What can be done to Encourage Women from Black, Asian and Minority Ethnic Backgrounds to Attend Breast Screening? - A Qualitative Synthesis of Barriers and Facilitators

Abstract

Objective: to identify the barriers to UK Black, Asian and Minority Ethnic (BAME) women attending breast screening and subsequently, support the growing evidence base providing solutions to the public health problem of ethnic variation within screening attendance.

Study design: A systematic review and thematic analysis of UK based, qualitative studies concerning BAME women.

Methods: the methodology of this review is based on Cochrane guidelines. A search strategy was applied to Embase, PubMed and Medline. Pre-defined inclusion and exclusion criteria yielded 8 final papers which were appraised and thematically analysed.

Results: The main findings of the review revealed three overarching themes: Knowledge-related, Access-related and Cultural-related factors. The emphasis of the importance of knowledge was highlighted by all studies identifying a lack of knowledge as a key barrier to screening attendance.

Key words: Screening, Ethnicity, Mammography

Introduction

According to Public Health England (PHE), breast cancer has been the most commonly diagnosed cancer amongst women since 1996. It accounts for 30.8% of all female diagnosed cancers and causes over 10,000 deaths in the UK annually.[1]

The 5-year survival rate for stage 1 breast cancer is 97% compared to 26% at stage 4. Early stage identification therefore, correlates to improved survival; the NHS funded National Breast Screening Programme was founded on this basis.[2–4] In the UK, 1,300 deaths are

prevented annually through breast cancer screening.[3] The breast screening programme is one of the most well participated screening programmes available on the NHS. Despite the benefits, screening attendance has fallen to its lowest level in the past decade with women from Black, Asian and Minority ethnic (BAME) backgrounds having disproportionally lower rates of participation.[4,5] Furthermore, there are few interventions aimed at increasing the breast screening attendance of BAME women.[6,7]

In 2017, the national breast screening attendance average across England was 71.1% with regional differences highlighting potential ethnic inequalities.[8] In London, an area of high ethnic diversity, 65.9% of females between 50-70 years were screened for breast cancer in the last 36 months.[9] The South-West, an area of low ethnic diversity, reports 75.5% attendance.[9,10]

To explain the disproportionately low screening uptake amongst BAME populations, primary qualitative studies regarding all types of screening services have cited possible barriers for low compliance and corresponding facilitators.[4,5,11] However, there is presently little UK specific evidence regarding the reasons for low breast screening participation amongst BAME women in UK.[4,5,12–14] The existing quantitative research confirms the respective health inequality yet, qualitative studies investigating why the inequality exists and what can be done to improve screening uptake are limited.[1,9]

Existing literature reveals that lack of education amongst BAME women regarding breast screening is a main contributor of low screening uptake.[15–17] Research from Stoll et al revealed only 33.5% of BAME women were aware of mammography yet, following educational interventions, screening attendance increased to 65%.[4]

Language barriers contributed to lack of knowledge with some BAME women stating their low compliance was attributable to difficulty reading their invitation letter.[5,18,19]

The need for public health and health promotion educational interventions is paramount to empower BAME women's understanding of breast screening and their subsequent health and wellbeing.[4,20,21]

Across all screening programmes, promoting participation remains a key priority. Both the bowel and cervical screening programmes have implemented interventions to overcome pre-defined barriers. For example, the 'how to do the bowel screening test' video by Cancer Research UK has been successful in addressing logistical barriers.[22] Furthermore, decreasing participation in the cervical screening programme was mitigated with health promotion articles featuring in popular, age appropriate magazines and targeted social media advertisement.[10,23,24]

Early detection of breast cancer and increased participation in the breast screening programme are important public health priorities, while understanding the barriers faced by BAME women to breast screening is important knowledge to ensure the existing health inequality gaps can be reduced. The systematic collation of findings from primary qualitative studies exploring barriers and facilitators enabled by this review has the potential to advance the evidence base and direct future interventions. Therefore, this review aims to achieve this with emphasis on the development of relevant facilitating interventions and guidelines to overcome the respective barriers and promote breast screening attendance amongst the UK BAME women.

Materials and Methods

MEDLINE, EMBASE and PubMed were searched up to December 2017 based on pre-defined inclusion and exclusion criteria. The PICo framework was used to formulate a search strategy. The Critical Appraisal Skills Programme (CASP) toolkit was used to appraise the identified studies. Two authors reviewed the search output, data extraction and appraisal

independently and resolved any disagreement through consensus. An adapted thematic framework analysis approach, based on Cochrane guidelines, was used to analyse and synthesise the extracted data.[25]

Study Selection

Studies were only included if they were UK specific, incorporated qualitative methodology, and considered women from an BAME background over the age of 18. For the purpose of this review, BAME background referred to women who were not white British.

The process of study selection was independently carried out by two reviewers (JB and GY) and discrepancies were amended by discussion.

Data synthesis and analysis

An adapted systematic review approach for qualitative research, based on the Cochrane guidelines, was used to extract data from articles.[25]

The extracted results were input into a data extraction form allowing for summarisation and thematic analysis. The overarching themes were finalised through discussion.

Since a qualitative approach was used, the presence of an identified theme did not necessarily indicate its importance within the specific study population. However, Table 1 details the number of barriers and facilitators relating to each theme which denotes, to a degree, the validity of the theme. A third reviewer (EW) independently performed a thematic analysis and results discussed which enabled a more valid identification of the most prevalent, hence significant, themes.

Quality of synthesis assessment

Currently, there is no universal consensus on criteria to assess the methodological quality of qualitative studies. This review combined the CASP quality assessment tool for both qualitative and cohort studies to develop a framework appropriate to the included studies.[26]

Any disagreements were resolved through discussion with a third author.

Results

A total of 8 studies satisfied the inclusion criteria detailed in Table 2; majority were based in London. Knowledge was reported as a barrier to screening attendance by all 8 of the included studies.(5,6,20,27–31) Table 1 lists the studies that reported the barriers and facilitators relevant to each study.

The main findings of the review revealed three overarching themes:

1. Knowledge-related factors
2. Access-related factors
3. Cultural-related factors

Knowledge-related factors

All eight included studies reported knowledge as either a barrier or facilitator to breast screening attendance.(5,6,20,27–31) Five studies specified risk factor unfamiliarity as a barrier.(5,20,27,28,30) Language presented as both a facilitator and a barrier with emphasis on the benefits of translated material.

Overall, the main barriers presented for BAME women were a lack of knowledge surrounding the following: what is breast cancer, how to identify it, what is the screening programme, who is at risk and the treatments available.

"I think I've read that women who have never married and had children are more likely to get it."(5)

"I think it's an infection… I don't know but it's not something that you can contract"(28)

"If we have a better understanding of what the procedure is and what it entails, people might be more receptive"(28)

Two of the included studies highlighted the influence healthcare professionals have on BAME women's health seeking behaviour; BAME women value and respect the advice of GPs.[20,31]

"Many of the BME focus group members spoke very highly of their GP, with a tendency to treat the GP as a higher authority, to be 'obeyed.'"[20]

Cultural-related factors

This broad category encompassed factors such as cultural values, religious beliefs and the influence of family and friends.

The influence of faith is generally more prevalent amongst BAME communities.[32]

Two studies drew associations between faith and decreased appreciation of preventative medicine, with women describing the development of breast cancer as 'up to God.'[5,28] These opinions were mitigated through incorporation of religious leaders into educational interventions.[27]

"There is a connection between our spiritual welfare and our health. If you are well spiritually, then you should be well physically."[5]

Stigma associated with cancer, fear of mastectomy and its marital consequences and deficient support from family and community were highlighted as barriers.

"...those of us that […] hear that the family that your daughter wants to marry into, they all have cancer, is that not a stigma? […] what of the child you are going to have for them if she is a woman, she might have cancer as well..."[28]

"Most African people don't like to talk about […] cancer. They see it as a taboo, in fact, I know a lot of people who do not even say the word cancer"[20]

Gender of healthcare professionals was identified by two studies as a barrier.[5,28] The possibility of a male radiographer made some women reluctant to partake and unanimously, across all ethnicities, a female radiographer was shown to be preferable.

"It's better if the woman does the examining. But if there isn't a woman there then you have to go with what there is. If I'm ill, I have to see a man if there's no woman."[5]

"It's embarrassing to be in front of a strange man."[5]

One study identified a reluctance of staff to engage with BAME women due to feelings of "cultural incompetence" and fears of causing offence.[6,20,27] Moreover, one study showed lack of awareness amongst healthcare workers regarding the specific needs of BAME women and how best to address them.[6]

Two studies revealed previous negative experiences with healthcare professionals dissuaded women from engaging with breast screening services; this was exacerbated in situations where women felt disrespected.[5,20]

"The professor [at the hospital] came into the room and put his hand forward and he wanted to shake my hand and so I was very embarrassed. I said, 'We don't shake hands.' He looked at me and said, "okay, take off your clothes.'''[5]

"My GP, he sits like he is getting impatient that I am there, I am watching his body language […]and I'm thinking don't worry about it — I'm just wasting your time."[20]

Forming interpersonal relationships between healthcare workers and BAME women was highlighted by two studies as a facilitator to encourage screening attendance.[6,29]

Acces*s-related factors*

Logistical (distance, inconvenience and cost) and emotional barriers were the main causes of decreased access of breast screening services.[5,6,20,27–31]

"Lack of confidence and expectation anxiety were shown to be barriers to attendance with women reporting their fear and apprehension regarding screening, self-examination and breast cancer."[28]

"Compliance can require considerable inconvenience"."[5]

Logistical related factors such as cost of attendance, time convivence and distance were shown to be barriers by three studies.[5,27,28]

Discussion

To our knowledge, this is first UK specific systematic analysis of the reasons for low breast screening attendance amongst BAME women. The three emerging themes from this review included: knowledge-related, access-related and cultural-related factors.

Knowledge-related Factors

Knowledge-related factors affected women's perceptions of breast screening and contributed to low attendance.

Women in five of the studies insinuated a low perceived risk which discouraged screening attendance.[5,20,27,28,30] A similar theme correlates to cervical screening; low risk perception

amongst BAME women drives low attendance.[33,34] Underpinning this perception, as concluded by Pfeffer and Bamidele et al, is the overall low incidence rate of breast cancer amongst BAME women and within their countries of origin.[5,28] Despite the comparatively lower incidence, BAME women typically present at advanced stages with worse outcomes.[35–37] This contributes to the mortality inequality amongst BAME communities hence is an important public health problem. Therefore, it is imperative that knowledge of breast cancer, benefits of screening, and engaging promptly with medical providers form part of targeted educational campaigns to BAME women.

This review highlighted that advice from healthcare professionals is widely respected amongst BAME communities; Thomas et al report BAME women suggesting that a GP's opinion should be 'obeyed.'[20] Although not inclusive to all BAME women, the widely adopted attitude of respect equips healthcare professionals with enormous potential to positively influence the health seeking behaviours of BAME women.[20,31] GP endorsement letters and positive messages from the health service were both shown to increase screening uptake amongst ethnic women.[6,38]

Unawareness of screening importance was exacerbated by language barriers.[6,31] Inability to comprehend relevant information, invitation letters or media campaigns leaves women dependent on family members' translations which can be subjective to their respective opinions and literacy levels.[5,31] Similarly, inability to read screening invitations presented as an important influencer of non-attendance for both bowel and cervical screening.[34,39,40] Jain et al highlighted the benefits of translated material yet, according to Thomas et al, even when translation was available, it was often inadequate.[6,20]

Educational facilitators determined by Jain et al focused on improving information accessibility for BAME women.[6] Readily available information leaflets in relevant languages improved uptake, as did offering different forms of information such as DVDs.[5,6]

Therefore, it may well be that the key to overcoming language barriers is utilising different forms of educational media such as videos, oral sessions in local community centres, social media and web-based educational formats.[22]

Within the three studies identifying successful educational interventions, emphasis on incorporating religious and community leaders, respective buildings and both men and women facilitated the engagement of a larger population and consequently, improved screening attendance.[20,27,28]

Cultural-related factors

Fear of mastectomy and the consequences on femininity, marital relations and cultural stigma prevented breast screening participation.[27,28] Insufficient support from partners further discouraged screening attendance hence, the necessity of male participation in educational interventions is reinforced.[27]

Educational interventions must also address treatment options as lack of awareness regarding post mastectomy reconstruction and alternative treatments pathways were identified as barriers to attendance. [28] [41,42]

Jain et al reports that healthcare professionals often felt culturally incompetent despite adequate training.[6] Parallels drawn by Kai et al reveal a reluctance amongst healthcare professionals to engage effectively with minority communities due to fear of causing offence.[43] Staff feeling 'cultural incompetent' is exacerbated by the insufficient support provided by national guidelines and training and inevitably contributes to BAME women's negative perception of healthcare staff's attitude.[5,6,20,27,31] This negative perception, as well

as previous experiences, discouraged BAME women from both consulting their GP and participating in screening.[5,20]

Cultural stigmas associated with breast cancer were effectively mitigated through integrating and respecting cultural beliefs via the incorporation of community and religious leaders within educational interventions.[5,27,28] Translating this to health care provision and public health outreach, encouraging the recruitment of BAME staff in culturally sensitive areas such as breast cancer care can aid rapport. Staff who can speak ethnic minority languages, 'link-workers', can facilitate rapport and are effective in encouraging screening attendance.[29] Additionally, the preference of a female radiographer was unanimously expressed by all ethnicities but particularly in BAME communities of certain religious backgrounds.[5,20] Therefore, the option guaranteed female staff could potentially promote screening unanimously.[5,17,32]

Access-related factors

Logistical challenges, such as cost of transport, timings and inconvenience, all hindered breast screening attendance amongst BAME women.[5,27,31] Studies attempting to mitigate the barrier of transport cost alone were largely ineffective suggesting that an interplay of multiple factors influence the decision of attendance.[6,28,31] Thomas et al incorporated this philosophy and demonstrated that establishing screening centres within prominent community centres, such as churches and mosques, effectively promoted screening through inclusivity of community needs as well as being highly convenient.[20]

Practical support from family and friends increased screening attendance; helping with childcare and getting to and from appointments.[27,29] Therefore, the need to incorporate all members of society in education interventions is again highlighted.[5,27,28]

Five studies indicated feelings of anxiety and embarrassment discouraged women from attending breast scans.[5,20,28–30] Participants in the Pfeffer study recounted embarrassment relating to male doctors and the unfamiliarity of the screening process as deterrents.[5] Forbes et al reaffirms this finding with reports of embarrassment and low confidence discouraging women from accessing screening services.[5,30]

Strengths and weaknesses of the review

To maximise the reliability and validity of results, the search strategy specified 'papers from peer reviewed journals.' Grey literature, such as PhD theses and unpublished research, was not included in the search and therefore, there is potential for selection bias to influence results as a consequence of this exclusion. Furthermore, generalisability is potentially impacted due to the exclusion limiting the evidence scope.

The primary papers included in this review were subjective to varying degrees of methodological shortcomings yielding less robust conclusions therefore, to limit the extent of this, evidence from weaker studies was only included if stronger studies supported it.

An adapted CASP tool was used to appraise quantitative studies in an attempt to maintain symmetry across study rankings. Inevitably the validity of the adapted CASP tool was lost, meaning the appraisal of quantitative study may have been less accurate which impacts the strength of conclusions.[26]

Implications of the research

Given the low uptake of breast screening services within the BAME community and the subsequent health inequalities, it is of paramount importance to work towards solving this public health issue. An important first step in tackling this problem is research into the reasons why the inequalities exist and what can be done to overcome them. This qualitative review, which focuses on the respective barriers and facilitators influencing breast screening attendance of UK BAME women, forms part of the evidence base needed to augment change. However, as most of the included studies were conducted in London, further research is required to assess the UK-wide generalisability of these results. Further to this, barriers and facilitators identified may have different levels of influence within different minority ethnic communities eliciting further research.

In addition to the need for community interventions and national public health campaigns, this review highlights the importance of public health promotion at the point of care. The patients' decision to attend screening is directly influenced by their encounters with healthcare staff.[5,27,29] There is, therefore, a real need to better educate healthcare staff on the public health implications following their patient interaction.[44] With Public Health England's recent emphasis on the importance of preventative medicine, it is more important than ever to encourage screening at all levels of healthcare to bridge the existing inequality gap.[45]

Conclusion

The health inequality gap regarding BAME women's breast screening attendance is a crucial public health issue to resolve. This review highlights potential ways to bridge this inequality gap with culturally sensitivity educational interventions as a promising first step.

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