The psychosocial experiences of breast cancer amongst Black, South Asian and White survivors: Do differences exist between ethnic groups?

Geeta Patel-Kerai<sup>1</sup>, Diana Harcourt<sup>1</sup>, Nichola Rumsey<sup>1</sup>, Habib Naqvi<sup>2</sup>, Paul White<sup>3</sup>

<sup>1</sup>Centre for Appearance Research, University of the West of England, Bristol, UK <sup>2</sup>NHS England, UK

<sup>3</sup>Department of Engineering Design and Mathematics, University of the West of England, Bristol, UK

## Abstract

*Objective:* Very little UK-based research has examined breast cancer-related experiences of Black and Minority Ethnic populations, and we do not know whether the psychosocial impact of diagnosis and treatment in this group is any different to that of White women. Therefore this study examined similarities and differences amongst Black, South Asian and White breast cancer survivors (BCS).

*Methods:* A quantitative, cross-sectional survey was conducted. 173 BCS (80 White, 53 South Asian and 40 Black) completed a questionnaire which assessed psychological functioning, social support, body image and beliefs about cancer.

*Results:* Significant differences (p<0.05) were reported between White and South Asian participants: Compared with White women, South Asian participants reported higher levels of anxiety and depression, poorer quality of life and held higher levels of internal and fatalistic beliefs pertaining to cancer. Black and South Asian women reported higher levels of body image concerns than White women, and held stronger beliefs that God was in control of their cancer. South Asian women turned to religion as a source of support more than Black and White women.

*Conclusion:* This study enhances current understanding of the experience and impact of breast cancer amongst Black and South Asian women, and demonstrates similarities and differences between the ethnic groups. The findings highlight implications for healthcare professionals, particularly in relation to providing culturally sensitive care and support to their patients.

Keywords: breast cancer, oncology, psychosocial, ethnicity, Black, South Asian.

#### Introduction

Breast cancer is the most common type of cancer worldwide. The latest United Kingdom (UK) data shows that more than 50,000 women were diagnosed with the disease in 2011 [1]. An extensive body of research has documented the various psychosocial issues associated with its diagnosis and treatment, including depression, anxiety, body image issues, variations in support networks and social stigma associated with the disease [2, 3], all of which can have a profound impact on patients' quality of life. The majority of this research has been conducted with White women and very little attention has been paid to the experiences of Black and Ethnic Minority (BME) women, particularly in the UK [4].

The most recent available figures, based on the 2011 Census, show that more than 8 million people living in the UK are from ethnic minority groups [5]. Black and South Asian populations represent the largest ethnic minority communities (8.8%). The need to conduct research on BME populations is reinforced by the UK's increasingly diverse multi-ethnic society. Researching Black and South Asian women's experiences of breast cancer is important for two reasons. First, these women may be influenced by elements of their cultural backgrounds (such as beliefs, values, language and religion) and, as a result, their healthcare needs may differ to White women's. Second, differences exist in the epidemiology of the disease in BME and White women. For example, UK data suggest that although Black and South Asian women have a lower incidence of breast cancer, they tend to be diagnosed at a younger age, are more likely to be diagnosed at an advanced stage and with more aggressive forms of the disease than White women [6-8]. These differences suggest that BME and White women's experiences of breast cancer may differ.

In recent years, a small number of studies exploring BME women's experiences of being diagnosed and treated for breast cancer have been reported [9-13]. These UK, Canadian and North American based studies have highlighted the relevance of socio-cultural norms, behaviours and beliefs in shaping BME women's experiences. For example, Gurm et al [10] interviewed 20 Canadian Punjabi BCS and found that the influence of their cultural background meant they felt obliged to resume daily chores and domestic responsibilities immediately after treatment. Many wanted to seek support from other BCS but felt isolated due to cultural pressures to keep personal issues private. Women's distress were further exacerbated by judgemental and insensitive comments they received from uneducated and older generation community members. 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 the experience. The only 2 qualitative studies conducted within the UK to date also highlight the importance of social support, spirituality, body image (including concerns regarding limited availability of suitable wigs and skin-coloured breast prostheses), and cultural issues (such as taboos around cancer and language issues, including a preference to communicate with healthcare professionals and other BCS in their mother tongue) [9, 12].

While there is a limited, albeit growing body of research exploring this phenomenon, these studies have mainly adopted qualitative methods, such as individual or focus group interviews. These have generated descriptive and detailed data that can provide in-depth understanding of a particular research question [14]. However, sample sizes tend to be small, as the focus is on understanding experiences rather than generalising to the wider population [15].

Quantitative research into the psychosocial impact of breast cancer in relation to ethnicity has included American-based populations of Black, White and/or Hispanic participants [16-19]. For example, Culver et al [17] compared coping patterns between Black, White and Hispanic BCS, and found that religion was a more commonly used coping strategy amongst BME groups. Quantitative research in the UK, particularly amongst South Asian BCS, is extremely sparse [18, 20]. The available comparative studies show that breast cancer experiences differ between White and BME women, where BME women tend to report the poorest outcomes [18, 20]. Further UK-based quantitative research is needed in order to gain a better understanding of the psychosocial impact of diagnosis and treatment of breast cancer amongst BME women, and how this may be similar or different to the experiences of White women. The majority (87.9%) of the UK population are White [21]. Comparing the experiences of BME and White BCS can help to identify whether changes to practice and/or policy are needed to ensure all patients are provided with appropriate care and support. The need for such research has been highlighted in the most recent government policy, aimed at improving cancer outcomes in order to reduce health inequalities and improve BME patients' cancer experiences [22]. Therefore the aim of this study was to compare the psychosocial impact of breast cancer amongst Black, South Asian and White BCS living in the UK.

This study was part of a larger mixed methods research programme exploring the psychosocial impact of breast cancer diagnosis and treatment in Black and South Asian women [23]. This included 3 qualitative studies which highlighted how psychosocial and cultural factors influence BME women's experiences of breast cancer, including psychological functioning, support, body image concerns and beliefs about cancer. These findings (discussed elsewhere [12, 24]) consequently informed the development of the present study. The use of qualitative findings to inform quantitative research is a useful strategy in developing high quality survey questions [25]. Based on the research highlighted above, it is hypothesised that BME women's experiences of breast cancer will differ to White women's. Specifically, Black and South Asian BCS will report greater levels of anxiety and depression, poorer levels of quality of life, greater body image concerns, and be more likely to turn to religion for support than White women.

Method

Design

A quantitative, cross-sectional design was adopted. The design of the questionnaire was based on findings from the previous qualitative studies and published literature. Relevant standardised measures were selected for the questionnaire, with the exception of 'support' which was measured using a self-constructed question (see details below). Rationale for the choice of measures and design of the questionnaire is described in detail elsewhere [23].

# **Participants**

Participants were recruited through breast cancer support groups and National Health Service (NHS) Trusts (hospitals) in cities with a high BME population in England, namely Bristol, Birmingham, London and Coventry. Inclusion criteria included English speaking/literate women, aged 18 and above, of White, Black or South Asian ethnicity, with a diagnosis of primary breast cancer and who were between 6 months and 5 years post diagnosis. Women still undergoing treatment and/or diagnosed with secondary cancer were excluded. Women who were not English speaking/literate were excluded as it was not possible to translate the questionnaire in the various South Asian languages that exist, and doing so could effect the psychometric properties of the measures.

A total of 581 (481 via the NHS and 100 via support groups) questionnaires packs were sent to potential participants. 185 women completed the questionnaire, giving a response rate of 31.8%. However, 12 of these responses were omitted from analysis as they did not meet the eligibility criteria (2 did not report their ethnic identity, 4 described their ethnic identity as East Asian (e.g. Chinese), 3 reported having breast cancer which exceeded the 5 year time frame, and 3 reported having secondary breast cancer). Therefore, data from a total of 173 BCS were available for analysis. 147 of these participants were recruited through the NHS and 26 through support groups.

# Procedure

Ethical approval was obtained from the NHS South West Research Ethics Committee, Bristol (Ref: 10/H0107/39) and School of Life Sciences Research Ethics Committee at the University of the West of England, Bristol (Ref: HLS10-1542).

Support group facilitators and NHS staff (breast care/research nurses) were contacted by the researcher to determine their interest in supporting recruitment for the study. Those interested were sent questionnaire packs to hand out to any potential participants. Alternatively, eligible participants could contact the researcher directly for an information pack. Support group facilitators and NHS staff identified eligible participants through their databases or during support group meetings or follow-up consultations. The questionnaire pack contained a letter of invitation, an information sheet, a questionnaire and a stamped addressed envelope for its return to the researcher. Consent was indicated by returning a completed questionnaire.

# Measures

Self-reported demographic and breast cancer information: The following information was collected: age, city/town of residence, employment status, marital status, education

background, ethnic identity, religion, type of breast cancer, time since diagnosis, and treatment(s) received.

*Quality of life* was assessed by the Functional Assessment of Cancer Therapy-General (FACT-G [26]) which consists of 27 items, with 4 sub-scales: physical, social/family, emotional and functional well-being. It is based on a 5-point Likert scale ranging from 0 (not at all) to 4 (very much). Each sub-scale can be summed to give an overall quality of life score (score range 0-108); the higher the score, the better the quality of life. Internal consistency (as measured by Cronbach's alpha): Physical well-being ( $\alpha = 0.88$ ), social/family well-being ( $\alpha = 0.87$ ), emotional well-being ( $\alpha = 0.76$ ) and functional well-being ( $\alpha = 0.90$ ).

*Psychological functioning* was measured with the Hospital Anxiety and Depression Scale (HADS [27]), which consists of 14 items on 2 sub-scales (anxiety and depression). Each item is rated on a 4-point Likert scale ranging from 0 to 3 (score range: 0-21); high scores indicate higher distress levels. Internal consistency: Anxiety ( $\alpha$ = 0.84) and Depression ( $\alpha$ = 0.83).

*Beliefs about cancer* was assessed using the Multidimensional Health Locus of Control (MHLC-Form C [28], consisting of 18 items, with 4 sub-scales: internal (ILOC), chance (CLOC), doctors (DLOC) and other people (OPLOC). The God Health Locus of Control (GHLOC – an adjunct to the MHLC [29] was also included. Each item is rated on a 6 point Likert scale, ranging from 1 (strongly disagree) to 6 (strongly agree) (score range: ILOC: 6-36, CLOC: 6-36, DLOC: 3-18, OPLOC: 3-18, GLOC: 6-36). The higher the score, the greater the beliefs pertaining to each sub-scale. Internal consistency: ILOC ( $\alpha$ = 0.67), CLOC ( $\alpha$ = 0.76), DLOC ( $\alpha$ = 0.45<sup>1</sup>), OPLOC ( $\alpha$ = 0.69) and GHLOC ( $\alpha$ =0.94).

*Body image* was assessed via the Body Image after Breast Cancer Questionnaire (BIBCQ [30] which consists of 53 items, with 6 sub-scales: vulnerability, limitations, body concerns, body stigma, transparency and arm concerns (the latter 3 sub-scales were used in this study because the items pertain to the relevant body image issues that were identified as particularly pertinent to participants in the previous qualitative studies that were part of the first author's programme of research). Responses are given on a 5 point Likert scale ranging from: 1 (strongly disagree) to 5 (strongly agree) or 1 (never/almost never) to 5 (always/almost always). A high score indicates greater body image concerns (score range: 1-135). Internal consistency of the sub-scales: body stigma ( $\alpha$ = 0.89), transparency ( $\alpha$ = 0.78) and arm concerns ( $\alpha$ = 0.77).

*Support:* A list of potential sources of support (family, husband/partner, friends, work colleagues, religion/spirituality, cancer support groups, community groups and healthcare professionals) were provided. Participants were required to select all the sources that provided them with support. Response options were yes (1) and no (0). The aim of this measure was to determine who provided participants with support. Standardised instruments such as the short form Supportive Care Needs Survey (NS-SF34 [31] and the Sources of Social Support Scale (SSSS [33]) were considered but did not meet the aim of what we wanted to assess. For example, the SSSS measures type of support (e.g. emotional,

<sup>&</sup>lt;sup>1</sup> As the alpha coefficient for the DLOC sub-scale was below 0.60, it was not used in subsequent analysis [32].

informational, practical support) received from husband/partner, adult women in the family, other family members, friends and healthcare professionals. It does not consider other sources such as work colleagues, community groups or support groups. Therefore, a self-constructed item was used for this study. Furthermore a single item was used to keep the overall questionnaire brief in order to avoid over-burdening participants.

#### Data analysis

A minimum of 120 participants (40 in each group) were needed in order to run appropriate statistical tests. This number is based on Cohen's [34] values of alpha (0.05), power (0.80) and a medium effect size (0.5).

Data were entered and analysed using the statistical program, SPSS (version 19). Descriptive statistics of the demographic and breast cancer information were performed for the overall sample and for each ethnic group (tables 1 and 2). One-way ANOVAs<sup>2</sup> and chi-square tests examined group differences for each variable (tables 3 and 4). Significant results were further examined using Tukey's post-hoc tests and cross tabulations, as appropriate.

#### Results

#### Descriptive data

Of the 173 participants, 80 (46%) described their ethnic identity as White, 53 (31%) as Asian or British Asian (42 Indian, 10 Pakistani and 1 Bangladeshi) and 40 as Black or British Black (35 Black Caribbean and 1 Black African). Participants' ages ranged from 32 to 81 years (mean age = 58.0 years; sd = 9.82). Time since diagnosis ranged from 6 to 60 months (mean = 29.2 months; sd = 14.2). The majority had undergone surgical and adjuvant treatments.

### Inferential data

Comparisons to other normative data are detailed elsewhere [23].

### **Quality of Life**

One-way ANOVA showed a significant difference on overall quality of life between the ethnic groups (F (2, 84.93) = 8.59, MSE = 319.74, p<0.001), where White women reported a better quality of life than South Asian women (p<0.05).

#### **Psychological functioning**

There was a significant difference on anxiety and depression scores reported by the ethnic groups ((F (2, 170) = 4.57, MSE = 10.64, p<0.05) and (F (2, 84.87) = 10.65, MSE = 13.86,

<sup>&</sup>lt;sup>2</sup> ANCOVAs were carried out, controlling for age at diagnosis. However, there were no differences between significance levels when testing variables using ANOVAs or ANCOVAs. Therefore ANOVAs were used in order to further examine group differences.

p<0.001), respectively), with South Asian women reporting higher levels of anxiety and depression than White women (p<0.05).

## **Beliefs about cancer**

Significant differences were found for ILOC, CLOC and GHLOC between the ethnic groups ((F (2, 164) = 3.62, MSE = 31.73, p<0.05), (F (2, 163) = 6.58, MSE = 45.05, p<0.05) and (F (2, 164) = 35.64, MSE = 76.55, p<0.001), respectively). South Asian women reported higher levels of ILOC compared to the White women (p<0.05). South Asian women reported higher levels of CLOC compared to the White and Black women (p<0.05). South Asian and Black women reported higher levels of GHLOC compared to the White and Black women (p<0.05). OPLOC did not differ significantly between the ethnic groups (p>0.05).

## **Body image**

There was a significant difference on body image scores reported by the groups (F (2, 165) = 9.84, MSE = 253.76, p<0.001); Black and South Asian women reported greater levels of body image concerns than the White women (p<0.05).

## **Social Support**

Family (95%), husband/partner (95%), friends (87%) and healthcare professionals (86%) were reported to be the main sources of support (table 4). Chi-square test showed no significant associations according to ethnic identity and the support received from: family, husband/partner, friends, support groups and healthcare professionals (p>0.05). However, there was a statistically significant difference in support received through religion/spirituality ( $x^2$  (2, n = 169) = 27.53, p<0.001, *phi* = 0.40), community groups ( $x^2$  (2, n = 169) = 7.56, p<0.05, *phi* = 0.02), and work colleagues ( $x^2$  (2, n = 75) = 11.53, p<0.05, *phi* = 0.39). Further examinations showed that a) a greater number of South Asian women (48%) turned to religion/spirituality for support compared to Black (28%) and White women (24%), b) Black women (37%) reported receiving support from their community groups more than South Asian (31%) and White women (31%), and c) more White women (60%) reported receiving support from work colleagues compared to South Asian (21%) and Black women (19%).

### Discussion

Our findings show that BME women's experiences of breast cancer are different to White women's experiences, and further support existing research that has examined ethnic group differences amongst cancer survivors [18, 20, 35]. Group differences were predominantly between White and South Asian women; South Asian women reported higher levels of anxiety, depression, internal and fatalistic beliefs pertaining to cancer, more likely to turn to religion for support, and poorer quality of life than White women. South Asian and Black women reported having a poorer body image, and held a greater belief that God was in control of their cancer than White women.

These findings can be explained by cultural differences that exist between different ethnic groups. The coping with breast cancer and ethnicity literature has consistently found that ethnic minority women rely more heavily on religion as a source of support compared to White women [16, 17]. The present findings corroborate with those findings and also show that Black and South Asian women held stronger beliefs that God was in control of their cancer. South Asian women were also more likely to attribute their cancer to chance. A fatalistic attitude such as 'it's written for me' and the belief that 'God is in control of the cancer' can easily be interpreted to mean the same thing, as concepts such as fate are often perceived to be influenced by God [12].

Within the western society, cancer as an illness is feared and is almost always associated with negative connotations such as killer and death, especially if the illness is not well understood. Additional cultural taboos and stigma related to cancer exist in BME communities. For example, modesty and honour are highly valued in these cultures and a great emphasis is placed on the woman (particularly in the South Asian communities) to maintain the family's honour and reputation [36]. Therefore, it is not considered appropriate to openly talk about an illness which can compromise the family's status and bring shame upon them. Another common belief in the BME communities is that cancer is seen as a form of punishment from God and consequently, women are often subjected to negative comments from their community members who insinuate they must have done something bad to deserve the cancer. It is possible that cultural taboos and stigma of cancer resulted in South Asian women keeping the cancer private. Not openly talking about it may have contributed to their high levels of anxiety, depression and poor quality of life, which can also explain why South Asian women were least likely to seek or receive support from their community groups. However, the findings show that Black women were more likely to seek/receive support from their community groups. This could be due to the fact that Black communities have a tendency to hold fictive kinships (regarding people as family without being related by blood or through marriage) with friends and church members, with whom they feel open to share their experiences and rely on for support [37]. This can aid our understanding as to why more Black women in the present study received support from their community.

Research has also found that BME women (particularly first generation immigrant women) tend to have a limited understanding and awareness of breast cancer, particularly those who are less educated and less acculturated to the western ways of living [38]. This can consequently result in a later diagnosis of cancer whereby the disease may be more advanced and therefore require more aggressive forms of treatment such as mastectomy or chemotherapy. A greater number of BME women in the present study underwent a mastectomy, received chemotherapy treatment and experienced lymphoedema compared to White women; all of which can have a negative impact on one's quality of life. A loss of breast(s) and/or hair are also more likely to instigate higher body image concerns than White women. As well as instigating body image concerns, lymphoedema can be painful and limit physical activity, which can have a negative impact on one's quality of life. Furthermore, culturally suitable wigs, breast prostheses and lymphoedema sleeves are not as readily

available for BME women which can further add to women's body image concerns [9, 12, 13].

The design of the study warrants discussion. A particular strength is the large sample size, allowing appropriate statistical comparisons to be made between BME and White BCS. However, as only Black and South Asian participants were recruited, the findings are not representative of other BME groups such as East Asian or Middle Eastern populations. It is possible that the experiences of women in these population subgroups may differ from not only White women but also with Black and South Asian women. Further research is needed to explore these issues amongst other BME populations. Another limitation is the exclusion of non-English speaking groups. It is possible that their experiences and needs may differ to English-speaking BME women. This also warrants further research.

It is also important to discuss the measures that were used for this study. The majority of measures have been assessed on White, English speaking populations [39]. Consequently, some measures may not reflect the concerns and problems that may be present in BME samples. Therefore, when researching BME groups, it is important to ensure that measures selected are appropriate to the sample being assessed, and include and/or develop culturally sensitive measures to enhance understanding of a particular group. However, this can be challenging when researching different ethnic populations, particularly when making comparisons between groups.

It would also be beneficial to translate measures into other languages. For example, the Hospital Anxiety and Depression Scale has been validated in Urdu [20], and Mental Adjustment to Cancer scale has been validated amongst patients of other ethnicities and countries [40, 41]. For the current study, it was not possible to translate measures into other languages as the time constraints of the project made it impossible to translate the surveys into the many South Asian languages that exist.

The findings of this study show that differences exist in women's breast cancer experiences. This has implications for health care professionals to be aware of the differing healthcare experiences and needs of BME patients. The need to improve cancer care by reducing inequalities has been highlighted by the Department of Health [42] and NCEI [43]. While cancer services have improved in recent years, the care and support provided to BME groups is still varied, suggesting that more needs to be done to ensure that the NHS is equipped to meet BME patients' cancer needs from a cultural perspective [22].

# Conclusion

This is one of very few UK-based studies to compare psychosocial issues amongst BCS from different ethnic groups. These findings add to the current literature to not only show how breast cancer experiences differ between ethnic groups but also why this may be the case; providing valuable information for healthcare professionals to help improve ethnic minority women's breast cancer experiences.

### Acknowledgements

This research was funded by a Breast Cancer Campaign PhD studentship (ref:2007NovPhD12). We would like to thank the support group organisations, research nurses and breast cancer consultants for supporting this study and helping with the recruitment of study participants and, most importantly, the women who took the time to complete the questionnaire.

## **Conflicts of Interest**

None.

# References

- Cancer Research UK (2014). Breast cancer statistics 2014 [online] Available from <u>http://www.cancerresearchuk.org/cancer-info/cancerstats/types/breast/</u> [accessed 22<sup>nd</sup> May 2015].
- Hegel MT, Moore CP, Collins ED, *et al.* "Distress, psychiatric syndromes, and impairment of function in women with newly diagnosed breast cancer." *Cancer* 2006; 107(12): 2924 2931.
- 3. Shapiro SL, Lopez AM, Schwartz GE, *et al.* Quality of life and breast cancer: Relationship to psychosocial variables. *Journal of Clinical Psychology* 2001; **57**(4): 501 519.
- Thompson A, Brennan K, Cox A, *et al.* Evaluation of the current knowledge imitations in breast cancer research: A gap analysis. *Breast Cancer Research* 2008; 10, R26.
- Office for National Statistics. 2011 Census: Ethnic group, local authorities in the United Kingdom. 2013 [online] Available from: <u>http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-and-quick-statisticsfor-local-authorities-in-the-united-kingdom---part-1/index.html</u> [accessed 25th October 2015].
- 6. Bowen RL, Duffy SW, Ryan DA, *et al.* Early onset of breast cancer in a group of British Black women. *British Journal of Cancer* 2008; **98**: 277 281.
- 7. Farooq S, Coleman MP. Breast cancer survival in South Asian women in England and Wales. *Journal of Epidemiology and Community Health* 2005; **59**: 402 406.
- Jack RH, Davies, EA, Moller H. Breast cancer incidence, stage, treatment and survival in ethnic groups in South East England. *British Journal of Cancer* 2009; 100: 545 - 550.
- 9. Blows E, Scanlon K, Hatfield J, *et al.* The Better Access Better Services (BABS) Project: Accessing information and support from the NHS and voluntary sector: Experiences of Asian and African Caribbean women with breast cancer 2009; **(6)**.
- Gurm KB, Stephen J, MacKenzie G, *et al.* Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study. *International Journal of Nursing Studies* 2008; 45: 266 - 276.

- 11. Henderson PD, Gore SV, Davis Bl *et al*. African American women coping with breast cancer: A qualitative analysis. *Oncology Nursing Forum* 2003; **30**: 641 647.
- Patel G, Harcourt D, Naqvi H, *et al.* Black and South Asian women's experiences of breast cancer: A qualitative study. *Diversity and Equality in Health and* Care 2014; 11: 135 149.
- 13. Wilmoth MC, Sanders ID. Accept me for myself: African American women's issues after breast cancer. *Oncology Nursing Forum* 2001; **28**: 875 879.
- 14. Johnson RB, Onwuegbuzie AJ. Mixed methods research: A research paradigm whose time has come. *Educational Researcher* 2004; **33** (7): 14 26.
- 15. Sale JEM, Lohfeld LH, Brazil K. Revisiting the quantitative-qualitative debate: Implications for mixed-methods research. *Quality and Quantity* 2002; **36**: 43 - 53.
- Bourjolly JN, Hirschman KB. Similarities in coping strategies but differences in sources of support among African-American and White women coping with breast cancer. *Journal of Psychosocial Oncology* 2007; 19 (2): 17 - 38.
- 17. Culver JL, Arena PL, Wimberly SR, *et al.* Coping among African-American, Hispanic, and non-Hispanic White women recently treated for early stage breast cancer. *Psychology and Health* 2004; **19** (2): 157 166.
- Paskett ED, Alfano CM, Davidson MA, *et al.* Breast cancer survivors' health-related quality of life: Racial differences and comparisons with non-cancer controls. *Cancer* 2008; **113**: 3222 - 3230.
- Reynolds P, Hurley S, Torres M, *et al.* Use of coping strategies and breast cancer survival: Results from the Black/White Cancer Survival Study. *American Journal of Epidemiology* 2000; **152**: 940 - 949.
- Roy R, Symonds RP, Kumar DM, *et al.* The use of denial in an ethnically diverse British cancer population: A cross-sectional study. *British Journal of Cancer* 2005; 92: 1393 - 1397.
- 21. Office for National Statistics. (2011). 2011 Census questions [online]. Available from www.census.gov.uk [Accessed 22<sup>nd</sup> May 2014].
- 22. Department of Health. Cancer Reform Strategy. 2007; London: Department of Health.
- 23. Patel G. The psychosocial impact of breast cancer diagnosis and treatment in Black and South Asian women 2013; PhD Thesis, University of the West of England, Bristol.
- 24. Patel-Kerai G, Harcourt D, Rumsey N, *et al.* Exploring the lived experience of breast cancer diagnosis and treatment amongst Gujarati-speaking women. *Diversity and Equality in Health and Care* 2015; **12** (1): 9 17.
- 25. Morgan DL. Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research* 1998; **8**: 362 376.
- 26. Cella DF, Tulsky DS, Gray G, *et al.* The Functional Assessment of Cancer Therapy Scale: Development and validation of the general measure. *Journal of Clinical Oncology* 1993; **11**(3): 570 579.
- 27. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 1983; **67** (6): 361 370.

- Wallston KA, Stein MJ, Smith CA. Form C of the MHLC scales: A condition-specific measure of locus of control. *Journal of Personality Assessment* 1994; 63 (3): 534 -553.
- 29. Wallston KA, Malcarne VL, Flores L, *et al.* Does God determine your health? The God Locus of Health Control Scale. *Cognitive Therapy and Research* 1999; **23** (2): 131 142.
- 30. Baxter N. *The Body Image After Breast Cancer Questionnaire: The design and testing of a disease-specific measure*. 1998; PhD dissertation, University of Toronto.
- Boyes A, Girgis A, Lecathelinais C. Brief assessment of adult cancer patients' perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS- SF34). *Journal of Evaluation in Clinical Practice* 2009; **15** (4): 602 606.
- 32. DeVellis RF. 1991. *Scale development: Theory and applications*. Newbury Park, CA: Sage Publications.
- 33. Carver CS. 2000. Sources of Social Support scales. Unpublished manuscript
- 34. Cohen J. 1988. *Statistical power analysis for the behavioural sciences (2nd Ed)*. Hillsdale, NJ: Lawrence Erlbaum.
- Janz, NK, Muhahid, MS, Hawley ST, *et al.* Racial/ethnic differences in quality of life after diagnosis of breast cancer. *Journal of Cancer Survivorship* 2009; 3 (4): 212 222.
- Bottorff JL, Johnson JL, Bhagat R, *et al.* Beliefs related to breast health practices: the perceptions of South Asian women living in Canada. *Social Science and Medicine* 1998; 47 (12): 2075 2084.
- 37. Alexander C, Edwards R, Temple B, *et al.* 2004. *Access to services with interpreters*. York: Joseph Rowntree Foundation.
- 38. Scanlon K, Wood A. Breast cancer awareness in Britain: Are there differences based on ethnicity? *Diversity in Health and Social Care* 2005; **2**: 211 221.
- 39. Shelby RA, Lamdan RM, Siegel JE, *et al.* Standardized versus open-ended assessment of psychosocial and medical concerns among African American breast cancer patients. Psycho-Oncology 2006; **15**: 382 397.
- Ho SM, Fung WK, Chan CL *et al.* Psychometric properties of the Chinese version of the Mini-Mental Adjustment to Cancer (MINI-MAC) scale. *Psycho-oncology* 2003; 12 (6): 547 - 556.
- 41. Mystaidou K, Watson M, Tsilika E, *et al.* Psychometric analyses of the Mental Adjustment to Cancer (MAC) scale in a Greek palliative care unit. *Psycho-oncology* 2005; **14** (1): 16 24.
- 42. Department of Health. Improving outcomes: A strategy for cancer. 2011; London: Department of Health.
- 43. National Cancer Equality Initiative. Reducing cancer inequality: Evidence, progress and making it happen. 2010; London: Department of Health.

## Tables

Table 1: Participants' demographic information

	Total sample	White	Black	South Asian
Age (years)				
Mean (standard deviation)	58.0 <b>(9.8</b> )	60.6 <b>(8.0)</b>	57.1 <b>(12.7)</b>	54.6 <b>(8.9)</b>
Residence				
Bristol	21 (12)	15 (71)	3 (14)	3 (14)
London	50 (29)	1 (2)	17 (34)	32 (64)
Birmingham	33 (19)	11 (33)	16 (48)	6 (18)
Coventry	60 (35)	48 (80)	4 (7)	8 (13)
Other	9 (5)	5 (56)	0 (0)	4 (44)
Employment status				
Employed	78 (45)	37 (47)	15 (19)	26 (33)
Student	2 (2)	0 (0)	2 (100)	0 (0)
Retired	67 (39)	39 (58)	15 (22)	13 (19)
Unemployed	14 (8)	1 (7)	6 (43)	7 (50)
Other	11 (6)	3 (27)	2 (18)	6 (55)
Marital status				
Single	19 (11)	2 (11)	13 (68)	4 (21)
In a relationship	8 (5)	5 (63)	3 (38)	0 (0)
Married	102 (60)	54 (53)	10 (10)	38 (37)
Separated	5 (3)	0 (0)	4 (80)	1 (20)

Divorced	14 (8)	6 (43)	3 (21)	5 (36)
				. ,
Widowed	22 (13)	12 (55)	6 (27)	4 (18)
Education level <sup>1</sup>				
High school	44 (26)	27 (61)	6 (14)	11 (25)
College	11 (6)	9 (82)	1 (9)	1 (9)
University	77 (45)	27 (35)	24 (31)	26 (34)
No qualification	38 (22)	16 (42)	9 (24)	13 (34)
Religious belief				
Christian	94 (55)	63 (67)	28 (30)	3 (3)
Buddhist	2 (1)	0 (0)	1 (50)	1 (50)
Jewish	2 (1)	2 (100)	0 (0)	0 (0)
Hindu	27 (16)	0 (0)	0 (0)	27 (100)
Sikh	9 (5)	0 (0)	0 (0)	9 (100)
Muslim	11 (6)	0 (0)	0 (0)	11 (100)
Other beliefs	12 (7)	4 (33)	7 (58)	1 (8)
No religious belief	14 (8)	11 (79)	3 (21)	0 (0)

Cell counts (n) and percentages (%) are reported for ordinal data; Mean and standard deviations (in parenthesis) are reported for interval data.

1. High school (aged 11-16 years) qualifications are equivalent to GCSEs; College level are equivalent to A-level/diploma; University level include advanced or higher diploma (HND), undergraduate degree (BSc/BA) or postgraduate degree (MSc/MA/PhD).

NB: Total percentages will not always equal 100 because figures have been rounded up to the nearest whole number.

	Total sample	White	Black	South Asian
Time since diagnosis (months)				
Mean (standard deviation)	29.2 <b>(14.2)</b>	29.5 <b>(14.3)</b>	28.6 (14.1)	29.2 (14.4)
Type of cancer				
Invasive	87 (54)	45 (52)	18 (21)	24 (28)
Non-invasive	29 (18)	11 (38)	8 (28)	10 (34)
Not known	46 (28)	20 (43)	13 (28)	13 (28)
Surgical treatment				
Mastectomy	67 (39)	26 (39)	20 (30)	21 (31)
Lumpectomy	97 (56)	54 (56)	18 (19)	25 (26)
No treatment	3 (2)	0 (0)	1 (33)	2 (67)
Not known	5 (3)	0 (0)	1 (20)	4 (80)
Adjuvant therapy <sup>*</sup>				
Chemotherapy	108 (40)	47 (44)	27 (25)	34 (31)
Radiotherapy	157 (58)	73 (46)	35 (22)	49 (31)
Neither	7 (3)	3 (43)	3 (43)	1 (14)
Hormone therapy <sup>*</sup>				
Tamoxifen	93 (54)	49 (53)	13 (14)	31 (33)
Aromatase inhibitors	50 (29)	24 (48)	12 (24)	14 (28)
Other	3 (2)	3 (100)	0 (0)	0 (0)

## Table 2: Participants' breast cancer diagnosis and treatment information

None	32 (18)	11 (34)	15 (47)	6 (19)
Not known	7 (4)	0 (0)	3 (43)	4 (57)
Lymhoedema	39 (23)	2 (5)	13 (33)	24 (62)

Cell counts (n) and percentages (%) are reported for ordinal data; Mean and standard deviations (in parenthesis) are reported for interval data.

NB: Total percentages will not always equal 100 because figures have been rounded up to the nearest whole number.

\* Participants had more than one treatment.

Table 3: Mean scores for each variable

Variables	Total sample	White	Black	South Asian
Quality of life**	81.76 (18.65)	87.39 (15.03)	80.21 (21.32)	74.42 (19.00)
Anxiety*	7.83 (3.33)	7.25 (3.06)	7.51 (3.33)	8.95 (3.20)
Depression <sup>**</sup>	4.62 (3.93)	3.31 (3.10)	4.98 (4.25)	6.32 (4.15)
ILOC*	19.01 (5.72)	17.95 (5.41)	18.96 (6.55)	20.69 (5.19)
CLOC*	22.86 (6.94)	22.10 (6.69)	20.84 (7.25)	25.68 (6.29)
OPLOC <sup>ns</sup>	10.44 (3.98)	10.37 (3.95)	9.58 (4.41)	11.18 (3.63)
GHLOC**	17.69 (10.42)	11.60 (7.98)	22.36 (9.65)	23.54 (9.16)
Body image <sup>**</sup>	45.40 (16.75)	39.87 (13.76)	47.78 (17.25)	52.26 (17.96)

Standard deviation in parenthesis;

\*\* Association is significant at the 0.01 level; \* Association is significant at the 0.05 level; ns = not significant (p>0.05)

Sources of support	Total sample	White	South Asian	Black
	n (%)	n (%)	n (%)	n (%)
Family <sup>ns</sup>	161 (95)	76 (47)	51 (32)	34 (21)
Husband/partner <sup>ns</sup>	103 (95)	56 (54)	36 (35)	11 (11)
Friends <sup>ns</sup>	147 (87)	70 (48)	45 (31)	32 (22)
Healthcare Professional <sup>ns</sup>	146 (86)	69 (47)	43 (30)	34 (23)
Religion/spirituality**	71 (42)	17 (24)	34 (48)	20 (28)
Work colleagues <sup>*</sup>	52 (69)	31 (60)	11 (21)	10 (19)
Support groups <sup>ns</sup>	49 (29)	18 (37)	19 (39)	12 (25)
Community groups <sup>*</sup>	35 (21)	11 (31)	11 (31)	13 (37)

\*\*Association is significant at the 0.01 level; \* Association is significant at the 0.05 level; ns = not significant (p>0.05)