



Fear, family and the placing of emotion: Black women's responses to a breast cancer awareness intervention



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ABSTRACT

This paper is based upon findings from the qualitative element of a mixed-methods study on the response of Black women aged 25–50 to a public health intervention related to breast cancer. The focus groups were conducted in the London Borough of Hackney, UK between 2013 and 2016, and were part of an evaluation of the effectiveness of a breast awareness DVD. While the content of the DVD was generally well-received by the participants, the focus group discussions revealed a complex and, at times, contradictory response to the women's construction as an 'at risk' community. As the paper highlights, for many of the women, breast cancer remains a disease of whiteness and the information provided in the DVD prompted a range of emotional responses; from anxiety and fear to a desire to become more knowledgeable and active in the promotion of self-care. As the paper argues, of particular importance to the women was the need to feel a much stronger emotional connection to the information presented in the DVD. The paper concludes by arguing that placing greater emphasis on feeling and emotion is an important dimension of future research in this area.

1. Introduction

The epidemiological picture of breast cancer in the UK appears significantly changed. Since the introduction of the National Health Service Breast Screening Programme (NHSBSP) in 1988, and the advances in systemic adjuvant therapies in the late 20th century, deaths from breast cancer have declined by 40% in women (Evans et al., 2016). Although improvements in therapy and the introduction of a comprehensive screening programme are an important part of the explanation (Advisory Committee on Breast Cancer Screening, 2006), there are many other factors that may have influenced this decline, including breast cancer awareness campaigns and the removal of barriers to early treatment. As Niksic et al. (2016) suggest, the assumption underpinning the national response to previously poor short-term cancer survival rates, especially when compared with other European nations (Autier et al., 2010), was that improving people's awareness of symptoms and encouraging them to seek medical advice before developing advanced-stage cancer would improve short-term survival. This approach appears to be paying dividends at the population level, but

there remain significant disparities in mortality from breast cancer. For example, while breast cancer incidence is lower amongst Black women in the UK – used here to reflect ethnic classifications employed in this study, which included Black African, Black Caribbean, White and Black African, White and Black Caribbean, and any other Black background – survival rates remain lower (Bowen et al., 2006; Jack et al., 2009; Møller et al., 2016); a picture which mirrors the experience of African American women in the USA (see Chlebowski et al., 2005; Grann et al., 2006; DeSantis et al., 2016).

The poor survival rates from breast cancer for Black women as compared to women from other ethnic backgrounds has, at least in part, been explained by differences in the biological characteristics of the tumours that many women develop (Jack et al., 2013; Januszewski et al., 2014). The interplay of age, ethnicity and risk is slightly complicated. Jack et al. (2012) show that up to around age 45, Black women have similar absolute incidence rates to White women and that, at later ages, incidence is lower. Thus, while the overall incidence of breast cancer is lower in Black women, for those who do develop the disease, they are more likely to develop it at younger ages than their

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White counterparts. This implies that the cancers they present with will be more likely to be estrogen receptor negative and therefore more aggressive. Jack et al. (2013) have shown that they are more likely to present with triple negative disease. Bowen et al. (2008) have argued that it is crucial to target this group of women to raise their awareness regarding the risks of breast cancer, the importance of early stage presentation, and the consequent importance of awareness of breast symptoms and prompt seeking of medical advice in response to these. Consistent with the lower overall incidence in Black women, the Million Women study in the UK has found that Black women are more likely to breastfeed and less likely to drink alcohol or have a family history of breast cancer (Gathani et al., 2014). For some women, this is incorrectly interpreted as meaning breast cancer is a 'white woman's disease' (Pfeffer, 2004; Jones et al., 2015).

It has long been known that levels of cancer awareness, including breast cancer, are lower amongst UK ethnic minority populations. Evidence suggests that these groups have lower levels of knowledge relating to breast cancer symptoms and, related to this, a greater range of barriers to accessing healthcare services including breast cancer screening programmes (Scanlon and Wood, 2005; Waller et al., 2009). Despite Bowen and colleagues' call for action, a recent systematic review suggests that this pattern persists (Jones et al., 2014; Jack et al., 2014). Furthermore, there has been a greater attempt to nuance understanding by considering differences within and between Black ethnic groups. Of particular relevance to this paper is a recent qualitative study of the barriers to early diagnosis of breast cancer in Black African, Black Caribbean and White British women in England (Jones et al., 2015). The study, which was conducted in two phases, and involved interviews and focus groups with women in London and other major British cities and regions, concluded that there continue to be important differences in barriers to diagnosis with breast cancer for this group of women. More specifically, this study suggested that first generation Black African women, more than any other women included in the survey, were particularly vulnerable because of conservative attitudes and cultural taboos relating to breast awareness. Moreover, '[w]omen from all ethnic groups were confused about what they needed to do to be breast aware' (2015, p. 17).

We report here on the qualitative findings from a mixed-methods evaluation of a breast awareness intervention targeted at Black women living in the Borough of Hackney, London, UK. The quantitative element of the project involved the evaluation of the effectiveness of a short, 7-minute breast awareness DVD in encouraging early presentation of breast cancer in black female patients aged under-50 years old. Conducted in two stages – a pilot study carried out between January and June 2013 was followed by the main study from June to November 2014 – the quantitative evaluation involved the participation of general practices in the Borough (4 at pilot stage and 10 in the main study). At each stage, the general practices were randomised with all Black women aged between 25 and 50 registered with the intervention practices receiving a copy of the DVD. The quantitative evaluation involved the analysis of data on consultations for breast symptoms by age and ethnicity (Black or non-Black populations) for all practices for 6 months prior to and after the intervention. The results of this aspect of the evaluation project have been reported on elsewhere (Greenhough et al., 2016).

The quantitative evaluation of the DVD's effectiveness was supported at each stage by focus group discussions with women from both the intervention and control practices. The focus groups were primarily set up to explore the women's responses to the DVD content and its delivery method (the DVD's were posted to the women in this intervention) and their perceptions of the DVD's possible effect on women's breast awareness and associated behaviours. As is often the case with focus groups, the women participating in the discussions shifted the direction of conversation beyond the prompts included in the focus group schedule. In what geographers Crang and Cook (2007) refer to as the 'liveliness' of doing focus group research, these shifts in direction

provided additional insights into the women's understanding of breast cancer, their awareness of and response to their heightened risk for forms of breast cancer that have poorer prognosis, and the importance of generating a greater emotional connection between the DVD intervention and its target audience. In order to confirm and further develop understanding of these emergent themes, an extension to the main study was granted by the project's funders and involved additional focus groups being conducted with a similar cohort of women (that is, Black women aged 25–50 living in Hackney) between October and December 2016. This report draws on all the collected focus group material to consider how the women responded to the DVD as a public health intervention and to wider questions about their construction as women at risk.

2. Methods

As noted in the introduction, this paper is based upon focus group research conducted with Black women aged 25–50 in the London Borough of Hackney between 2013 and 2016. The women were recruited to the study in one of two ways: either through general practices in the Borough ($n = 69$) or for the extension study, through a variety of community organisations based in Hackney ($n = 32$). Community organisations included black women's support groups and faith-based organisations. Given the potential for participant drop-out and as a partial compensation for their time, the women received a nominal cash payment of £20. Additionally, focus groups were conducted either in the general practices from which the women were recruited, or in the case of those women recruited through community organisations, in the places where the organisations regularly met. It is recognised that this might have impacted upon some women's willingness to engage in discussion with people already known to them; however, with the exception of one focus group, the discussions were described as 'lively' by the researchers facilitating them and attendance for just over half met the desired threshold of between 5 and 10 participants. Those focus groups where only two participants attended ($n = 2$) were not included in the analysis.

The focus group discussions were facilitated by a single researcher with previous experience of conducting qualitative research of this nature. Although the identity of the researcher changed across the course of the project, they were all female and had been directly involved in recruiting participants to the study. The focus groups were conducted using a pre-agreed focus group schedule that was designed by the qualitative research team (made up of geographers with extensive health-related research experience) and ratified by the project steering group, as well as by appropriate NHS and university ethics boards. At the beginning of each focus group session, the participant's awareness and knowledge of breast cancer were recorded using a questionnaire survey based on the Breast CAM survey instrument developed by Cancer Research UK, King's College London and University College London in 2009 (Cancer Research UK, 2011). Additionally, each focus group discussion opened with the researcher playing the DVD to the women; this acted as a reminder for those women in the intervention groups and as a prompt for women who had not previously seen the DVD. The focus group discussions lasted from between thirty minutes to over an hour in length and all were audio recorded, transcribed and cross-checked by at least one other researcher on the project before being entered on to QVR NVivo V.10 for coding and analysis.

Analysis of the focus group transcripts was developed using both deductive and inductive approaches and was based upon the framework method often employed in multidisciplinary health-related research (Gale et al., 2013). With regards the former, deductive codes related to the study's primary goal of evaluating the women's response to the DVD, its mode of delivery and their perceptions of its effectiveness. However, in keeping with the flexibility of this analytical approach, inductive codes were also developed by each of the researchers

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