the sampling process and their experiences require investigation. The women were all recruited from the London area and therefore the findings may not be representative of South Asian breast cancer survivors with LEP across the UK.

### Implications

These findings have implications for healthcare professionals wishing to provide culturally appropriate care and support to South Asian women with breast cancer. It is important that patients with LEP are provided with detailed information in their own language, together with an opportunity to ask questions, in order to facilitate an understanding of their diagnosis and treatment. It is also possible that women whose first language is not English yet have a fluent understanding of the English language may also find this useful and prefer to receive information in their mother-tongue. Healthcare professionals should also be aware that not everyone, particularly first generation immigrants, can read or write in their own language (as was the case in the present study). Ideally, information should also be available using other media such as audiotapes, CDs, DVDs or videos. These have been reported to be beneficial

in overcoming literacy barriers and deemed an effective mode of delivering information to patients with LEP (Husson et al, 2010).

It is important to acknowledge that the women in this study were diagnosed and treated for cancer some time ago. Information about breast cancer is now readily available in many South Asian languages (Macmillan Cancer Support, 2014). Furthermore, Macmillan have set up the first national interpreting telephone cancer helpline service, which is available in over 200 languages. The provision of interpreters during consultations can encourage effective communication between the patient and healthcare professionals, and enhance the patient's understanding and knowledge of health related issues (Szczepura, 2005). It is important to note that the onus for effective communication need not be entirely on health professionals; they may not know that patients lack fluency in English until they arrive at the consultation. Interpreters need to be booked in advance and patients should inform healthcare professionals that they need an interpreter. However, in our study, several women were unaware of the potential for such services to be provided. Barron et al, (2010) noted in their study that participants from BME groups were also unaware that healthcare professionals could access interpreting services during medical appointments if requested. This problem could be overcome if the patient's language ability and need for an interpreter were to be assessed at the point of referral. It would also be useful for GPs to inform patients of the availability of interpreter services in secondary care settings should the patient need them.

### Conclusion

This is, to the best of our knowledge, the first UK-based study to explore breast cancer diagnosis and treatment amongst Gujarati-speaking Indian women who have limited proficiency in English. The results offer insights into the psychosocial impact of breast cancer in Indian women with LEP, specifically from a cultural perspective. The study adds to the existing BME and breast cancer literature and offers valuable pointers to improve effective communication between patients and healthcare professionals. Future studies should continue to explore the psychosocial impact of breast cancer amongst BME women, paying particular attention to other non-English speaking groups.

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### CONFLICT OF INTERESTS

None

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