A systematic review of barriers to early presentation and diagnosis with cancer among Black women

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004076
Article Type:	Research
Date Submitted by the Author:	19-Sep-2013
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Primary Subject Heading:	Oncology
Secondary Subject Heading:	Oncology
Keywords:	ONCOLOGY, Adult oncology < ONCOLOGY, Breast tumours < ONCOLOGY

ABSTRACT

Objectives: To explore barriers to early presentation and diagnosis with cancer among Black women.

Design: Systematic review.

Setting: n/a

Participants: n/a

Interventions: n/a

Methods: We searched multiple bibliographic databases (January 1991-February 2013) for primary research, English language publications conducted in developed countries investigating barriers to early presentation /diagnosis with symptomatic cancer among Black women (≥ 18 years). Studies were excluded if they did not report separate findings by ethnic group, gender or reported differences in time to presentation/diagnosis by ethnic group, interventions and barriers to cancer screening. We followed the Cochrane and PRISMA statement approach to identify research and thematic synthesis to integrate results. The design of the quantitative studies meant a meta-analysis was not conducted.

Results: We identified 23 studies (8,872 participants). Delay was multifactorial, individual and complex. Factors contributing to delay included: poor symptom/risk factor knowledge; fear of detecting breast abnormality; fear of cancer treatments; fear of partner abandonment; fear of others' reactions to a cancer diagnosis; embarrassment of disclosing symptoms to healthcare professionals and associated investigations; taboo of cancer and stigmatism. Presentation appears quicker following disclosure. The influence of fatalism and religiosity on delay is unclear. We compared older studies (≥ 10 years) with newer ones (< 10 years) to determine trends in factors studied and changes in findings over time. In older studies factors increasing time to presentation included: accessibility of healthcare services; competing priorities; and concerns about partner abandonment. Partner abandonment was studied in older studies but not newer ones. Comparisons of healthy women and cancer populations revealed differences between how people perceive they would behave, and actually behave, on finding breast abnormality.

Conclusions: Strategies to improve early cancer presentation and diagnosis among Black women need to both address symptom recognition and interpretation of risk and address fears of the consequences of cancer.

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Word count: 5,112

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ARTICLE SUMMARY

Article focus

- To understand barriers to early presentation with, and diagnosis of, symptomatic cancer among women of Black African and Black Caribbean descent living in developed counties

Key messages

- Black women have limited understanding of cancer – in particular breast cancer and its risk factors– when compared to White women and are reluctant to check their breasts
- The paucity of data did not permit comparisons between Black ethnic groups or US and UK populations to be drawn
- Presentation is not solely dependent on knowledge but also influenced by fear, taboos, empowerment, trust in the healthcare system, changes in perceptions over time and whether women have symptomatic cancer or are healthy

Strengths and limitations of this study

- Several of the themes were present in a large number of studies, indicating the strength of its findings. Findings from quantitative and qualitative studies were broadly similar, providing further corroborative evidence of this.
- However, some conflicting findings were potentially due to differences in when research was published and whether studies included women who had been diagnosed with cancer or general populations.
- Most studies were conducted in the US which made it difficult to draw conclusions and implications for women across developed countries due to the particular cultural history of the US population and the particular way that US healthcare is funded.
- Further, studies varied in their definition of, and groupings of, ethnicities. This meant that we were unable to explore differences between Black ethnic groups.
- Studies also varied in their methodological quality; small samples, limited information on data analysis and demographic characteristics were common.
- US studies which reported on the health insurance coverage of participants showed that the majority (between 58% and 92%) were insured. Therefore, the inclusion of relatively affluent samples in some studies may not reflect the general Black and African American female population. The influence of age on women's perceptions and delay was also not explored systematically in any of the studies.

BACKGROUND

Cancer is a leading cause of disease and death worldwide [1] although incidence and survival rates vary across ethnic group. Data from the US determined that African American women have a 6% lower incidence rate of cancer but a 16% higher death rate than White women. Further, they are less likely than White women to present with localized cancer [2]. Analysis of UK cancer registry data has shown that despite lower breast cancer incidence rates in the UK among Black African and Black Caribbean than White women, Black women are more likely to be diagnosed with metastatic disease and have poorer survival than White British women [3]. One factor contributing to this disparity in both the UK and US relates to differing access to, and uptake of, screening. In both nations screening uptake is lower in Black than White populations and communities [4]. There is also evidence – largely from the US – of Black and African American women delaying longer with symptomatic cancer before seeking health professional help than White women. 'Fatalism', fear, embarrassment, lack of trust in health services, lower education and limited knowledge about cancer and its symptoms have been cited as barriers to early presentation in Black and African American women [5-8]. Provider delays, such as delayed GP referral to hospital diagnostic services, can also contribute to late diagnosis.

The disparity in cancer outcomes between Black and White women in both the US and the UK provided the impetus for appraising and synthesising research exploring barriers to early presentation and diagnosis with cancer in Black women in this review. A search of previous literature reviews on the Cochrane Database of Systematic Reviews and other electronic databases did not identify any reviews relevant to the one undertaken.

AIM OF THE REVIEW

This review aimed to understand barriers to early presentation with, and diagnosis of, symptomatic cancer among women of Black African and Black Caribbean descent living in developed counties. The review was undertaken to inform a qualitative study exploring these issues among Black African, Black Caribbean and White British women in the UK. The focus was on research carried out in developed countries only as delays in presentation and diagnosis with cancer in developing countries are likely to be more influenced by the availability and accessibility of diagnostic services.

METHODS

The review methodology was informed by the Cochrane Handbook for Systematic Reviews of Interventions [9]. The following electronic databases were searched on the 27th February 2013 to identify relevant studies: Medline, PsychINFO, The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scopus. Searches were restricted to research published from 1991-2013 and to English-language publications published in peer-reviewed journals. A detailed search strategy (Table 1) was used to identify relevant papers in Medline. Similar search strategies were applied in CINAHL, PsychInfo and SCOPUS.

Table 1: Example of search strategy (Medline)

Concept 1 AND	Concept 2 AND	Concept 3 AND	Concept 4
Neoplasms (SH) neoplasm* (free text) cancer* (free text) tumor* (free text)	African Continental Ancestry Group (SH) West Indian* (free text) “Afro Caribbean*” (free text) “Afro American*” African American* (free text) African Caribbean* (free text) Black* not (Blackwell) (free text), minority group* (free text) ethnic minorit* (free text) “Black Minority Ethnic” (free text) “BME” (free text)	Perception (SH) Social Perception (SH perception* (free text) social perception* (free text) opinion* (free text) Attitude to Health (SH) attitude* (free text) social value* (free text) social norm* (free text) Culture (SH) belief* (free text) understanding* (free text) language* (free text) communicat* (free text) fear* (free text) mistrust (free text) trust (free text) cultur* (free text) relig* (free text) knowledge* (free text) barrier* (free text) embarrass* (free text) fatalism (free text) fatalistic (free text) income (free text) socioeconomic* (free text) depriv* (free text) educat* (free text) poor* (free text) poverty (free text)	Early Diagnosis (SH) Early Detection of Cancer (SH) “Late presentation” (free text) “Early presentation” (free text) “Early diagnos*” (free text) “Late diagnos*” (free text) “early detection cancer” delay* (free text)

Criteria for including studies in this review

Papers included in the review reported on studies conducted with female adults (≥18 years) who were Black, African American, Caribbean or African.

Inclusion criteria

To be included in the review papers had to be:

- Published in English language peer-reviewed journals in the last twenty years
- Primary research articles
- Studies that explored barriers to early presentation and diagnosis with any symptomatic cancer in Black women of 18 years or over of African or Caribbean descent
    - Including studies that explored factors affecting women’s return for follow-up following abnormal test results
    - Including studies that explored diagnostic delays due to service-related factors after suspicious findings by health professionals

  - Including studies that explored attitudes to, and undertaking of, self examination (relating to breast cancer)
  - Including healthy women and those who had cancer
- Conducted in developed countries

Exclusion criteria

Papers were excluded from the review if they:

- Did not report separate findings by ethnic group
- Did not report separate findings for men and women
- Only reported research carried out in developing countries
- Only reported differences in time to presentation/diagnosis by ethnic group but did not explore factors accounting for these differences
- Only reported uptake of, or barriers to, cancer screening
- Only described interventions to increase uptake of cancer screening and/or improve early presentation/detection rates
- Only described Black women's perceptions of cancer without discussing how their perceptions related to/influenced early presentation and diagnosis

Data collection and analysis

Titles and abstracts of all studies identified by the searches were retrieved and reviewed by CJ who excluded all irrelevant papers (Appendix 1). Abstracts from approximately 10% of all retrieved papers, randomly sampled, (n=80) were independently reviewed by ER. Studies not excluded at this point were retrieved in full text and assessed for eligibility by CJ. Excluded articles were reviewed independently by ER to ensure studies were not erroneously excluded.

Data extraction and quality appraisal

Data were extracted systematically from eligible papers using Data Extraction Forms (DEFs) developed by the team (Appendices 2 and 3). Data were extracted from eligible papers independently by two from the team of reviewers (CJ, RJ, LF, and GL).

Methodological quality was appraised using six attributes of research design that impact directly on the veracity of research findings irrespective of the particular research design (based on [10-12]):

1) Appropriateness of study design

2) Suitability of data collection strategy

3) Appropriateness of sample and sampling method

4) Appropriateness of analytic approach/tools

5) Level of control over confounding variables (quantitative studies) or level to which research context was adequately considered (qualitative studies)

6) Whether interpretation of findings was justified by the data

No papers were excluded based on quality but lower quality studies were given less weight in the discussion.

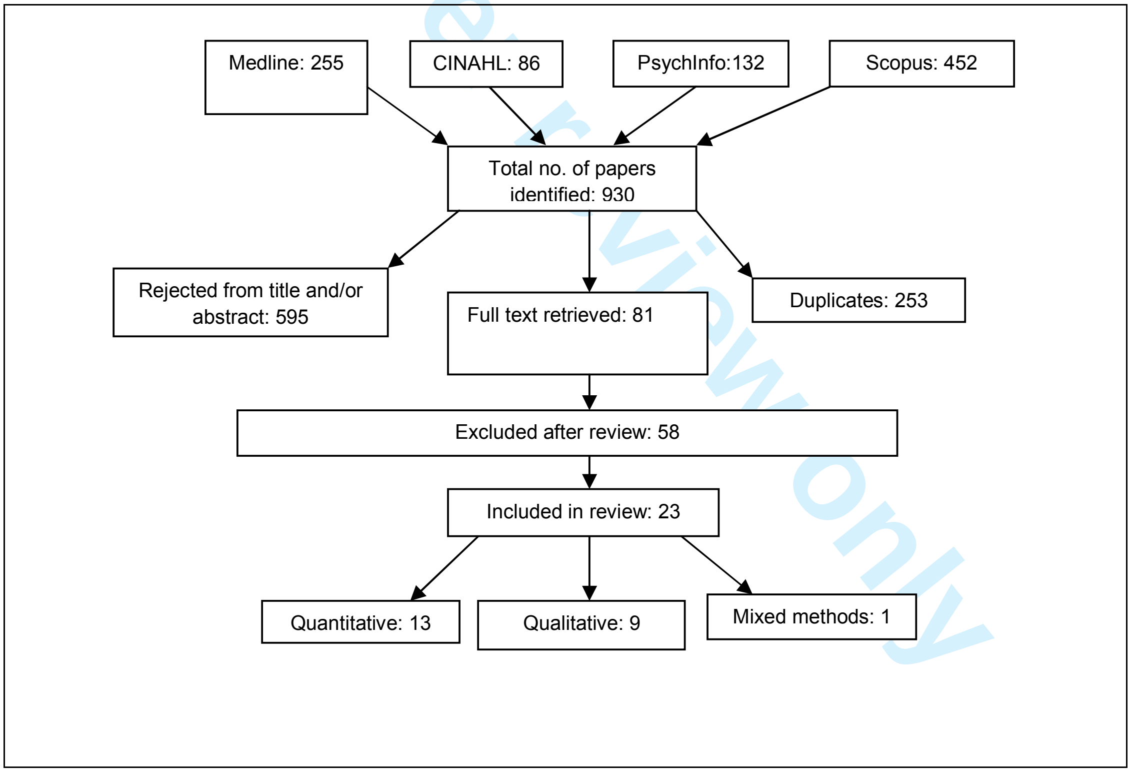
Data synthesis

Thematic synthesis was used to integrate findings from qualitative and quantitative studies [13]. This entailed line-by-line coding of text from the qualitative studies. Codes were compared to identify recurrent concepts and patterns between themes which were subsequently organised into a framework of descriptive themes. Findings from the quantitative studies were summarised descriptively (as the design of the quantitative studies rendered it impossible to undertake meta-analysis) and integrated into the thematic framework. We developed new interpretative constructs (we compared studies that were <10 years old with studies conducted ≥ 10 years ago and studies of women with and without breast cancer to explain our findings) in order to go beyond the primary studies and to generate new explanations and hypotheses.

RESULTS

We identified 23 papers that met our inclusion criteria (Figure 1) providing data for 8,872 individuals who were between 19 and 99 years old. Of these, 20 were conducted in the US and 3 in the UK. As most studies were conducted in the US, explicit reference will be made when referring to a UK study. 13 papers were quantitative, 9 qualitative and 1 mixed methods.

Figure 1: Data search and retrieval



18 papers focused on breast cancer, 2 on breast and cervical cancer, 1 on cervical cancer and 2 focused on cancer of any type. Studies included women who had been diagnosed with cancer (11), general population samples (10) and women with abnormal mammogram or clinical breast examinations (1). In 1 study it was unclear whether or not the sample had been diagnosed with cancer.

5 quantitative studies were considered high quality [14-18] 5 were deemed to be of medium quality [19-23] and 3 of low quality [24-26]. All qualitative studies, were considered medium quality [27-34] except 1 which was considered poor [35]. The mixed-methods study was considered medium quality [36].

Table 2: Summary information on selected papers (AA = African American) (Appendix 4 for results of individual studies)

Reference	Site of cancer	Country	Type of study	Sampling method	Methods	*N*	Participants	Quality
14	Breast	US	Quantitative	Cross-sectional, purposive	Face to face interview	213	Black women with abnormal mammogram or clinical breast examination	High
15	Breast	US	Quantitative	Cross-sectional, case control	Face to face interview	636	AA women General population sample	High
16	All cancers	UK	Quantitative	Cross-sectional, quota, representative of UK population	Face to face interview	1500	Women(n=758), Indian (n=234), Pakistani (n=166), Bangladeshi (n=60) Caribbean (n=134), African (n= 112), Chinese (n=52) Men (n=742) General population sample	High
17	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	129	AA women with breast cancer	High
18	Breast	UK	Quantitative	Cross-sectional, Population-representative sample plus booster sample for non-white ethnic groups/women >55 yrs	Face to face, computer assisted interview	1515	Black (n=265), White (n=806), and South Asian (n=333) women General population sample	High
19	Breast	US	Quantitative	Cross-sectional, 70% random sample of Black women. Comparison White sample matched by age groups	Face to face interview	370	Black (n=206) and White (n=161) women with breast cancer	Medium
20	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	352	Black and AA women (breakdown by ethnic group not provided) General population sample	Medium
21	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered by post	349	AA (n=152) and White (n=197) women. General population sample	Medium
22	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire administered in person by investigator	699	Black, White and Latino women (breakdown by ethnic group not provided) General population sample	Medium
23	Breast and cervical	US	Quantitative	Cross-sectional, population based	Self-report questionnaire (method of administration not provided)	1377	AA (n=185), White American (n=449), Latina American (n=468) and Asian American (n=275) women. Diagnosed with breast or cervical cancer 1-5 years previously	Medium
24	Breast	US	Quantitative	Cross-sectional, convenience and case control	Face to face interview	540	AA (n=378, White (n=162) women Women with breast cancer and community controls	Low
25	Breast	US	Quantitative	Cross-sectional, random-stratified	Face to face structured interview	682	AA (n=280), White (n=402) General population sample	Low
26	Breast	US	Quantitative	Cross-sectional, convenience	Self report questionnaire, administered in person by investigator	60	AA women with breast cancer	Low

27	Breast	US	Qualitative	Convenience	Focus groups, thematic and pattern analysis	32	AA women General population sample	Medium
28	Breast	US	Qualitative	Convenience sample	Focus groups, narrative analysis	80	Black (mainly AA) (n= 26), White (n=23), Latino (n=31) women with breast cancer	Medium
29	Breast and cervical	US	Qualitative	Convenience and snowball	Interviews, narrative and content analysis	20	Black women with breast cancer	Medium
30	Breast	US	Qualitative	Not provided	Focus groups, thematic and pattern analysis	100	AA women Not stated whether they had breast cancer or not	Medium
31	Breast	US	Qualitative	Purposive	Ethnographic interviews, observations, fieldnotes, photographs, ethnographic analysis	13	AA women with breast cancer	Medium
32	Breast	US	Qualitative	Convenience	Interviews, narrative and thematic analysis	23	AA women with breast cancer	Medium
33	Breast	US	Qualitative	Convenience and snowball	Focus groups, thematic and pattern analysis	30	AA (n=12) women, AA (n=12) men General population sample	Medium
34	Cervical	US	Qualitative	Convenience and snowball	Interviews, focus groups	51	Focus groups – all women AA (n=10), Caucasian (n=5), Chinese (n=6), Mixed Asian (n=4) Latina (n=26) with breast cancer	Medium
35	All cancers	UK	Qualitative	Purposive	Focus groups, thematic and pattern analysis	53	Nigerian women (n=10), Ghanaian women(n=10) Ghanaian men (n=9)	Poor
36	Breast	US	Mixed-methods	Mixed- method (cross-sectional survey with subsequent interviews	Self-report questionnaire, administered by post Follow up telephone interview	48	AA women with breast cancer	Medium

Knowledge

Low awareness of cancer symptoms and/or personal risk

A consistent finding across studies was the low level of knowledge among Black and African American women about symptoms of breast cancer and/or risk factors for developing the disease [18, 21, 24, 27-30, 32, 34, 35]. Poor knowledge of symptoms and risk factors was associated with delay in presentation among Black and African American women with breast cancer [28, 29, 31].

Poor symptom awareness and knowledge of risk factors/personal risk

Comparisons of risk perceptions among African American and White women with breast cancer in two studies revealed a significantly lower percentage of African American women (25%) than White American women (44%) felt susceptible to the disease before they were diagnosed [21] and that African American women were less likely than White women to believe that if a woman has cancer it increases the risk for their daughter [24]. In the UK, few Black (13%) and White women (12%) without breast cancer knew that women over 70 years are at higher risk of breast cancer than women of any age [18]. A Ghanaian woman reported knowing nothing about the causes of cancer [35].

Further, a number of studies suggested that Black and African American women were unaware of both risk factors for breast cancer and of their personal risk of developing it [27, 29, 30, 32]. Some women believed breast cancer was a 'White woman's disease' and others that they were not at risk because they did not have a family history of breast cancer. Two studies reported that these perceptions were reinforced by media messages which focused on White women [27, 32]. Underestimation of risk appeared to influence delayed presentation [29]. Women who thought their chance of getting cancer was low, in some cases lacked the motivation or inclination to check their breasts [27, 29].

Recognising significance of cancer symptoms

There was strong evidence to suggest that in the US, Black and African American women lacked knowledge of, and information about, symptoms of breast and cervical cancer [27-29, 32]. In the UK, Black women (16%) were slightly less likely to recognise five or more non-lump symptoms of breast cancer than White women (22%) [18]. Many of those with cancer had underestimated the significance of their symptoms which contributed to them delaying presentation [29, 31, 32, 34, 36]. For some African American women, there was confusion over whether or not pain was a symptom of breast cancer. Presence of pain reassured some African American women that their breast symptom was not cancer [28, 32]. One had *'read that pain [was] not a risk factor'* [32]. Further, some studies suggested a tendency among African American women to tolerate or ignore symptoms, until they were severe, before seeking medical attention [31, 34, 36]:

> *At first, I tried to ignore my pain but it continued to get worse.'* [36]

In one study, some African American women with breast cancer only presented when their symptoms worsened or they developed additional symptoms [31]. Further, another study suggested African American women were more likely than White women to delay presentation if their lump was not bothering them [24]. Other contributing factors to delay included women who assessed that their symptoms were simply caused by stress [29] or women who had previous diagnoses of a benign breast lump [31].

Empowerment and confidence

Making time to check for and/or present with symptoms

One study identified that women who were unaware of breast cancer symptoms lacked confidence to check their breasts [27]. In a UK study, breast checking differed by ethnic group; Black women were less likely than White women to report breast checking (after controlling for age and socioeconomic status) [18]. However, similarly high percentages of Black (50%) and White (55%) women were fairly or very confident that they would notice a breast change [18].

It is unclear from the UK studies whether Black women were less likely than other ethnic groups to make time to present with suspected cancer symptoms. In one study of the general population, African and Caribbean women were less likely to report as barriers to early presentation either having too many other things to worry about (20% African, 25% Caribbean) or being too busy to make time (20% African, 25% Caribbean) compared with women from other ethnic groups [16]. Another UK study found that barriers to symptomatic presentation were not more common in Black than White women without breast cancer. Moreover, Black women (32%) were slightly less likely than White women (37%) to report having too many other things to worry about, and similar proportions reported being too busy to make time to see the doctor (34% Black, 35% White) [18].

Evidence from the US suggested there was no discernible difference between African American and White women. For example, low percentages of both African American (3%) and White (2%) women who had survived breast or cervical cancer reported having delayed symptomatic presentation because of work commitments [23]. In a further study, African American women with cancer said they presented despite family caring obligations [31].

Studies conducted over ten years ago found some evidence that responsibilities might lead to delayed presentation: some African American women and one Black woman reported lacking time [27, 29] to check their breasts. Some Black and African American women without breast cancer but with childcare, employment and partnership responsibilities reported they would be less likely than those without these responsibilities to seek help for breast symptoms should they arise [20].

Lack of partner support

Among Black and African American women, both with and without breast cancer, lack of partner support and concerns around partner abandonment were raised when discussing the physical effects of breast surgery on their relationships. However, the specific influence of partner support/abandonment on delay was unclear [24, 28, 30, 31]. In one study, Black and African American with breast cancer reported that fear of partner abandonment inhibited help-seeking. However, this also appeared the case for White women [28]. In another study, help-seeking was not affected despite one woman's partner saying he did not want to live with *'no one titty bitch*' and others saying they were concerned they would be less appealing to their partners [31]. Limited evidence indicates that African American women are more likely than White women to delay seeking help due to lack of partner support [24].

Stigma, taboo and fear

Stigma and taboo emerged as salient themes among Black, African American, Ghanaian and Nigerian women in the US and UK. They were reluctant to talk about cancer and reported that in their communities, the word 'cancer' was whispered [32, 33] and referred to as *'the big* C' [28]. Cancer diagnoses were kept secret [30, 35] because of a '*hush hush attitude'* [35] and feelings of shame [35]. Further, in a UK study, Ghanaian and Nigerian women reported a reluctance to disclose symptoms to others due to feeling ashamed of potentially having cancer [35]. However in a US study, disclosure to others (particularly family or friends) was associated with shorter delays in presentation in African American women [17]. Whether disclosure influenced decisions to seek care or reflected openness to discuss cancer symptoms with others (including healthcare professionals) was less clear. A further study found two thirds of African American participants felt they made their own decision to seek help [36].

Black and African American women who were fearful of cancer were significantly more likely to delay presentation than those who were not [14, 23, 31]. In the UK, Caribbean women were more likely than African women to delay seeking help because of fear [16]. In one study, some African American women were too scared to check their breasts [27] while in another 32% of African American participants with breast cancer reported feeling scared when they discovered their symptoms [36]. However, this and another study found no relationship between fear and delay [26, 36]. Lack of quality information in one study was thought to increase fear [34] but was not examined in any others. In the UK, Ghanaian and Nigerian women described feelings of fear and apprehension about cancer but this was not explored in relation to delay [35].

Religiosity

There was very little evidence to suggest that religiosity impacted time to presentation with cancer in symptomatic Black and African American women. Three studies exploring the influence of religiosity found it did not inhibit help-seeking in women with symptomatic cancer [17, 28, 34]. However, there was some evidence that age [31] and African American ethnic group [24, 25] may predict a belief that religious intervention influences the outcome of cancer rather than medical treatment, as well as a resigned acceptance of death. The link between what has been termed 'fatalism' – a belief that cancer is pre-ordained – and delayed presentation is unclear. One study of healthy women suggested an association between fatalism and help-seeking intention [20], but a study of women with breast cancer found no association between fatalism and actual delay in presentation [17].

Trust in healthcare system

Curability of cancer

There was strong evidence to suggest that Black and African American women with and without cancer believed cancer could be cured [15, 17, 20, 21, 34]. Across three studies, 77- 98% of

African American women did not believe death was an inevitable outcome of cancer [15, 17, 21]. In another study, only a small percentage of African American (13%) and White women (16%) believed that cancer inevitably led to death. [21]. However, two studies of African American women and one UK study of Ghanaian and Nigerian women without cancer, reported that these groups of women believed cancer was a deadly and incurable disease [30, 33, 35]. In two of these studies, very few of those interviewed knew of women who had survived the disease [30, 33] however the influence of their belief (cancer equates with death) on help-seeking intention was not discussed.

Fear of conventional treatment

Black and African American women reported fearing the implications of cancer treatments and surgery [15, 24, 28, 31, 34] and some said they preferred non-conventional therapies [24, 34]. Treatment fear prolonged delay among some women with cancer. One study reported that 57% of African American women with and without breast cancer believed treatments for breast cancer were worse than the disease itself, [15] while three studies reported reluctance among African American women to have surgery [24, 28, 31]. Some African American women reported fearing unpleasant side-effects and were worried about what treatments comprised. One study reported that African American women were more likely than White women to prefer non-conventional treatments in place of surgery [24].

Quality of relationships with healthcare professionals

Concerns about interactions with doctors

In one UK population-based study, a smaller proportion of African than Caribbean women reported that feeling worried about experiencing embarrassment (24% African, 49% Caribbean) or wasting the doctor's time (10% African, 28% Caribbean) were barriers to presentation. Further, proportionally fewer African than Caribbean women reported lacking confidence to talk about their symptoms (21% African, 40% Caribbean). In both groups, around a fifth of women expressed concern that it would be difficult to talk to a doctor [16]. These barriers were not only experienced by Black women. Another UK study showed that they were just as likely to be reported by White women [18].

Lack of confidence in healthcare professionals

There was strong evidence suggesting Black and African American women lacked confidence in medical professionals due to breast symptoms being misdiagnosed. They expressed concerns over standards of care and the type of care they would receive; they were concerned about discrimination in medical settings. In one study three African American women with cancer were initially told their symptoms were benign and this contributed to delayed diagnosis. For example, one was told, '*It's just cysts, it's nothing to worry about.'* [31]. Further, some Black and African American women with cancer were concerned about doctors providing substandard, aggressive (*'she wound up with a mastectomy two weeks later just because of her mammogram')* [28] or experimental care [28, 29, 34]. The Tuskegee syphilis study [37] was cited by Black and African American study participants in support of this belief [28, 29]. However, one study reported that African American women felt healthcare professionals should conduct breast examinations rather than women themselves suggesting they trusted the skills of healthcare professionals [27].

Five studies examined Black and African American women's perceptions of discrimination in medical settings [14, 20, 22, 28, 29]. Two determined that although women perceived a degree of racism and discrimination, this did not appear to influence delay or help-seeking intent [14, 20] but in two studies it did influence help-seeking intention and delay [22, 28].

Practical and service barriers

Financial burden of healthcare and influence of health insurance on patient and provider delays

The impact of the financial burden of healthcare (affordability of healthcare and health insurance coverage) on delay was unclear. No statistically significant association between perceived affordability of healthcare and delay was found in one study [36] and in another, only 4% of African American and 3% of White American women reported delaying because of financial reasons [23]. Moreover, women with health insurance were not significantly more likely to be diagnosed within 90 days than those without insurance [14].

The influence of Caribbean, African, Black and African American women's socioeconomic status on delay was also unclear. In one UK study, Caribbean and African women's socioeconomic status had no effect on help-seeking intention [16] nor did it influence delay among Black women with cancer in the US [14, 26]. However, the majority of US studies reported that less affluent Black and African American women were less likely to seek help for cancer symptoms and that this contributed to delayed presentation [17, 20, 23, 24].

Perceptions of access to healthcare services

In one UK study, access issues (ease of booking appointments, arranging transport and distance between home and health centre) were more prevalent among Caribbean than African women. Almost half the Caribbean women sampled agreed that difficulty making an appointment was a barrier to help-seeking; whereas, only a quarter of African women reported the same barrier. Difficulties arranging transport were less of a barrier to help-seeking than making appointments for both groups. However, for 21% of Caribbean women (in contrast to 6% of African women) transport issues did have an impact [16]. In another UK study these barriers appeared no more common in Black than White women. Rather, Black women were less likely than White women to report difficulties making an appointment as a barrier to help-seeking (Black 30%, White 36%). Difficulties arranging transport were again less of a barrier (Black 14%, White 16%) than making appointments [18].

In the US, the effect of access issues on delay was unclear. In a study of Black and African American women without breast cancer, being more likely to intend to seek help was significantly linked to positive perceptions of accessibility to healthcare [28]. Further, in another study poorer access to healthcare among Black women with cancer made attending appointments difficult [19]. However, more recent studies reported little evidence indicating access issues impacted on delay among Black and African American women with cancer [14, 36].

FACTORS WHICH MAY EXPLAIN THE REVIEW FINDINGS

It was evident that some barriers to early presentation with cancer were more prevalent ten years ago than today and vice versa. Our analysis suggests that this is an important finding and not merely a consequence of study methodology. Accessibility of healthcare services [19, 20] and competing priorities [20, 27, 29] were important issues influencing delay in Black, African American, Caribbean and African women in older (≥10 years) studies. However, in more recent studies (≤ 10 years) access to healthcare [14, 16, 18, 36] and competing priorities [16, 18, 23, 31] were reported to neither influence delay nor help-seeking intention.

Although the influence of partner abandonment was examined in one early quantitative study [24] and emerged from women's narratives in three early qualitative studies, [28, 30, 31], this theme was not examined in any recent quantitative studies and did not emerge as a barrier in a recent qualitative study [34].

Several differences were also noted between women with and without cancer. Competing priorities did not influence delay in women with symptomatic breast cancer [23, 31] but they did influence healthy women's stated help-seeking intention should they develop cancer symptoms [20]. Further, the financial burden of healthcare [14, 23, 26, 36] and access issues [14, 36] did not influence delay among women with breast cancer, although healthy women cited both of these issues as potential barriers to help-seeking [20]. These differences highlight that researchers may get different answers depending on whether they ask healthy women or women with cancer about delay/help-seeking intention.

DISCUSSION

Delayed presentation with cancer in Black women living in developed countries appears influenced by multiple factors, highly individual and complex. Logically, all women may present late with cancer if they have limited awareness of the disease and its symptoms [38]. Although a relatively small number of studies comparing Black and White women were included in the review, Black women appear more likely than White women to have limited understanding of cancer – in particular breast cancer and its risk factors. This could be influenced by a number of factors. Some may have limited knowledge of cancer, notably 1) migrant women from countries where health campaigns about the disease are limited, 2) women with limited command of the host nation's language and/or have low literacy and thus not reached by the host nation's health messages; and 3) women from communities where it is culturally unacceptable to discuss cancer and thus do not gain understanding of the disease through word of mouth.

This review, consistent with health behaviour models [39, 40], illustrates how women's understanding of risk factors and their perceived personal risk influence their sensitivity to cancer symptoms and help-seeking on identifying them. Black women rightly perceive their risk of one of the commonest female cancers (breast cancer) to be lower than in White women (Jack et al, 2009, Siegel et al 2012). Consequently, they may have retained little information provided by healthcare professionals and portrayed in health promotion campaigns regarding breast cancer as they may have believed it had limited relevance for them. .

Findings from studies incorporated in this review determined many women lack confidence in, or are reluctant to, check their breasts. However, if women are unaware of how their breasts typically feel as a consequence, they will face challenges in recognising subtle changes and may only detect change when the disease is relatively advanced.

Clearly, early presentation with cancer is not solely dependent on knowledge. Women with good knowledge of the disease may not seek help from healthcare professionals on detecting symptoms of cancer [41]. This review suggests fear may be an important factor preventing Black women from seeking help. It appears multifaceted - women referred to fear of cancer treatments, abandonment by partners, and fear of what others would say in response to a cancer diagnosis. Arguably, health messages communicating negative consequences of delayed presentation may be less effective than those framed in ways outlining benefits of early presentation. Fear-led messages may lead to avoidance and denial in people who fear a cancer diagnosis [39].

Further, although it appears that disclosure of symptoms indicative of cancer to others can be important in promoting early presentation with the disease [42], it is not uncommon for Black women to feel uncomfortable about disclosing breast cancer symptoms to others including healthcare professionals due to the taboo, and their embarrassment, associated with the disease [43]. Women's previous encounters and rapport with healthcare professionals and any exposure to discrimination or misdiagnosis will influence their time to presentation. Practical (e.g. access issues) or financial barriers may contribute to delay among some women. In the UK there was some evidence that these practical and financial issues were barriers for Black women, although the degree to which they influenced help-seeking intention varied considerably between Caribbean and African women. This highlights that Black women are not a homogenous group – nor should they be treated as such in research – labeling women as 'Black' may mask diverse attitudes and behaviours and lead researchers to overlook important nuances [44].

Notions of 'fatalism' in women born outside the country they live in host country may be influenced by their experiences from their country of origin , where treatments for cancer may be less effective and death more likely [45]. Religiosity might influence help-seeking behaviour but this will depend on how people perceive their own role and that of a higher influence in managing their health [46]. The highly individual nature and influence of religious beliefs may explain why the influence of religiosity on delay was unclear in this review.

There was some evidence that barriers to early diagnosis had altered during the period of this review. This suggests that awareness-raising campaigns may have been successful in raising the importance of early presentation and overcoming practical challenges and personal concerns. Equally, the findings could reflect the time that Black women migrating to developed countries had spent there. Arguably, migrants views will change over time as they adapt to their surroundings and become influenced by new cultures and health systems [47]

There was also some evidence of differences between women with and without cancer, suggesting a distinction between what women say they would do if they discovered a symptom versus what they do with the onset of symptoms. However, it is less easy to determine differences between Black ethnic groups or to compare between populations in the US and UK because the paucity of information reported in the papers did not permit these comparisons. Further, most of the research was undertaken in the US and tended to focus on breast cancer rather than other common cancers such as colorectal. This makes it difficult to apply findings to other developed countries due to the particular cultural history of the US population and the particular way that US healthcare is funded. Research on early diagnosis should focus on other cancers.

Further high quality research is needed to better understand barriers to early presentation and diagnosis with cancer in Black ethnic groups living outside the US. In particular, studies of, and comparisons between, ethnic groups in the UK are needed to determine influences on delay in presentation with all cancers and their possible contribution to the poorer survival of Black African and Black Caribbean women in the UK [3]. Findings of this review have several implications for policy and practice. Our review indicates that Black women should feature more prominently in media campaigns, and educational materials to prevent cancer being perceived as a ‘white women’s’ disease. Information about the risk of breast cancer and its early symptoms and women’s concerns about breast checking, surgery, and side-effects of treatment also need to be addressed in ways that are culturally sensitive to Black women receiving a cancer diagnosis [48, 49].

Vulnerable women, who fear partner abandonment and who may be reluctant to have treatment as a result, need to be identified and supported by healthcare professionals. Further, enhancing women’s experiences of being diagnosed and treated for cancer, and encouraging engagement and discussion regarding the disease may help to address stigma and taboo, promote disclosure and allay women’s fears; factors believed to impact positively on early presentation and diagnosis.

ACKNOWLEDGEMENTS AND FUNDING

This article was funded by the National Awareness and Early Diagnosis Initiative (NAEDI). Thanks to Grace Lucas for extracting data and editing the review.

ETHICS COMMITTEE APPROVAL

As this article describes a systematic review of the literature, no ethical approval was needed for the study.

COMPETING INTERESTS

None

EXCLUSIVE LICENCE STATEMENT

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APPENDIX 1: BREAKDOWN OF EXCLUDED STUDIES (WEB ONLY FILES)

Reason for exclusion on preliminary screening	Number of studies
Aetiology	17
Barriers to, or uptake of, cancer screening	126
Clinical Studies	105
Duplicates	253
Incidence, prevalence and survival studies	71
Methods studies	11
Not about barriers to presentation and diagnosis	137
Not cancer, not Black African or Black Caribbean participants, or not conducted in Western countries	98
Not research	13
Risk factors	13
Unpublished material	5
TOTAL	**849**

Reason for exclusion on data extraction	Number
Data not reported separately for men and women and/or ethnic groups	22
Not Black African or Black Caribbean participants	3
Did not explore barriers	12
Investigated knowledge, attitudes and beliefs	10

and their relationship to cancer screening utilisation	
Study >20 years	1
Investigated stage at presentation and cancer detection methods	4
Investigated perceptions of risk factors	1
Investigated factors/barriers to treatment	1
Investigated association between socioeconomic status and race in cancer stage, treatment, survival and/or cancer screening uptake	4
TOTAL	**58**

Studies retrieved	Studies excluded on preliminary screening	Studies excluded on data extraction	Studies included
930	849	58	23

APPENDIX 2: QUANTITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION
Reviewer:
Title:
Author(s):
Year:
Journal:
Volume:
Issue:
Pages:
STUDY DESIGN
Aim(s) of study:
Description of study design:

Setting	
Country	
ELIGIBILITY CRITERIA	
Exclusion criteria	
SAMPLING	
Sampling procedure	
PARTICIPANTS	
Total no. of eligible participants	
Number of participants recruited	
Number of surveys and/or participants included in the analysis	
What was the response rate?	
Mean age (standard deviation)	
Age range	
Females n (%)	
Males n(%)	
Ethnicities (provide breakdown, n (%))	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
OUTCOMES (please include data)	
Knowledge or attitudes	
Barriers to early presentation (include both patient and	

provider related factors)		
Barriers to early diagnosis (include both patient and provider related factors)		
Other outcomes/findings		
Measurement scales/units used: **Were they: investigator designed/tools with already established reliability and validity?**		
Timing of outcomes measured. When were measures taken?		
Other important outcome information		
Key conclusions as reported by authors:		
Key issues with the study:		
QUALITY APPRAISAL		
		Additional comments
Was the study design suitable?	Yes No Unclear	
Was the sampling method appropriate?	Yes No Unclear	
Were the tools suitable to measure study outcomes?	Yes No Unclear	
Were the tools used psychometrically sound?	Yes No Unclear	
Was the sample appropriate?	Yes No Unclear	
Were the measurements justified?	Yes No Unclear	
Which tests were performed? Were they suitable to satisfy study aims?	Yes No Unclear	
What were the confounding variables? Were there other factors that impacted on the results?		

Were confounding variables adequately controlled for? How were they controlled for in the analysis?	Yes No Unclear	
Was sensitivity to ethical concerns demonstrated? How?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: Evidence generated is strong, unbiased and generalisable		
B - Some flaws: unlikely to affect the reliability and validity of study findings greatly		
C - Many flaws: likely to impact on the reliability and validity of study findings		
D - Highly flawed study, data generated are likely to be biased and lacking reliability and validity		
REVIEWER'S COMMENTS		
Include		
Exclude		
Needs checking by another reviewer (please specify why)		
Contact author for further information (please specify which information)		

APPENDIX 3: QUALITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Endnote reference no:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Setting	
Country	
Sampling procedure	
Inclusion criteria	
Exclusion criteria	
Data collection methods	
Data analysis approach/ procedure	
PARTICIPANTS	
Total no. participants	
Age range	

Females n				
Males n				
Ethnicities (provide breakdown, n)				
Other demographic details (e.g. employment status, location) – please include data from tables/figures				
FINDINGS OF INTEREST	**(please include data)**			
Knowledge or attitudes				
Barriers to early presentation (include both patient and provider related factors)				
Barriers to early diagnosis (include both patient and provider related factors)				
Other findings:				
Key conclusions as reported by authors:				
Key issues with/limitations of the study:				
QUALITY APPRAISAL				
				Additional comments
Research design				
Was a qualitative methodology appropriate?	Yes	No	Unclear	
Was the method/design apparent, and consistent with research intent?	Yes	No	Unclear	
Was the data collection strategy apparent and appropriate?	Yes	No	Unclear	
Sampling strategy				
Was the sample and sampling method appropriate?	Yes	No	Unclear	

Analysis		
Was the analytic approach appropriate?	Yes No Unclear	
Was there evidence of data saturation?	Yes No Unclear	
Were deviant case/contradictory findings discussed? What were they?	Yes No Unclear	
Was there evidence of member checking and/or independent analysis of data by more than one researcher?	Yes No Unclear	
Presentation and interpretation of findings		
Was the context described and taken account of in interpretation?	Yes No Unclear	
Were appropriate quotes used in the presentation of findings and discussion of findings?	Yes No Unclear	
Was the interpretation of findings justified by the data that are presented?		
Reflexivity		
Was researcher reflexivity demonstrated?	Yes No Unclear	
Ethical considerations		
Was sensitivity to ethical concerns demonstrated?	Yes No Unclear	
Relevance and transferability		
Is relevance and transferability evident generally about the study?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: The study credibility, transferability, dependability, and confirmability is high		
B - Some flaws, unlikely to affect the credibility, transferability, dependability,		

and/or confirmability of the study	
C - Some flaws, which may affect the credibility, transferability, dependability, and/or confirmability of the study	
D - Significant flaws, which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study	

APPENDIX 4: RESULTS OF INDIVIDUAL STUDIES (WEB ONLY FILE)

Reference	**Findings**
14	Women who are fearful more likely to delay (OR: 0.50, 95% CI: 0.27-0.92) No statistically significant evidence that financial barriers relate to delay (Unadjusted 1.06, 95% CI, 0.59-1.91) System barriers not significantly related to delay (Unadjusted 0.54, 95% CI, 0.59-1.00) Women with health insurance not significantly more likely to be diagnosed within 90 days (Unadjusted: 0.85, 95% CI, 0.44-1.63) Perceived discrimination not related to delay (data not provided)
15	Would rather know they had cancer:17% Agreed cancer treatments worse than cancer itself: 57% Believed cancer is curable: 74%
16	Barriers to help-seeking: Worried about what a doctor might find: 24% African, 50% Caribbean Too embarrassed: 24% African, 49% Caribbean Too scared: 21% African, 43% Caribbean Would not feel confident talking about symptom: 21% African, 40% Caribbean Worry about wasting doctor's time: 10% African, 28% Caribbean Doctor would be difficult to talk to: 21% African; 28% Caribbean Too many other things to worry about: 21% African, 20% Caribbean Too busy to make time: 20% African, 25% Caribbean Difficult to arrange transport: 6% African, 21% Caribbean Difficult to make an appointment: 23% African, 43% Caribbean
17	Believed death is imminent if someone is diagnosed with breast cancer: 1.6% Believed it is too late to do anything if someone is diagnosed with breast cancer: 3.9% Logistic regressions to determine impact of religiosity, spirituality and fatalism on time to presentation determined income is a significant indicator of time to seek medical care in these models: - Religiosity: (OR: 0.79, 95% CI: 0.68-0.92) - Spirituality: (OR: 0.77, 95% CI: 0.65-0.90) - Fatalism: ((OR: 0.78, 95% CI, 0.67, 0.92) Income is a significant indicator of time to seek medical care (OR: 0.77-0.79, 95% CI: 0.65-0.92) (higher the income, the more likely women were to seek medical care promptly) Disclosure reduces delay (OR: 0.25, 95% CI: 0.11- 0.57) Religiosity & spirituality in themselves do not affect delay (OR:1.00, 95% CI: 0.98-1.03) (OR: 1.06, 95% CI: 0.99-1.13)
18	Recognised 5 or more non-lump symptoms of breast cancer: 16% Black, 22% White Knew that a 70 yr old was at a higher risk of breast cancer than younger women: 13% Black, 12% White Was fairly or very confident about noticing change in breasts: 50% Black, 55% White Reported breast checking at least once a month: 18% Black, 28% White Barriers to help-seeking Worried about what a doctor might find: White 44%; Black 46% Too embarrassed to go and see the doctor: White 31%; Black 30% Lacked confidence to talk about symptoms: 19% White; Black 24% Too scared to go and see doctor: White 29%; Black 20% Too many other things to worry about: White 37%; Black 31% Too busy to make time to go to the doctor: White 35%; Black 34% Find it difficult to arrange transport: White 16%; Black 14% Find doctor difficult to talk to: White 23%; Black 23% Worried about wasting doctor's time: White 53%; Black 21% Find it difficult to make an appointment: White 36%; Black 30%

19	More Black than White women attributed system- oriented delays to scheduling delays (no figures provided)
20	Racism (r=-0.08) independent of help-seeking Intention Childcare, employment, partnership (r=-0.48) and healthcare access (r=0.49) associated with help-seeking intention Fear of cancer has weak association with help-seeking intention (r=0.11) Income associated with seeking help (r=0.32) Perceived negative consequences of delay associated with more timely presentation (r=0.443)
21	Believed death is outcome of cancer: 13% AA, 16% White Believed early diagnosis increases chance of cure: 83% AA, 96% White Felt at risk of developing breast cancer: 25% AA, 44% White
22	Black women more likely to delay if they reported personally experiencing prejudice in healthcare delivery (P <0.001) than White women
23	Proportion of women who cited financial hardship (4% AA, 3% White women) showed significant differences in length of delay compared with women who did not (P= < 0.001) Women who cited fear of cancer (16% AA, 9% White women) showed significant differences in length of delay compared with women who did not: (P= < 0.001) Women who cited work-related reasons (3% AA, 2% White women)did not show a significant difference in length of delay compared with women who did not (P < 0.001)
24	AA more likely than White women to: believe men would not want to know about cancer (3.1, 95% CI: 2.0-4.6), not go to doctor if lump not bothersome (6.0, 95% CI: 2.3-15), believe surgery would be the worst thing (1.6, 95% CI: 1.1-2.2), have a belief in herbal remedies (2.6, 95% CI: 1.7-4.1), over the counter medicines (2.0, 95% CI: 1.3-2.9) and chiropractic regimens (3.0, 95% CI: 1.8-5.2) as treatments for cancer AA less likely than White women to: have a belief in surgery (0.5, 95% CI: 0.3-0.9) and believe if a woman has cancer it increases the risk for daughter (0.6, 95% CI: 0.5-0.8)
25	Being AA is primary predictor of belief in religious intervention in place of treatment rather than religious intervention with treatment (p<0.0001)
26	No relationship between worry and delay No relationship between sociodemographic variables and delay
27	Afraid to conduct breast self-examination due to fear Advertising aimed at White women Lack confidence to breast check (e.g. unsure of symptoms) Lack time/family support to conduct breast self-examination
28	AA women: Concerned about substandard, aggressive or experimental care Fear of partner abandonment - inhibits help-seeking Lack knowledge to identify symptoms Religiosity does not constrain help-seeking
29	Felt at low risk Fear of physical examinations due to sexual abuse in past Breast self-examination low priority Mistrust of medical professionals Symptoms misinterpreted
30	Cancer is stigmatised Fear partner will abandon if cancer diagnosis is shared Very few women with experience or knowledge of breast cancer knew other women who had survived it Belief that breast cancer is primarily a white women's disease

31	Caring obligations were not barriers to presentation Fear and anxiety (e.g. of treatment) can lead to delay Lack of knowledge not always reason for delay Dismissal of lump led to delay Previous benign diagnosis by health professional led to delay Fear of partner abandonment may inhibit help-seeking Other symptoms(e.g. feeling unwell) prompt help-seeking
32	Believed breast cancer is a White woman's disease Lack of adequate information about risk factors/symptoms Cancer is taboo
33	AA women: Believed cancer is taboo Equated cancer with death Previous negative experiences influenced perceptions
34	AA women: Believed early presentation is important Tolerated severe symptoms before seeking help Reported fear due to lack of information Believed doctors lack sensitivity in medical examinations
35	Ghanaian women: Limited knowledge of cancer Ghanaian & Nigerian women: Feelings of fear and apprehension Cancer is a deadly disease, fear is enough to kill someone Secrecy about cancer "hush hush attitude" People hide diagnosis from others Reluctance to disclose symptoms to others due to shame
36	Felt fear on symptom discovery: 32% Fear may be influenced by whether women believe in God (1 woman) Made own decision to seek care rather than being influenced by others: 65% Confrontive coping (confronting/dealing with cancer directly) correlated with shorter delays (r=-0.32, no p value provided) Denial associated with longer delays (r=0.36), p<0.05) Fear not correlated with delay Affordability and accessibility of healthcare not correlated with delay Tolerate pain until it worsens (1 woman)

APPENDIX 1: BREAKDOWN OF EXCLUDED STUDIES (WEB ONLY FILES)

Reason for exclusion on preliminary screening	Number of studies
Aetiology	17
Barriers to, or uptake of, cancer screening	126
Clinical Studies	105
Duplicates	253
Incidence, prevalence and survival studies	71
Methods studies	11
Not about barriers to presentation and diagnosis	137
Not cancer, not Black African or Black Caribbean participants, or not conducted in Western countries	98
Not research	13
Risk factors	13
Unpublished material	5
TOTAL	**849**

Reason for exclusion on data extraction	Number
Data not reported separately for men and women and/or ethnic groups	22
Not Black African or Black Caribbean participants	3
Did not explore barriers	12
Investigated knowledge, attitudes and beliefs and their relationship to cancer screening utilisation	10
Study >20 years	1
Investigated stage at presentation and cancer detection methods	4
Investigated perceptions of risk factors	1
Investigated factors/barriers to treatment	1
Investigated association between socioeconomic status and race in cancer stage, treatment, survival and/or cancer screening uptake	4
TOTAL	**58**

Studies retrieved	Studies excluded on preliminary screening	Studies excluded on data extraction	Studies included
930	849	58	23

APPENDIX 2: QUANTITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Description of study design:	
Setting	
Country	
ELIGIBILITY CRITERIA	
Exclusion criteria	
SAMPLING	
Sampling procedure	
PARTICIPANTS	
Total no. of eligible participants	
Number of participants recruited	
Number of surveys and/or participants included in the analysis	
What was the response rate?	
Mean age (standard deviation)	
Age range	
Females n (%)	
Males n(%)	
Ethnicities (provide breakdown, n (%))	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
OUTCOMES (please include data)	
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	
Barriers to early diagnosis (include both patient and provider related factors)	
Other outcomes/findings	
Measurement scales/units used: **Were they: investigator designed/tools with already established**	

reliability and validity?		
Timing of outcomes measured. When were measures taken?		
Other important outcome information		
Key conclusions as reported by authors:		
Key issues with the study:		
QUALITY APPRAISAL		
		Additional comments
Was the study design suitable?	Yes No Unclear	
Was the sampling method appropriate?	Yes No Unclear	
Were the tools suitable to measure study outcomes?	Yes No Unclear	
Were the tools used psychometrically sound?	Yes No Unclear	
Was the sample appropriate?	Yes No Unclear	
Were the measurements justified?	Yes No Unclear	
Which tests were performed? Were they suitable to satisfy study aims?	Yes No Unclear	
What were the confounding variables? Were there other factors that impacted on the results?		
Were confounding variables adequately controlled for? How were they controlled for in the analysis?	Yes No Unclear	
Was sensitivity to ethical concerns demonstrated? How?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: Evidence generated is strong, unbiased and generalisable		
B - Some flaws: unlikely to affect the reliability and validity of study findings greatly		
C - Many flaws: likely to impact on the reliability and validity of study findings		
D - Highly flawed study, data generated are likely to be biased and lacking reliability and validity		
REVIEWER'S COMMENTS		
Include		
Exclude		
Needs checking by another reviewer (please specify why)		
Contact author for further information		

(please specify which information)	

APPENDIX 3: QUALITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Endnote reference no:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Setting	
Country	
Sampling procedure	
Inclusion criteria	
Exclusion criteria	
Data collection methods	
Data analysis approach/ procedure	
PARTICIPANTS	
Total no. participants	
Age range	
Females n	
Males n	
Ethnicities (provide breakdown, n)	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
FINDINGS OF INTEREST	**(please include data)**
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	
Barriers to early diagnosis (include both patient and provider related factors)	

Other findings:		
Key conclusions as reported by authors:		
Key issues with/limitations of the study:		
QUALITY APPRAISAL		
		Additional comments
Research design		
Was a qualitative methodology appropriate?	Yes No Unclear	
Was the method/design apparent, and consistent with research intent?	Yes No Unclear	
Was the data collection strategy apparent and appropriate?	Yes No Unclear	
Sampling strategy		
Was the sample and sampling method appropriate?	Yes No Unclear	
Analysis		
Was the analytic approach appropriate?	Yes No Unclear	
Was there evidence of data saturation?	Yes No Unclear	
Were deviant case/contradictory findings discussed? What were they?	Yes No Unclear	
Was there evidence of member checking and/or independent analysis of data by more than one researcher?	Yes No Unclear	
Presentation and interpretation of findings		
Was the context described and taken account of in interpretation?	Yes No Unclear	
Were appropriate quotes used in the presentation of findings and discussion of findings?	Yes No Unclear	
Was the interpretation of findings justified by the data that are presented?		
Reflexivity		
Was researcher reflexivity demonstrated?	Yes No Unclear	
Ethical considerations		
Was sensitivity to ethical concerns demonstrated?	Yes No Unclear	
Relevance and transferability		
Is relevance and transferability evident generally about the study?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: The study credibility, transferability, dependability, and confirmability is high		
B - Some flaws, unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study		
C - Some flaws, which may affect the credibility, transferability, dependability,		

and/or confirmability of the study	
D - Significant flaws, which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study	

APPENDIX 4: RESULTS OF INDIVIDUAL STUDIES (WEB ONLY FILE)

Reference	**Findings**
14	Women who are fearful more likely to delay (OR: 0.50, 95% CI: 0.27-0.92) No statistically significant evidence that financial barriers relate to delay (Unadjusted 1.06, 95% CI, 0.59-1.91) System barriers not significantly related to delay (Unadjusted 0.54, 95% CI, 0.59-1.00) Women with health insurance not significantly more likely to be diagnosed within 90 days (Unadjusted: 0.85, 95% CI, 0.44-1.63) Perceived discrimination not related to delay (data not provided)
15	Would rather know they had cancer:17% Agreed cancer treatments worse than cancer itself: 57% Believed cancer is curable: 74%
16	Barriers to help-seeking: Worried about what a doctor might find: 24% African, 50% Caribbean Too embarrassed: 24% African, 49% Caribbean Too scared: 21% African, 43% Caribbean Would not feel confident talking about symptom: 21% African, 40% Caribbean Worry about wasting doctor's time: 10% African, 28% Caribbean Doctor would be difficult to talk to: 21% African; 28% Caribbean Too many other things to worry about: 21% African, 20% Caribbean Too busy to make time: 20% African, 25% Caribbean Difficult to arrange transport: 6% African, 21% Caribbean Difficult to make an appointment: 23% African, 43% Caribbean
17	Believed death is imminent if someone is diagnosed with breast cancer: 1.6% Believed it is too late to do anything if someone is diagnosed with breast cancer: 3.9% Logistic regressions to determine impact of religiosity, spirituality and fatalism on time to presentation determined income is a significant indicator of time to seek medical care in these models: - Religiosity: (OR: 0.79, 95% CI: 0.68-0.92) - Spirituality: (OR: 0.77, 95% CI: 0.65-0.90) - Fatalism: ((OR: 0.78, 95% CI, 0.67, 0.92) Income is a significant indicator of time to seek medical care (OR: 0.77-0.79, 95% CI: 0.65-0.92) (higher the income, the more likely women were to seek medical care promptly) Disclosure reduces delay (OR: 0.25, 95% CI: 0.11- 0.57) Religiosity & spirituality in themselves do not affect delay (OR:1.00, 95% CI: 0.98-1.03) (OR: 1.06, 95% CI: 0.99-1.13)
18	Recognised 5 or more non-lump symptoms of breast cancer: 16% Black, 22% White Knew that a 70 yr old was at a higher risk of breast cancer than younger women: 13% Black, 12% White Was fairly or very confident about noticing change in breasts: 50% Black, 55% White Reported breast checking at least once a month: 18% Black, 28% White Barriers to help-seeking Worried about what a doctor might find: White 44%; Black 46% Too embarrassed to go and see the doctor: White 31%; Black 30% Lacked confidence to talk about symptoms: 19% White; Black 24% Too scared to go and see doctor: White 29%; Black 20% Too many other things to worry about: White 37%; Black 31% Too busy to make time to go to the doctor: White 35%; Black 34% Find it difficult to arrange transport: White 16%; Black 14% Find doctor difficult to talk to: White 23%; Black 23% Worried about wasting doctor's time: White 53%; Black 21% Find it difficult to make an appointment: White 36%; Black 30%
19	More Black than White women attributed system- oriented delays to scheduling delays (no figures provided)

20	Racism (r=-0.08) independent of help-seeking Intention Childcare, employment, partnership (r=-0.48) and healthcare access (r=0.49) associated with help-seeking intention Fear of cancer has weak association with help-seeking intention (r=0.11) Income associated with seeking help (r=0.32) Perceived negative consequences of delay associated with more timely presentation (r=0.443)
21	Believed death is outcome of cancer: 13% AA, 16% White Believed early diagnosis increases chance of cure: 83% AA, 96% White Felt at risk of developing breast cancer: 25% AA, 44% White
22	Black women more likely to delay if they reported personally experiencing prejudice in healthcare delivery (P <0.001) than White women
23	Proportion of women who cited financial hardship (4% AA, 3% White women) showed significant differences in length of delay compared with women who did not (P= < 0.001) Women who cited fear of cancer (16% AA, 9% White women) showed significant differences in length of delay compared with women who did not: (P= < 0.001) Women who cited work-related reasons (3% AA, 2% White women)did not show a significant difference in length of delay compared with women who did not (P < 0.001)
24	AA more likely than White women to: believe men would not want to know about cancer (3.1, 95% CI: 2.0-4.6), not go to doctor if lump not bothersome (6.0, 95% CI: 2.3-15), believe surgery would be the worst thing (1.6, 95% CI: 1.1-2.2), have a belief in herbal remedies (2.6, 95% CI: 1.7-4.1), over the counter medicines (2.0, 95% CI: 1.3-2.9) and chiropractic regimens (3.0, 95% CI: 1.8-5.2) as treatments for cancer AA less likely than White women to: have a belief in surgery (0.5, 95% CI: 0.3-0.9) and believe if a woman has cancer it increases the risk for daughter (0.6, 95% CI: 0.5-0.8)
25	Being AA is primary predictor of belief in religious intervention in place of treatment rather than religious intervention with treatment (p<0.0001)
26	No relationship between worry and delay No relationship between sociodemographic variables and delay
27	Afraid to conduct breast self-examination due to fear Advertising aimed at White women Lack confidence to breast check (e.g. unsure of symptoms) Lack time/family support to conduct breast self-examination
28	AA women: Concerned about substandard, aggressive or experimental care Fear of partner abandonment - inhibits help-seeking Lack knowledge to identify symptoms Religiosity does not constrain help-seeking
29	Felt at low risk Fear of physical examinations due to sexual abuse in past Breast self-examination low priority Mistrust of medical professionals Symptoms misinterpreted
30	Cancer is stigmatised Fear partner will abandon if cancer diagnosis is shared Very few women with experience or knowledge of breast cancer knew other women who had survived it Belief that breast cancer is primarily a white women's disease
31	Caring obligations were not barriers to presentation Fear and anxiety (e.g. of treatment) can lead to delay Lack of knowledge not always reason for delay Dismissal of lump led to delay Previous benign diagnosis by health professional led to delay Fear of partner abandonment may inhibit help-seeking Other symptoms(e.g. feeling unwell) prompt help-seeking
32	Believed breast cancer is a White woman's disease Lack of adequate information about risk factors/symptoms Cancer is taboo
33	AA women: Believed cancer is taboo Equated cancer with death

	Previous negative experiences influenced perceptions
34	AA women: Believed early presentation is important Tolerated severe symptoms before seeking help Reported fear due to lack of information Believed doctors lack sensitivity in medical examinations
35	Ghanaian women: Limited knowledge of cancer Ghanaian & Nigerian women: Feelings of fear and apprehension Cancer is a deadly disease, fear is enough to kill someone Secrecy about cancer “hush hush attitude” People hide diagnosis from others Reluctance to disclose symptoms to others due to shame
36	Felt fear on symptom discovery: 32% Fear may be influenced by whether women believe in God (1 woman) Made own decision to seek care rather than being influenced by others: 65% Confrontive coping (confronting/dealing with cancer directly) correlated with shorter delays (r=-0.32, no p value provided) Denial associated with longer delays (r=0.36), p<0.05) Fear not correlated with delay Affordability and accessibility of healthcare not correlated with delay Tolerate pain until it worsens (1 woman)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	5, 21
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5, 22-9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	n/a
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	5-6

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	21-22
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	7-8
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	30-32
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	9-14
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	14-16
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	3, 15-16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	14-16
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	16

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

A systematic review of barriers to early presentation and diagnosis with cancer among Black women

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004076.R1
Article Type:	Research
Date Submitted by the Author:	19-Dec-2013
Complete List of Authors:	Jones, Claire; King's College London, Florence Nightingale School of Nursing and Midwifery Maben, Jill; King's College London, Florence Nightingale School of Nursing and Midwifery Jack, Ruth; Public Health England, Knowledge and Intelligence Team Davies, Elizabeth; King's College London, Thames Cancer Registry Forbes, Lindsay; King's College London, Promoting Early Cancer Presentation Group Lucas, Grace; King's College London, Florence Nightingale School of Nursing and Midwifery Ream, Emma; King's College London, Florence Nightingale School of Nursing and Midwifery
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Oncology
Keywords:	ONCOLOGY, Adult oncology < ONCOLOGY, Breast tumours < ONCOLOGY

A systematic review of barriers to early presentation and diagnosis with breast cancer among Black women

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Word count: 5,070

ABSTRACT

Objective: To explore barriers to early presentation and diagnosis with breast cancer among Black women.

Design: Systematic review.

Methods: We searched multiple bibliographic databases (January 1991-February 2013) for primary research, English language publications conducted in developed countries investigating barriers to early presentation and diagnosis with symptomatic breast cancer among Black women (≥ 18 years). Studies were excluded if they did not report separate findings by ethnic group or gender, only reported differences in time to presentation/diagnosis, or reported on interventions and barriers to cancer screening. We followed the Cochrane and PRISMA statement approach to identify relevant research and thematic synthesis to integrate results. The design of the quantitative studies meant meta-analysis was not conducted.

Results: We identified 18 studies (6,183 participants). Delay was multifactorial, individual and complex. Factors contributing to delay included: poor symptom and risk factor knowledge; fear of detecting breast abnormality; fear of cancer treatments; fear of partner abandonment; fear of others' reactions to a cancer diagnosis; embarrassment of disclosing symptoms to healthcare professionals and associated investigations; taboo of cancer and stigmatism. Presentation appears quicker following disclosure. The influence of fatalism and religiosity on delay is unclear from the evidence in these studies. We compared older studies (≥ 10 years) with newer ones (< 10 years) to determine trends in factors studied and changes in findings over time. In older studies factors increasing time to presentation included: accessibility of healthcare services; competing priorities; and concerns about partner abandonment. Partner abandonment was studied in older studies but not newer ones. Comparisons of healthy women and cancer populations revealed differences between how people perceive they would behave, and actually behave, on finding breast abnormality.

Conclusions: Strategies to improve early presentation and diagnosis with breast cancer among Black women need to both address symptom recognition and interpretation of risk as well as address fears of the consequences of cancer. The review is limited by the paucity of studies conducted outside the US and the limited detail reported by published studies preventing comparison between ethnic groups.

ARTICLE SUMMARY

Article focus

- To understand barriers to early presentation with, and diagnosis of, symptomatic breast cancer among Black women living in developed countries

Key messages

- Black women have limited understanding of cancer – in particular breast cancer and its risk factors – when compared to White women and are reluctant to check their breasts
- The paucity of data did not permit comparisons between Black ethnic groups or US and UK populations to be drawn
- Presentation is not solely dependent on knowledge but also influenced by fear, taboos, personal empowerment, and trust in the healthcare system.

Strengths and limitations of this study

- Several of the themes were present in a large number of studies, indicating the strength of the review's findings. Findings from quantitative and qualitative studies were broadly similar, providing further corroborative evidence of this.
- However, there were some conflicting findings. These were potentially due to differences in when research was published and whether studies included women who had been diagnosed with cancer or general populations.
- Most studies were conducted in the US, which made it difficult to draw conclusions and assess implications for women across other developed countries due to the particular cultural history of the US population and the way that US healthcare is funded.
- Further, studies varied in their definition of, and groupings of, ethnicities. This meant we were unable to explore differences between Black ethnic groups.
- Studies also varied in their methodological quality; small samples, limited information on data analysis and on demographic characteristics were common.
- US studies which reported on the health insurance coverage of participants showed that the majority (between 58% and 92%) were insured. Inclusion of relatively affluent samples in some studies may not reflect the general US Black female population. The influence of age on women's perceptions and delay was also not explored systematically in any of the studies.

BACKGROUND

Breast cancer is the most common cancer among women and leading cause of death worldwide [1] although incidence and survival rates vary across ethnic group. Data from the US determined that African American women have a 6% lower incidence rate of cancer but a 16% higher death rate than White women. Further, they are less likely than White women to present with localised breast cancer [2] Analysis of UK cancer registry data has also shown that despite lower breast cancer incidence rates in the UK among Black African and Black Caribbean than White women, Black women are more likely to be diagnosed with metastatic disease and have poorer survival than White British women [3]. This may reflect the higher proportion of Black women than White women developing triple negative breast cancer - an aggressive from of the disease associated with poorer outcomes [4, 5]. A second factor contributing to this disparity in both the UK and US relates to differing access to, and uptake of, breast cancer screening. In both nations screening uptake is lower in Black than White populations and communities [6]. There is also evidence – largely from the US – of Black and African American women delaying longer with symptomatic breast cancer before seeking health professional help than White women. 'Fatalism', fear, embarrassment, lack of trust in health services, lower education and limited knowledge about cancer and its symptoms have been cited as barriers to early presentation with breast cancer in Black and African American women [7-10]. Provider delays, such as delayed GP referral to hospital diagnostic services, can also contribute to late diagnosis.

The disparity in cancer outcomes between Black and White women in both the US and the UK provided the impetus for appraising and synthesising research exploring barriers to early presentation and diagnosis with breast cancer in Black women in this review. A search of previous literature reviews on the Cochrane Database of Systematic Reviews and other electronic databases did not identify any reviews relevant to the one undertaken.

AIM OF THE REVIEW

This review aimed to understand barriers to early presentation with, and diagnosis of, 'symptomatic' breast cancer among women of Black African and Black Caribbean descent living in developed counties. In the UK there is a national breast screening programme. All women aged 50 to 70 are invited for breast screening every 3 years. However, separate to this, women present symptomatically to their doctor when they discover a breast change. It is this 'symptomatic' presentation which is the focus of this review. The review includes research carried out in developed countries only as delays in presentation and diagnosis with cancer in developing countries are likely to be more influenced by the availability and accessibility of diagnostic services. The review was undertaken to inform a qualitative study exploring issues around symptomatic presentation with breast cancer among Black African, Black Caribbean and White British women in the UK.

METHODS

The review methodology was informed by the Cochrane Handbook for Systematic Reviews of Interventions [11]. The following electronic databases were searched on the 27th February 2013 to identify relevant studies: Medline, PsychINFO, The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scopus. Searches were restricted to research published from 1991-2013 and to English-language publications published in peer-reviewed journals. A detailed search strategy (Table 1) was used to identify relevant papers in Medline. Similar search strategies were applied in CINAHL, PsychInfo and SCOPUS.

Table 1: Example of search strategy (Medline)

Concept 1 AND	Concept 2 AND	Concept 3 AND	Concept 4
Neoplasms (SH) neoplasm* (free text) cancer* (free text) tumor* (free text)	African Continental Ancestry Group (SH) West Indian* (free text) “Afro Caribbean*” (free text) “Afro American*” African American* (free text) African Caribbean* (free text) Black* not (Blackwell) (free text), minority group* (free text) ethnic minorit* (free text) “Black Minority Ethnic” (free text) “BME” (free text)	Perception (SH) Social Perception (SH perception* (free text) social perception* (free text) opinion* (free text) Attitude to Health (SH) attitude* (free text) social value* (free text) social norm* (free text) Culture (SH) belief* (free text) understanding* (free text) language* (free text) communicat* (free text) fear* (free text) mistrust (free text) trust (free text) cultur* (free text) relig* (free text) knowledge* (free text) barrier* (free text) embarrass* (free text) fatalism (free text) fatalistic (free text) income (free text) socioeconomic* (free text) depriv* (free text) educat* (free text) poor* (free text) poverty (free text)	Early Diagnosis (SH) Early Detection of Cancer (SH) “Late presentation” (free text) “Early presentation” (free text) “Early diagnos*” (free text) “Late diagnos*” (free text) “early detection cancer” delay* (free text)

Criteria for including studies in this review

Papers included in the review reported on studies conducted with female adults (≥18 years) who were Black, African American, Caribbean or African.

Inclusion criteria

To be included in the review papers had to be:

- Published in English language peer-reviewed journals in the last twenty years
- Primary research articles
- Studies that explored barriers to early presentation and diagnosis with symptomatic breast cancer in Black women of 18 years or over of African or Caribbean descent
    - Including studies that explored factors affecting women’s return for follow-up following abnormal test results
    - Including studies that explored diagnostic delays due to service-related factors after suspicious findings by health professionals
    - Including studies that explored attitudes to, and undertaking of, self-examination (relating to breast cancer)
    - Including healthy women and those who had cancer
- Conducted in developed countries

Exclusion criteria

Papers were excluded from the review if they:

- Did not report separate findings by ethnic group
- Did not report separate findings for men and women
- Did not report separate findings for breast cancer
- Only reported research carried out in developing countries

- Only reported differences in time to presentation/diagnosis by ethnic group but did not explore factors accounting for these differences
- Only reported uptake of, or barriers to, cancer screening
- Only described interventions to increase uptake of cancer screening and/or improve early presentation/detection rates
- Only described Black women's perceptions of cancer without discussing how their perceptions related to/influenced early presentation and diagnosis

Data collection and analysis

Titles and abstracts of all studies identified by the searches were retrieved and reviewed by CJ who excluded all irrelevant papers (Appendix 1). Abstracts from approximately 10% of all retrieved papers, randomly sampled, (n=80) were independently reviewed by ER. Studies not excluded at this point were retrieved in full text and assessed for eligibility by CJ. Excluded articles were reviewed independently by ER or JM to ensure studies were not erroneously excluded.

Data extraction and quality appraisal

Data were extracted systematically from eligible papers using Data Extraction Forms (DEFs) developed by the team (Appendices 2 and 3). Data were extracted from eligible papers independently by two from the team of reviewers (CJ, JM, RJ, LF, and GL).

Methodological quality was appraised using six attributes of research design that impact directly on the veracity of research findings irrespective of the particular research design (based on [12-14]):

1) Appropriateness of study design
2) Suitability of data collection strategy
3) Appropriateness of sample and sampling method
4) Appropriateness of analytic approach/tools
5) Level of control over confounding variables (quantitative studies) or level to which research context was adequately considered (qualitative studies)
6) Whether interpretation of findings was justified by the data

No papers were excluded based on quality but lower quality studies were given less weight in the discussion.

Data synthesis

Thematic synthesis was used to integrate findings from qualitative and quantitative studies [15]. This entailed line-by-line coding of text from the qualitative studies. Codes were compared to identify recurrent concepts and patterns between themes which were subsequently organised into a framework of descriptive themes. Findings from the quantitative studies were summarised descriptively (as the design of the quantitative studies rendered it impossible to undertake meta-analysis) and integrated into the thematic framework. We developed new interpretative constructs (we compared studies that were <10 years old with studies conducted ≥ 10 years ago and studies of women with and without breast cancer to explain our findings) in order to go beyond the primary studies and to generate new explanations and hypotheses.

RESULTS

We identified 18 papers that met our inclusion criteria (Figure 1) providing data for 6,183 individuals who were between 19 and 99 years old. Of these, 17 were conducted in the US and 1 in the UK. As most studies were conducted in the US, explicit reference will be made when referring to the UK study. 11 papers were quantitative, 6 qualitative and 1 mixed methods.

Studies included women who had been diagnosed with cancer (8), general population samples (7) and women with abnormal mammogram or clinical breast examinations (1). One study included both women who had been diagnosed with breast cancer and a general control group. In 1 study it was unclear whether or not the sample had been diagnosed with cancer.

5 quantitative studies were considered high quality [16-20], 4 were deemed to be of medium quality [21-24] and 2 of low quality [25, 26]. All 6 qualitative studies were considered medium quality [27-32]. The mixed-methods study was considered medium quality [33] (Table 2).

Ethnic definitions in the findings and discussion are taken from the papers included in the review.

Table 2: Summary information on selected papers (AA = African American) (Appendix 4 for results of individual studies)

Reference	Site of cancer	Country	Type of study	Sampling method	Methods	*N*	Participants	Quality
16	Breast	US	Quantitative	Cross-sectional, purposive	Face to face interview	184	Black women with abnormal mammogram or clinical breast examination	High
17	Breast	US	Quantitative	Cross-sectional, case control	Face to face interview	576	AA women General population sample	High
18	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	129	AA women with breast cancer	High
19	Breast	UK	Quantitative	Cross-sectional, Population-representative sample plus booster sample for non-white ethnic groups/women >55 yrs	Face to face, computer assisted interview	1515	Black (n=265), White (n=806), and South Asian (n=333) women General population sample	High
20	Breast	US	Quantitative	Cross-sectional, convenience and case control	Face to face interview	954	AA (n=378), White (n=162) women with breast cancer and community controls (n=414)	High
21	Breast	US	Quantitative	Cross-sectional, 70% random sample of Black women. Comparison White sample matched by age groups	Face to face interview	367	Black (n=206) and White (n=161) women with breast cancer	Medium
22	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	352	Black and AA women (breakdown by ethnic group not provided) General population sample	Medium
23	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered by post	349	AA (n=152) and White (n=197) women. General population sample	Medium
24	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire administered in person by investigator	699	Black, White and Latino women (breakdown by ethnic group not provided) General population sample	Medium
25	Breast	US	Quantitative	Cross-sectional, random-stratified	Face to face structured interview	682	AA (n=280), White (n=402) General population sample	Low
26	Breast	US	Quantitative	Cross-sectional, convenience	Self report questionnaire, administered in person by investigator	60	AA women with breast cancer	Low
27	Breast	US	Qualitative	Convenience	Focus groups, thematic and pattern analysis	32	AA women General population sample	Medium
28	Breast	US	Qualitative	Convenience sample	Focus groups, narrative analysis	80	Black (mainly AA) (n= 26), White (n=23), Latino (n=31) women with breast cancer	Medium
29	Breast	US	Qualitative	Convenience and snowball	Interviews, narrative and content analysis	20	Black women with breast cancer	Medium

30	Breast	US	Qualitative	Not provided	Focus groups, thematic and pattern analysis	100	AA women Not stated whether they had breast cancer or not	Medium
31	Breast	US	Qualitative	Purposive	Ethnographic interviews, observations, fieldnotes, photographs, ethnographic analysis	13	AA women with breast cancer	Medium
32	Breast	US	Qualitative	Convenience	Interviews, narrative and thematic analysis	23	AA women with breast cancer	Medium
33	Breast	US	Mixed-methods	Mixed- method (cross-sectional survey with subsequent interviews	Self-report questionnaire, administered by post Follow up telephone interview	48	AA women with breast cancer	Medium

Knowledge

Low awareness of cancer symptoms and/or personal risk

A consistent finding across studies was the low level of knowledge among Black and African American women about symptoms of breast cancer and/or risk factors for developing the disease [19, 20, 23, 27, 28, 29, 30, 32]. Poor knowledge of symptoms and risk factors was associated with delay in presentation among Black and African American women with breast cancer [28, 29, 31].

Poor symptom awareness and knowledge of risk factors/personal risk

Comparisons of risk perceptions among African American and White women with breast cancer in two studies revealed a significantly lower percentage of African American women (25%) than White American women (44%) felt susceptible to the disease before they were diagnosed [23] and that African American women were less likely than White women to believe that if a woman has cancer it increases the risk for their daughter [20]. In the UK, few Black (13%) and White women (12%) without breast cancer knew that women over 70 years are at higher risk of breast cancer than women of any age [19].

Further, a number of US studies suggested that Black and African American women were unaware of both risk factors for breast cancer and of their personal risk of developing it [27, 29, 30, 32]. Some women believed breast cancer was a ‘White woman’s disease’ and others that they were not at risk because they did not have a family history of breast cancer. Two studies reported that these perceptions were reinforced by media messages which focused on White women [27, 32]. Underestimation of risk appeared to influence delayed presentation [29]. Women who thought their chance of getting cancer was low, in some cases lacked the motivation or inclination to check their breasts [27, 29].

Recognising significance of cancer symptoms

There was strong evidence to suggest that in the US, Black and African American women lacked knowledge of, and information about, symptoms of breast cancer [27-29, 32]. In the UK, Black women (16%) were less likely to recognise five or more non-lump symptoms of breast cancer than White women (22%) [19]. Many of those with cancer had underestimated the significance of their symptoms which contributed to them delaying presentation [29, 31, 32, 33]. For some African American women, there was confusion over whether or not pain was a symptom of breast cancer. Presence of pain reassured some African American women that their breast symptom was not cancer [28, 32]. One had *‘read that pain [was] not a risk factor’* [32]. Further, some studies suggested a tendency among African American women to tolerate or ignore symptoms, until they were severe, before seeking medical attention [31, 33]:

> *At first, I tried to ignore my pain but it continued to get worse.’* [33]

In one study, some African American women with breast cancer only presented when their symptoms worsened or they developed additional symptoms [31]. Further, another study suggested African American women were more likely than White women to delay presentation if their lump was not bothering them [20]. Other contributing factors to delay included women who assessed that their symptoms were caused by stress [29] or women who had previous diagnoses of a benign breast lump [31].

Empowerment and confidence

Making time to check for and/or present with symptoms

One US study identified that women who were unaware of breast cancer symptoms lacked confidence to check their breasts [27]. In the UK general population study, breast checking differed by ethnic group; Black women were less likely than White women to report breast checking (after controlling for age and socioeconomic status) [19]. However, similarly high percentages of Black (50%) and White (55%) women were fairly or very confident that they would notice a breast change [19].

The same UK study found that barriers to symptomatic presentation were not more common in Black than White women. Moreover, Black women (32%) were slightly less likely than White women (37%) to report having too many other things to worry about, and similar proportions reported being too busy to make time to see the doctor (34% Black, 35% White) [19].

Evidence from the US also suggested that women with family commitments would still find time to visit the doctor. In one study, African American women with cancer said they presented despite family caring obligations [31].

Studies conducted over ten years ago found some evidence that responsibilities might lead to delayed presentation: some African American women and one Black woman reported lacking time [27, 29] to check their breasts. Some Black and African American women without breast cancer but with childcare, employment and partnership responsibilities reported they would be less likely than those without these responsibilities to seek help for breast symptoms should they arise [22].

Lack of partner support

Among Black and African American women, both with and without breast cancer, lack of partner support and concerns around partner abandonment were raised when discussing the physical effects of breast surgery on their relationships. However, the specific influence of partner support/abandonment on delay was unclear [20, 28, 30, 31]. In one study, Black and African American women with breast cancer reported that fear of partner abandonment inhibited help-seeking. However, this also appeared the case for White women [28]. In another study, help-seeking was not affected, despite one woman's partner saying he did not want to live with, '*no one titty bitch*' and others saying they were concerned they would be less appealing to their partners [31] . Limited evidence indicates that African American women are more likely than White women to delay seeking help due to lack of partner support [20].

Stigma, taboo and fear

Stigma and taboo emerged as salient themes among Black women both in the US and UK. They were reluctant to talk about cancer and reported that in their communities, the word 'cancer' was whispered [32] and referred to as '*the big* C' [28]. Cancer diagnoses often remained undisclosed even to family members [30]. However in a US study, disclosure to others (particularly family or friends) was associated with shorter delays in presentation in African American women [18]. Whether disclosure influenced decisions to seek care or reflected openness to discuss cancer symptoms with others (including healthcare professionals) was less clear. A further study found two thirds of African American participants felt they made their own decision to seek help [33]. Black and African American women who were fearful of cancer were significantly more likely to delay presentation than those who were not [16, 31]. In one study, some African American women were too scared to check their breasts [27] while in another 32% of African American participants with breast cancer reported feeling scared when they discovered their symptoms [33]. However, this and another study found no relationship between fear and delay [26, 33].

Religiosity

There was limited evidence to suggest that religiosity impacted time to presentation with cancer in symptomatic Black and African American women. Two studies exploring the influence of religiosity found it did not inhibit help-seeking in women with symptomatic breast cancer [18, 28]. However, there was some evidence that age [31] and African American ethnic group [20, 25] may predict a belief that religious intervention influences the outcome of cancer rather than medical treatment, as well as a resigned acceptance of death. The link between what has been termed ‘fatalism’ – a belief that cancer is pre-ordained – and delayed presentation is unconfirmed. One study of healthy women suggested that fatalism negatively influenced help-seeking intention [22], but a study of women with breast cancer found no association between fatalism and actual delay in presentation [18].

Trust in healthcare system

Curability of cancer

There was strong evidence to suggest that Black and African American women with and without cancer believed cancer could be cured [17, 18, 22, 23]. Across three studies, 77- 98% of African American women did not believe death was an inevitable outcome of cancer [17, 18, 23]. In another study, only a small percentage of African American (13%) and White women (16%) believed that cancer inevitably led to death [23].However another study of African American women reported that they believed cancer was a deadly and incurable disease and very few of those interviewed knew of women who had survived the disease [30]. However the influence of that belief (cancer equates with death) on help-seeking intention was not discussed [30].

Fear of conventional treatment

Black and African American women reported fearing the implications of cancer treatments and surgery [17, 20, 28, 31] and some said they preferred non-conventional therapies [20]. Treatment fear prolonged delay among some women with cancer. One study reported that 57% of African American women with and without breast cancer believed treatments for breast cancer were worse than the disease itself, [17] while three studies reported reluctance among African American women to have surgery [20, 28, 31].. Some African American women reported fearing unpleasant side-effects and were worried about what treatments comprised. One study reported that African American women were more likely than White women to prefer non-conventional treatments in place of surgery [20].

Quality of relationships with healthcare professionals

Concerns about interactions with doctors

In the UK study, concerns about wasting the doctor's time, or finding it difficult to talk to a doctor were barriers to early presentation. However, these issues were just as likely to be reported by White women as Black women [19].

Lack of confidence in healthcare professionals

There was strong evidence suggesting Black and African American women lacked confidence in medical professionals due to breast symptoms being previously misdiagnosed. They expressed concerns over standards of care and the type of care they would receive; they were concerned about discrimination in medical settings. In one study, three African American women with cancer were initially told their symptoms were benign and this contributed to delayed diagnosis. For example, one was told, '*It's just cysts, it's nothing to worry about.'* [31]. Further, some Black and African American women with cancer were concerned about doctors providing substandard, aggressive (*'she wound up with a mastectomy two weeks later just because of her mammogram')*[28] or experimental care [28, 29]. The Tuskegee syphilis study [34] was cited by Black and African American study participants in support of this belief [28, 29]. However, one study reported that African American women felt healthcare professionals should conduct breast examinations rather than women themselves, which suggested trust in the skills of healthcare professionals [27].

Five studies examined Black and African American women's perceptions of discrimination in medical settings [16, 22, 24, 28, 29]. Two determined that although women perceived a degree of racism and discrimination, this did not appear to influence delay or help-seeking intent [16, 22] but in another two studies it did influence help-seeking intention and delay [24, 28].

Practical and service barriers

Financial burden of healthcare and influence of health insurance on patient and provider delays

The impact of the financial burden of healthcare (affordability of healthcare and health insurance coverage) on delay was unclear based on the limited evidence provided by these studies. In one study there was no statistically significant association between perceived affordability of healthcare and delay [33]. In another study, women with health insurance were not significantly more likely to be diagnosed within 90 days than those without insurance [16].

There was also a mixed picture of the influence of Black and African American women's socioeconomic status on delay within these studies. In two of them, socioeconomic status did not appear to influence delay among Black women with cancer [16, 26]. However, three studies reported that less affluent Black and African American women were less likely to seek help for cancer symptoms and that this did contribute to delayed presentation [18, 22, 20].

Perceptions of access to healthcare services

In the UK study access issues such as ease of booking appointments, arranging transport and distance between home and health centres appeared no more common in Black than White women. Rather, Black women were less likely than White women to report difficulties making an appointment as a barrier to help-seeking (Black 30%, White 36%). Difficulties arranging transport were again less of a barrier (Black 14%, White 16%) in Black women. Overall, transport appeared a less common barrier that challenges with making appointments to see their doctor [19].

In the US studies, the effect of access issues on delay was mixed. In a study of Black and African American women without breast cancer, being more likely to intend to seek help was significantly linked to positive perceptions of accessibility to healthcare [28]. Further, in another study poorer access to healthcare among Black women with breast cancer made attending appointments difficult [21]. However, two studies reported little evidence indicating access issues impacted on delay among Black and African American women with cancer [16, 33].

FACTORS WHICH MAY EXPLAIN THE REVIEW FINDINGS

It was evident that some barriers to early presentation with cancer were more prevalent ten years ago than today and vice versa. Accessibility of healthcare services [21, 22] and competing priorities [22, 27, 29] were important issues influencing delay in Black, African American, Caribbean and African women in older (≥10 years) studies. However, in some more recent studies (≤ 10 years) access to healthcare [16, 19, 33] and competing priorities [19, 31] were reported to neither influence delay nor help-seeking intention.

Although the influence of partner abandonment was examined in one early quantitative study [20] and emerged from women's narratives in three early qualitative studies, [28, 30, 31] , this theme was not examined in any recent quantitative studies. This does not mean, however, that it is not a current problem, only that it has not been examined as a potential influence over time.

Several differences were also noted between women with and without cancer. Competing priorities did not influence delay in a recent study of women with symptomatic breast cancer [31] but they did influence how healthy women felt they would approach seeking help should they develop cancer symptoms [22]. Further, although in some studies the financial burden of healthcare [16, 26, 33] and access issues [16, 33] did not influence delay among those women with breast cancer, healthy women cited both of these issues as potential barriers to their future help-seeking [22]. These differences highlight that researchers may get different answers depending on whether they ask healthy women or women with cancer about delay/help-seeking intention.

DISCUSSION

Delayed presentation with breast cancer in Black women living in the US and UK appears influenced by multiple factors and to be highly individual and complex. Logically, all women may present late if they have limited awareness of the disease and its symptoms [35]. Although a relatively small number of studies comparing Black and White women were included in the review, Black women appear more likely than White women to have limited understanding of breast cancer and its risk factors. This might be the case particularly among 1) migrant women from countries where health campaigns about the disease are scarce, 2) women with limited command of the host nation's language and/or low literacy who are therefore not reached by the host nation's health messages; and 3) women from communities where it is culturally unacceptable to discuss cancer and who, as a result, do not gain understanding of the disease through word of mouth.

This review, consistent with health behaviour models [36, 37], illustrates how women's understanding of risk factors and their perceived personal risk influence their sensitivity to breast cancer symptoms and help-seeking on identifying them. Black women rightly perceive their risk of breast cancer to be lower than in White women [2, 3]. Consequently, they may retain little information provided to them by healthcare professionals or portrayed in breast cancer health promotion campaigns, as they may believe it to be of limited personal relevance.

Findings from studies incorporated in this review determined that many women lack confidence in checking, or are reluctant to check their breasts. However, if women are unaware of how their breasts typically feel they will, as a consequence, face challenges in recognising subtle changes and may only detect change when the disease is relatively advanced.

Clearly, early presentation with cancer is not solely dependent on knowledge. Women with good knowledge of the disease may not seek help from healthcare professionals on detecting symptoms of breast cancer [38]. This review suggests fear may be an important factor preventing Black women from seeking help. It appears multifaceted – women referred to fear of cancer treatments and abandonment by partners. Arguably, health messages communicating negative consequences of delayed presentation with breast cancer may be less effective than those framed in ways outlining benefits of early presentation. Fear-led messages may lead to avoidance and denial in people who fear a cancer diagnosis [36]. Further, although it appears that disclosure to others about symptoms indicative of breast cancer can be important in promoting early presentation with the disease; [39] it is not uncommon for Black women to feel uncomfortable about disclosing symptoms to others, including healthcare professionals. This is due to the taboo and embarrassment associated with the disease [40]. Women's previous encounters and rapport with healthcare professionals, and any exposure to discrimination or misdiagnosis, also appear to influence time to presentation.

Beliefs about the curability of breast cancer (a factor impacting positively on early presentation) may be influenced in women born outside the country they live in by experiences from their country of origin, where treatments for cancer may be less effective and death more likely [41]. Religiosity might influence help-seeking behaviour but this will depend on how people perceive their own role and that of a higher influence in managing their health [42]. The highly individual nature of religious beliefs may explain why the influence of religiosity on delay was unclear in this review. Further, it may reflect the nature of the samples recruited to the reviewed studies.

Papers incorporated into the review did not unequivocally support an association in the US between financial barriers and late presentation with breast cancer in Black and African American women. It is likely that this finding reflects sampling issues; Black women sampled in these studies appeared relatively affluent, 58-92% had health insurance. Work of others, including Schneider, demonstrates clearly both the coexistence of socioeconomic factors and ethnicity and their impact on cancer staging and outcomes [43]. However, it is important to note that outside the US socioeconomic factors may be more or less associated with ethnicity. They may also impact differently on time to presentation with breast cancer in differing healthcare systems.

Evidence from the sole UK study indicated that poor knowledge of breast cancer and its associated symptoms, and both practical and financial issues, may act as barriers to early presentation with breast cancer in Black African and Black Caribbean women. However, this study alone is insufficient to enable conclusions to be drawn on factors impacting delayed diagnosis with breast cancer in Black women living in the UK. Further, it grouped all Black women together in the analysis. This would suggest that Black women are a homogenous group; it is very likely that attitudes, help-seeking intention and help-seeking behaviours will vary considerably within and between Black African and Black Caribbean women in the UK and possibly between first and second generation migrants. Merely labeling women as 'Black' may mask diverse attitudes and behaviours and lead researchers to overlook important nuances [44]. Further research is needed in the UK to explore factors impacting early diagnosis with symptomatic breast cancer and to study in detail similarities and differences by ethnic group.

Unfortunately, whilst we aimed to compare in detail barriers to early presentation with symptomatic breast cancer between different groups of Black women in the US and UK this proved impossible due to paucity of UK studies and poor level of reporting in many of the published US studies. Consequently, the specific nuances between different ethnic groups of Black women could not be determined. However, it is striking that so many of the beliefs, taboos, and fears were similar among Black women, irrespective of their country of residence. These factors are clearly not genetic which suggests cultural factors are durable over many generations.

There was some evidence that some barriers to early diagnosis had lessened during the period of this review. This suggests that awareness-raising campaigns may have been successful in raising the importance of early presentation and overcoming practical challenges and personal concerns. Equally, the findings could reflect the time that Black women migrating to developed countries had spent there. Arguably, migrants' views will change over time as they adapt to their surroundings and become influenced by new cultures and health systems [45]. There was also some evidence of differences between women with and without cancer, suggesting a distinction between what women say they would do if they discovered a symptom, versus what they do with the onset of symptoms.

Further high quality research is needed to better understand barriers to early presentation and diagnosis with breast cancer in Black ethnic groups living outside the US. In particular, studies of, and comparisons between, ethnic groups in the UK are needed to determine influences on delay in presentation and their possible contribution to the poorer survival of Black African and Black Caribbean women in the UK [3]. Researchers need to compare stage at diagnosis and cancer survival between ethnic groups after stratifying for tumour prognostic and biological factors. This would allow the relative influence of cancer biology, women's delay and system delay on outcomes to be determined. Findings of this review have several implications for policy and practice. Our review indicates that Black women should feature more prominently in media campaigns, and educational materials to prevent breast cancer being perceived as a 'white women's' disease. Information about the risk of breast cancer and its early symptoms, concerns about breast checking, surgery, and the side-effects of treatment also need to be addressed in ways that are culturally sensitive to Black women [46, 47]. Vulnerable women, who fear partner abandonment and who may be reluctant to have treatment for breast cancer as a result, need to be identified and supported by healthcare professionals. Further, enhancing women's experiences of being diagnosed and treated for breast cancer, and encouraging engagement and discussion regarding the disease, may help to address stigma and taboo, promote disclosure and allay women's fears; factors believed to impact positively on early presentation and diagnosis.

FIGURE LEGEND

Figure 1: Data search and retrieval

ACKNOWLEDGEMENTS AND FUNDING

This article was funded by the National Awareness and Early Diagnosis Initiative (NAEDI).

CONTRIBUTORSHIP STATEMENT

Contributors ER, CJ, JM, RJ, and LF were responsible for the systematic review design. CJ, was responsible for data collection. CJ, ER, RJ, LF and GL were responsible for data extraction and appraising studies. CJ, JM and ER were responsible for data analysis and interpretation. All authors contributed to drafting the manuscript. Emma Ream is responsible for the overall content as the corresponding author.

EXCLUSIVE LICENCE STATEMENT

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DATA SHARING STATEMENT

No additional data available

COMPETING INTERESTS

None

ETHICS COMMITTEE APPROVAL

As this article describes a systematic review of the literature, no ethical approval was needed for the study.

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A systematic review of barriers to early presentation and diagnosis with breast cancer among Black women

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Word count: 5,070

ABSTRACT

Objective: To explore barriers to early presentation and diagnosis with breast cancer among Black women.

Design: Systematic review.

Methods: We searched multiple bibliographic databases (January 1991-February 2013) for primary research, English language publications conducted in developed countries investigating barriers to early presentation and diagnosis with symptomatic breast cancer among Black women (≥ 18 years). Studies were excluded if they did not report separate findings by ethnic group or gender, only reported differences in time to presentation/diagnosis, or reported on interventions and barriers to cancer screening. We followed the Cochrane and PRISMA statement approach to identify relevant research and thematic synthesis to integrate results. The design of the quantitative studies meant meta-analysis was not conducted.

Results: We identified 18 studies (6,183 participants). Delay was multifactorial, individual and complex. Factors contributing to delay included: poor symptom and risk factor knowledge; fear of detecting breast abnormality; fear of cancer treatments; fear of partner abandonment; fear of others' reactions to a cancer diagnosis; embarrassment of disclosing symptoms to healthcare professionals and associated investigations; taboo of cancer and stigmatism. Presentation appears quicker following disclosure. The influence of fatalism and religiosity on delay is unclear from the evidence in these studies. We compared older studies (≥ 10 years) with newer ones (< 10 years) to determine trends in factors studied and changes in findings over time. In older studies factors increasing time to presentation included: accessibility of healthcare services; competing priorities; and concerns about partner abandonment. Partner abandonment was studied in older studies but not newer ones. Comparisons of healthy women and cancer populations revealed differences between how people perceive they would behave, and actually behave, on finding breast abnormality.

Conclusions: Strategies to improve early presentation and diagnosis with breast cancer among Black women need to both address symptom recognition and interpretation of risk as well as address fears of the consequences of cancer. The review is limited by the paucity of studies conducted outside the US and the limited detail reported by published studies preventing comparison between ethnic groups.

ARTICLE SUMMARY

Article focus

- To understand barriers to early presentation with, and diagnosis of, symptomatic breast cancer among Black women living in developed countries

Key messages

- Black women have limited understanding of cancer – in particular breast cancer and its risk factors – when compared to White women and are reluctant to check their breasts
- The paucity of data did not permit comparisons between Black ethnic groups or US and UK populations to be drawn
- Presentation is not solely dependent on knowledge but also influenced by fear, taboos, personal empowerment, and trust in the healthcare system.

Strengths and limitations of this study

- Several of the themes were present in a large number of studies, indicating the strength of the review's findings. Findings from quantitative and qualitative studies were broadly similar, providing further corroborative evidence of this.
- However, there were some conflicting findings. These were potentially due to differences in when research was published and whether studies included women who had been diagnosed with cancer or general populations.
- Most studies were conducted in the US, which made it difficult to draw conclusions and assess implications for women across other developed countries due to the particular cultural history of the US population and the way that US healthcare is funded.
- Further, studies varied in their definition of, and groupings of, ethnicities. This meant we were unable to explore differences between Black ethnic groups.
- Studies also varied in their methodological quality; small samples, limited information on data analysis and on demographic characteristics were common.
- US studies which reported on the health insurance coverage of participants showed that the majority (between 58% and 92%) were insured. Inclusion of relatively affluent samples in some studies may not reflect the general US Black female population. The influence of age on women's perceptions and delay was also not explored systematically in any of the studies.

BACKGROUND

Breast cancer is the most common cancer among women and leading cause of death worldwide [1] although incidence and survival rates vary across ethnic group. Data from the US determined that African American women have a 6% lower incidence rate of cancer but a 16% higher death rate than White women. Further, they are less likely than White women to present with localised breast cancer [2] Analysis of UK cancer registry data has also shown that despite lower breast cancer incidence rates in the UK among Black African and Black Caribbean than White women, Black women are more likely to be diagnosed with metastatic disease and have poorer survival than White British women [3]. This may reflect the higher proportion of Black women than White women developing triple negative breast cancer - an aggressive from of the disease associated with poorer outcomes [4, 5]. A second factor contributing to this disparity in both the UK and US relates to differing access to, and uptake of, breast cancer screening. In both nations screening uptake is lower in Black than White populations and communities [6]. There is also evidence – largely from the US – of Black and African American women delaying longer with symptomatic breast cancer before seeking health professional help than White women. 'Fatalism', fear, embarrassment, lack of trust in health services, lower education and limited knowledge about cancer and its symptoms have been cited as barriers to early presentation with breast cancer in Black and African American women [7-10]. Provider delays, such as delayed GP referral to hospital diagnostic services, can also contribute to late diagnosis.

The disparity in cancer outcomes between Black and White women in both the US and the UK provided the impetus for appraising and synthesising research exploring barriers to early presentation and diagnosis with breast cancer in Black women in this review. A search of previous literature reviews on the Cochrane Database of Systematic Reviews and other electronic databases did not identify any reviews relevant to the one undertaken.

AIM OF THE REVIEW

This review aimed to understand barriers to early presentation with, and diagnosis of, ‘symptomatic’ breast cancer among women of Black African and Black Caribbean descent living in developed counties. In the UK there is a national breast screening programme. All women aged 50 to 70 are invited for breast screening every 3 years. However, separate to this, women present symptomatically to their doctor when they discover a breast change. It is this ‘symptomatic’ presentation which is the focus of this review. The review includes research carried out in developed countries only as delays in presentation and diagnosis with cancer in developing countries are likely to be more influenced by the availability and accessibility of diagnostic services. The review was undertaken to inform a qualitative study exploring issues around symptomatic presentation with breast cancer among Black African, Black Caribbean and White British women in the UK.

METHODS

The review methodology was informed by the Cochrane Handbook for Systematic Reviews of Interventions [11]. The following electronic databases were searched on the 27th February 2013 to identify relevant studies: Medline, PsychINFO, The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scopus. Searches were restricted to research published from 1991-2013 and to English-language publications published in peer-reviewed journals. A detailed search strategy (Table 1) was used to identify relevant papers in Medline. Similar search strategies were applied in CINAHL, PsychInfo and SCOPUS.

Table 1: Example of search strategy (Medline)

Concept 1	AND	Concept 2	AND	Concept 3	AND	Concept 4
Neoplasms (SH) neoplasm* (free text) cancer* (free text) tumor* (free text)		African Continental Ancestry Group (SH) West Indian* (free text) “Afro Caribbean*” (free text) “Afro American*” African American* (free text) African Caribbean* (free text) Black* not (Blackwell) (free text), minority group* (free text) ethnic minorit* (free text) “Black Minority Ethnic” (free text) “BME” (free text)		Perception (SH) Social Perception (SH perception* (free text) social perception* (free text) opinion* (free text) Attitude to Health (SH) attitude* (free text) social value* (free text) social norm* (free text) Culture (SH) belief* (free text) understanding* (free text) language* (free text) communicat* (free text) fear* (free text) mistrust (free text) trust (free text) cultur* (free text) relig* (free text) knowledge* (free text) barrier* (free text) embarrass* (free text) fatalism (free text) fatalistic (free text) income (free text) socioeconomic* (free text) depriv* (free text) educat* (free text) poor* (free text) poverty (free text)		Early Diagnosis (SH) Early Detection of Cancer (SH) “Late presentation” (free text) “Early presentation” (free text) “Early diagnos*” (free text) “Late diagnos*” (free text) “early detection cancer” delay* (free text)

Criteria for including studies in this review

Papers included in the review reported on studies conducted with female adults (≥18 years) who were Black, African American, Caribbean or African.

Inclusion criteria

To be included in the review papers had to be:

- Published in English language peer-reviewed journals in the last twenty years
- Primary research articles
- Studies that explored barriers to early presentation and diagnosis with symptomatic breast cancer in Black women of 18 years or over of African or Caribbean descent
    - Including studies that explored factors affecting women's return for follow-up following abnormal test results
    - Including studies that explored diagnostic delays due to service-related factors after suspicious findings by health professionals
    - Including studies that explored attitudes to, and undertaking of, self examination (relating to breast cancer)
    - Including healthy women and those who had cancer
- Conducted in developed countries

Exclusion criteria

Papers were excluded from the review if they:

- Did not report separate findings by ethnic group
- Did not report separate findings for men and women
- Did not report separate findings for breast cancer
- Only reported research carried out in developing countries
- Only reported differences in time to presentation/diagnosis by ethnic group but did not explore factors accounting for these differences
- Only reported uptake of, or barriers to, cancer screening
- Only described interventions to increase uptake of cancer screening and/or improve early presentation/detection rates
- Only described Black women's perceptions of cancer without discussing how their perceptions related to/influenced early presentation and diagnosis

Data collection and analysis

Titles and abstracts of all studies identified by the searches were retrieved and reviewed by CJ who excluded all irrelevant papers (Appendix 1). Abstracts from approximately 10% of all retrieved papers, randomly sampled, (n=80) were independently reviewed by ER. Studies not excluded at this point were retrieved in full text and assessed for eligibility by CJ. Excluded articles were reviewed independently by ER or JM to ensure studies were not erroneously excluded.

Data extraction and quality appraisal

Data were extracted systematically from eligible papers using Data Extraction Forms (DEFs) developed by the team (Appendices 2 and 3). Data were extracted from eligible papers independently by two from the team of reviewers (CJ, JM, RJ, LF, and GL).

Methodological quality was appraised using six attributes of research design that impact directly on the veracity of research findings irrespective of the particular research design (based on [12-14]):

1) Appropriateness of study design

2) Suitability of data collection strategy

3) Appropriateness of sample and sampling method

4) Appropriateness of analytic approach/tools

5) Level of control over confounding variables (quantitative studies) or level to which research context was adequately considered (qualitative studies)

6) Whether interpretation of findings was justified by the data

No papers were excluded based on quality but lower quality studies were given less weight in the discussion.

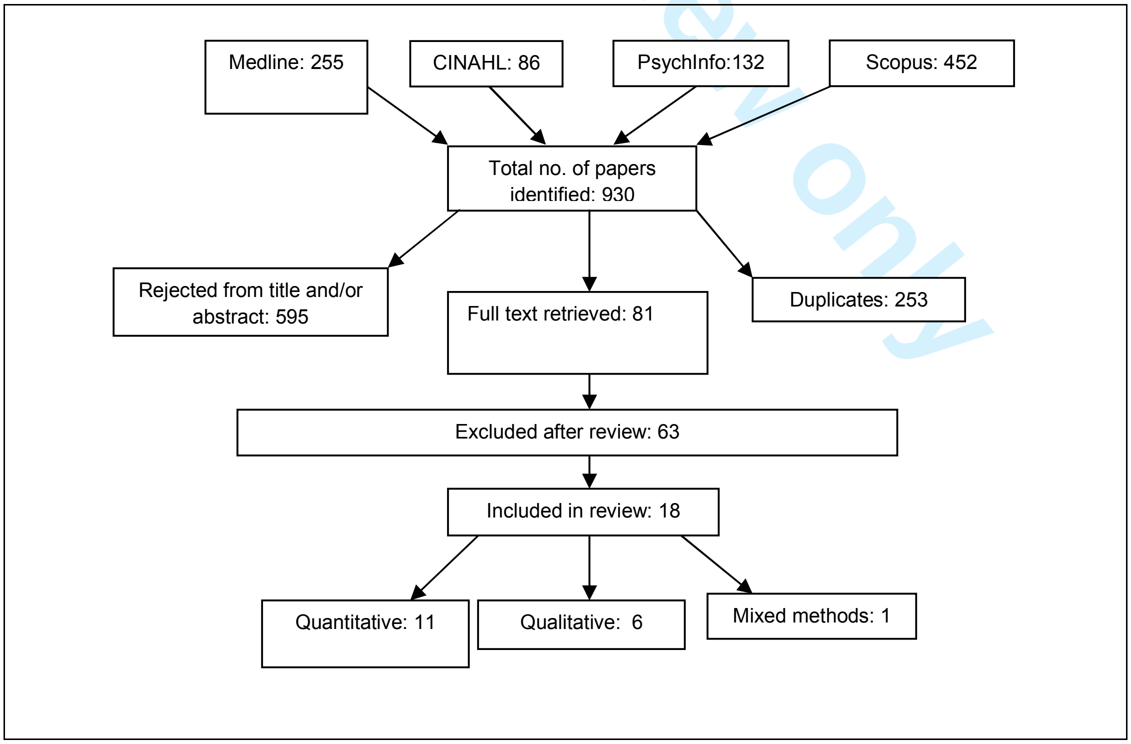
Data synthesis

Thematic synthesis was used to integrate findings from qualitative and quantitative studies [15]. This entailed line-by-line coding of text from the qualitative studies. Codes were compared to identify recurrent concepts and patterns between themes which were subsequently organised into a framework of descriptive themes. Findings from the quantitative studies were summarised descriptively (as the design of the quantitative studies rendered it impossible to undertake meta-analysis) and integrated into the thematic framework. We developed new interpretative constructs (we compared studies that were <10 years old with studies conducted ≥ 10 years ago and studies of women with and without breast cancer to explain our findings) in order to go beyond the primary studies and to generate new explanations and hypotheses.

RESULTS

We identified 18 papers that met our inclusion criteria (Figure 1) providing data for 6,183 individuals who were between 19 and 99 years old. Of these, 17 were conducted in the US and 1 in the UK. As most studies were conducted in the US, explicit reference will be made when referring to the UK study. 11 papers were quantitative, 6 qualitative and 1 mixed methods.

Figure 1: Data search and retrieval



Studies included women who had been diagnosed with cancer (8), general population samples (7) and women with abnormal mammogram or clinical breast examinations (1). One study included both women who had been diagnosed with breast cancer and a general control group. In 1 study it was unclear whether or not the sample had been diagnosed with cancer.

5 quantitative studies were considered high quality [16-20], 4 were deemed to be of medium quality [21-24] and 2 of low quality [25, 26]. All 6 qualitative studies were considered medium quality [27-32]. The mixed-methods study was considered medium quality [33] (Table 2).

Ethnic definitions in the findings and discussion are taken from the papers included in the review.

Table 2: Summary information on selected papers (AA = African American) (Appendix 4 for results of individual studies)

Reference	Site of cancer	Country	Type of study	Sampling method	Methods	*N*	Participants	Quality
16	Breast	US	Quantitative	Cross-sectional, purposive	Face to face interview	184	Black women with abnormal mammogram or clinical breast examination	High
17	Breast	US	Quantitative	Cross-sectional, case control	Face to face interview	576	AA women General population sample	High
18	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	129	AA women with breast cancer	High
19	Breast	UK	Quantitative	Cross-sectional, Population-representative sample plus booster sample for non-white ethnic groups/women >55 yrs	Face to face, computer assisted interview	1515	Black (n=265), White (n=806), and South Asian (n=333) women General population sample	High
20	Breast	US	Quantitative	Cross-sectional, convenience and case control	Face to face interview	954	AA (n=378), White (n=162) women with breast cancer and community controls (n=414)	High
21	Breast	US	Quantitative	Cross-sectional, 70% random sample of Black women. Comparison White sample matched by age groups	Face to face interview	367	Black (n=206) and White (n=161) women with breast cancer	Medium
22	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered in person by investigator	352	Black and AA women (breakdown by ethnic group not provided) General population sample	Medium
23	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire, administered by post	349	AA (n=152) and White (n=197) women. General population sample	Medium
24	Breast	US	Quantitative	Cross-sectional, convenience	Self-report questionnaire administered in person by investigator	699	Black, White and Latino women (breakdown by ethnic group not provided) General population sample	Medium
25	Breast	US	Quantitative	Cross-sectional, random-stratified	Face to face structured interview	682	AA (n=280), White (n=402) General population sample	Low
26	Breast	US	Quantitative	Cross-sectional, convenience	Self report questionnaire, administered in person by investigator	60	AA women with breast cancer	Low
27	Breast	US	Qualitative	Convenience	Focus groups, thematic and pattern analysis	32	AA women General population sample	Medium
28	Breast	US	Qualitative	Convenience sample	Focus groups, narrative analysis	80	Black (mainly AA) (n= 26), White (n=23), Latino (n=31) women with breast cancer	Medium
29	Breast	US	Qualitative	Convenience and snowball	Interviews, narrative and content analysis	20	Black women with breast cancer	Medium

30	Breast	US	Qualitative	Not provided	Focus groups, thematic and pattern analysis	100	AA women Not stated whether they had breast cancer or not	Medium
31	Breast	US	Qualitative	Purposive	Ethnographic interviews, observations, fieldnotes, photographs, ethnographic analysis	13	AA women with breast cancer	Medium
32	Breast	US	Qualitative	Convenience	Interviews, narrative and thematic analysis	23	AA women with breast cancer	Medium
33	Breast	US	Mixed-methods	Mixed- method (cross-sectional survey with subsequent interviews	Self-report questionnaire, administered by post Follow up telephone interview	48	AA women with breast cancer	Medium

Knowledge

Low awareness of cancer symptoms and/or personal risk

A consistent finding across studies was the low level of knowledge among Black and African American women about symptoms of breast cancer and/or risk factors for developing the disease [19, 20, 23, 27, 28, 29, 30, 32]. Poor knowledge of symptoms and risk factors was associated with delay in presentation among Black and African American women with breast cancer [28, 29, 31].

Poor symptom awareness and knowledge of risk factors/personal risk

Comparisons of risk perceptions among African American and White women with breast cancer in two studies revealed a significantly lower percentage of African American women (25%) than White American women (44%) felt susceptible to the disease before they were diagnosed [23] and that African American women were less likely than White women to believe that if a woman has cancer it increases the risk for their daughter [20]. In the UK, few Black (13%) and White women (12%) without breast cancer knew that women over 70 years are at higher risk of breast cancer than women of any age [19].

Further, a number of US studies suggested that Black and African American women were unaware of both risk factors for breast cancer and of their personal risk of developing it [27, 29, 30, 32]. Some women believed breast cancer was a ‘White woman’s disease’ and others that they were not at risk because they did not have a family history of breast cancer. Two studies reported that these perceptions were reinforced by media messages which focused on White women [27, 32]. Underestimation of risk appeared to influence delayed presentation [29]. Women who thought their chance of getting cancer was low, in some cases lacked the motivation or inclination to check their breasts [27, 29].

Recognising significance of cancer symptoms

There was strong evidence to suggest that in the US, Black and African American women lacked knowledge of, and information about, symptoms of breast cancer [27-29, 32]. In the UK, Black women (16%) were less likely to recognise five or more non-lump symptoms of breast cancer than White women (22%) [19]. Many of those with cancer had underestimated the significance of their symptoms which contributed to them delaying presentation [29, 31, 32, 33]. For some African American women, there was confusion over whether or not pain was a symptom of breast cancer. Presence of pain reassured some African American women that their breast symptom was not cancer [28, 32]. One had *‘read that pain [was] not a risk factor’* [32]. Further, some studies suggested a tendency among African American women to tolerate or ignore symptoms, until they were severe, before seeking medical attention [31, 33]:

> *At first, I tried to ignore my pain but it continued to get worse.’* [33]

In one study, some African American women with breast cancer only presented when their symptoms worsened or they developed additional symptoms [31]. Further, another study suggested African American women were more likely than White women to delay presentation if their lump was not bothering them [20]. Other contributing factors to delay included women who assessed that their symptoms were caused by stress [29] or women who had previous diagnoses of a benign breast lump [31].

Empowerment and confidence

Making time to check for and/or present with symptoms

One US study identified that women who were unaware of breast cancer symptoms lacked confidence to check their breasts [27]. In the UK general population study, breast checking differed by ethnic group; Black women were less likely than White women to report breast checking (after controlling for age and socioeconomic status) [19]. However, similarly high percentages of Black (50%) and White (55%) women were fairly or very confident that they would notice a breast change [19].

The same UK study found that barriers to symptomatic presentation were not more common in Black than White women. Moreover, Black women (32%) were slightly less likely than White women (37%) to report having too many other things to worry about, and similar proportions reported being too busy to make time to see the doctor (34% Black, 35% White) [19].

Evidence from the US also suggested that women with family commitments would still find time to visit the doctor. In one study, African American women with cancer said they presented despite family caring obligations [31].

Studies conducted over ten years ago found some evidence that responsibilities might lead to delayed presentation: some African American women and one Black woman reported lacking time [27, 29] to check their breasts. Some Black and African American women without breast cancer but with childcare, employment and partnership responsibilities reported they would be less likely than those without these responsibilities to seek help for breast symptoms should they arise [22].

Lack of partner support

Among Black and African American women, both with and without breast cancer, lack of partner support and concerns around partner abandonment were raised when discussing the physical effects of breast surgery on their relationships. However, the specific influence of partner support/abandonment on delay was unclear [20, 28, 30, 31]. In one study, Black and African American women with breast cancer reported that fear of partner abandonment inhibited help-seeking. However, this also appeared the case for White women [28]. In another study, help-seeking was not affected, despite one woman's partner saying he did not want to live with, '*no one titty bitch*' and others saying they were concerned they would be less appealing to their partners [31] . Limited evidence indicates that African American women are more likely than White women to delay seeking help due to lack of partner support [20].

Stigma, taboo and fear

Stigma and taboo emerged as salient themes among Black women both in the US and UK. They were reluctant to talk about cancer and reported that in their communities, the word 'cancer' was whispered [32] and referred to as '*the big* C' [28]. Cancer diagnoses often remained undisclosed even to family members [30]. However in a US study, disclosure to others (particularly family or friends) was associated with shorter delays in presentation in African American women [18]. Whether disclosure influenced decisions to seek care or reflected openness to discuss cancer symptoms with others (including healthcare professionals) was less clear. A further study found two thirds of African American participants felt they made their own decision to seek help [33]. Black and African American women who were fearful of cancer were significantly more likely to delay presentation than those who were not [16, 31]. In one study, some African American women were too scared to check their breasts [27] while in another 32% of African American participants with breast cancer reported feeling scared when they discovered their symptoms [33]. However, this and another study found no relationship between fear and delay [26, 33].

Religiosity

There was limited evidence to suggest that religiosity impacted time to presentation with cancer in symptomatic Black and African American women. Two studies exploring the influence of religiosity found it did not inhibit help-seeking in women with symptomatic breast cancer [18, 28]. However, there was some evidence that age [31] and African American ethnic group [20, 25] may predict a belief that religious intervention influences the outcome of cancer rather than medical treatment, as well as a resigned acceptance of death. The link between what has been termed ‘fatalism’ – a belief that cancer is pre-ordained – and delayed presentation is unconfirmed. One study of healthy women suggested that fatalism negatively influenced help-seeking intention [22], but a study of women with breast cancer found no association between fatalism and actual delay in presentation [18].

Trust in healthcare system

Curability of cancer

There was strong evidence to suggest that Black and African American women with and without cancer believed cancer could be cured [17, 18, 22, 23]. Across three studies, 77- 98% of African American women did not believe death was an inevitable outcome of cancer [17, 18, 23]. In another study, only a small percentage of African American (13%) and White women (16%) believed that cancer inevitably led to death [23].However another study of African American women reported that they believed cancer was a deadly and incurable disease and very few of those interviewed knew of women who had survived the disease [30]. However the influence of that belief (cancer equates with death) on help-seeking intention was not discussed [30].

Fear of conventional treatment

Black and African American women reported fearing the implications of cancer treatments and surgery [17, 20, 28, 31] and some said they preferred non-conventional therapies [20]. Treatment fear prolonged delay among some women with cancer. One study reported that 57% of African American women with and without breast cancer believed treatments for breast cancer were worse than the disease itself, [17] while three studies reported reluctance among African American women to have surgery [20, 28, 31].. Some African American women reported fearing unpleasant side-effects and were worried about what treatments comprised. One study reported that African American women were more likely than White women to prefer non-conventional treatments in place of surgery [20].

Quality of relationships with healthcare professionals

Concerns about interactions with doctors

In the UK study, concerns about wasting the doctor's time, or finding it difficult to talk to a doctor were barriers to early presentation. However, these issues were just as likely to be reported by White women as Black women [19].

Lack of confidence in healthcare professionals

There was strong evidence suggesting Black and African American women lacked confidence in medical professionals due to breast symptoms being previously misdiagnosed. They expressed concerns over standards of care and the type of care they would receive; they were concerned about discrimination in medical settings. In one study, three African American women with cancer were initially told their symptoms were benign and this contributed to delayed diagnosis. For example, one was told, '*It's just cysts, it's nothing to worry about.'* [31]. Further, some Black and African American women with cancer were concerned about doctors providing substandard, aggressive (*'she wound up with a mastectomy two weeks later just because of her mammogram')*[28] or experimental care [28, 29]. The Tuskegee syphilis study [34] was cited by Black and African American study participants in support of this belief [28, 29]. However, one study reported that African American women felt healthcare professionals should conduct breast examinations rather than women themselves, which suggested trust in the skills of healthcare professionals [27].

Five studies examined Black and African American women's perceptions of discrimination in medical settings [16, 22, 24, 28, 29]. Two determined that although women perceived a degree of racism and discrimination, this did not appear to influence delay or help-seeking intent [16, 22] but in another two studies it did influence help-seeking intention and delay [24, 28].

Practical and service barriers

Financial burden of healthcare and influence of health insurance on patient and provider delays

The impact of the financial burden of healthcare (affordability of healthcare and health insurance coverage) on delay was unclear based on the limited evidence provided by these studies. In one study there was no statistically significant association between perceived affordability of healthcare and delay [33]. In another study, women with health insurance were not significantly more likely to be diagnosed within 90 days than those without insurance [16].

There was also a mixed picture of the influence of Black and African American women's socioeconomic status on delay within these studies. In two of them, socioeconomic status did not appear to influence delay among Black women with cancer [16, 26]. However, three studies reported that less affluent Black and African American women were less likely to seek help for cancer symptoms and that this did contribute to delayed presentation [18, 22, 20].

Perceptions of access to healthcare services

In the UK study access issues such as ease of booking appointments, arranging transport and distance between home and health centres appeared no more common in Black than White women. Rather, Black women were less likely than White women to report difficulties making an appointment as a barrier to help-seeking (Black 30%, White 36%). Difficulties arranging transport were again less of a barrier (Black 14%, White 16%) in Black women. Overall, transport appeared a less common barrier that challenges with making appointments to see their doctor [19].

In the US studies, the effect of access issues on delay was mixed. In a study of Black and African American women without breast cancer, being more likely to intend to seek help was significantly linked to positive perceptions of accessibility to healthcare [28]. Further, in another study poorer access to healthcare among Black women with breast cancer made attending appointments difficult [21]. However, two studies reported little evidence indicating access issues impacted on delay among Black and African American women with cancer [16, 33].

FACTORS WHICH MAY EXPLAIN THE REVIEW FINDINGS

It was evident that some barriers to early presentation with cancer were more prevalent ten years ago than today and vice versa. Accessibility of healthcare services [21, 22] and competing priorities [22, 27, 29] were important issues influencing delay in Black, African American, Caribbean and African women in older (≥10 years) studies. However, in some more recent studies (≤ 10 years) access to healthcare [16, 19, 33] and competing priorities [19, 31] were reported to neither influence delay nor help-seeking intention.

Although the influence of partner abandonment was examined in one early quantitative study [20] and emerged from women's narratives in three early qualitative studies, [28, 30, 31] , this theme was not examined in any recent quantitative studies. This does not mean, however, that it is not a current problem, only that it has not been examined as a potential influence over time.

Several differences were also noted between women with and without cancer. Competing priorities did not influence delay in a recent study of women with symptomatic breast cancer [31] but they did influence how healthy women felt they would approach seeking help should they develop cancer symptoms [22]. Further, although in some studies the financial burden of healthcare [16, 26, 33] and access issues [16, 33] did not influence delay among those women with breast cancer, healthy women cited both of these issues as potential barriers to their future help-seeking [22]. These differences highlight that researchers may get different answers depending on whether they ask healthy women or women with cancer about delay/help-seeking intention.

DISCUSSION

Delayed presentation with breast cancer in Black women living in the US and UK appears influenced by multiple factors and to be highly individual and complex. Logically, all women may present late if they have limited awareness of the disease and its symptoms [35]. Although a relatively small number of studies comparing Black and White women were included in the review, Black women appear more likely than White women to have limited understanding of breast cancer and its risk factors. This might be the case particularly among 1) migrant women from countries where health campaigns about the disease are scarce, 2) women with limited command of the host nation's language and/or low literacy who are therefore not reached by the host nation's health messages; and 3) women from communities where it is culturally unacceptable to discuss cancer and who, as a result, do not gain understanding of the disease through word of mouth.

This review, consistent with health behaviour models [36, 37], illustrates how women's understanding of risk factors and their perceived personal risk influence their sensitivity to breast cancer symptoms and help-seeking on identifying them. Black women rightly perceive their risk of breast cancer to be lower than in White women [2, 3]. Consequently, they may retain little information provided to them by healthcare professionals or portrayed in breast cancer health promotion campaigns, as they may believe it to be of limited personal relevance.

Findings from studies incorporated in this review determined that many women lack confidence in checking, or are reluctant to check their breasts. However, if women are unaware of how their breasts typically feel they will, as a consequence, face challenges in recognising subtle changes and may only detect change when the disease is relatively advanced.

Clearly, early presentation with cancer is not solely dependent on knowledge. Women with good knowledge of the disease may not seek help from healthcare professionals on detecting symptoms of breast cancer [38]. This review suggests fear may be an important factor preventing Black women from seeking help. It appears multifaceted – women referred to fear of cancer treatments and abandonment by partners. Arguably, health messages communicating negative consequences of delayed presentation with breast cancer may be less effective than those framed in ways outlining benefits of early presentation. Fear-led messages may lead to avoidance and denial in people who fear a cancer diagnosis [36]. Further, although it appears that disclosure to others about symptoms indicative of breast cancer can be important in promoting early presentation with the disease; [39] it is not uncommon for Black women to feel uncomfortable about disclosing symptoms to others, including healthcare professionals. This is due to the taboo and embarrassment associated with the disease [40]. Women's previous encounters and rapport with healthcare professionals, and any exposure to discrimination or misdiagnosis, also appear to influence time to presentation.

Beliefs about the curability of breast cancer (a factor impacting positively on early presentation) may be influenced in women born outside the country they live in by experiences from their country of origin, where treatments for cancer may be less effective and death more likely [41]. Religiosity might influence help-seeking behaviour but this will depend on how people perceive their own role and that of a higher influence in managing their health [42]. The highly individual nature of religious beliefs may explain why the influence of religiosity on delay was unclear in this review. Further, it may reflect the nature of the samples recruited to the reviewed studies.

Papers incorporated into the review did not unequivocally support an association in the US between financial barriers and late presentation with breast cancer in Black and African American women. It is likely that this finding reflects sampling issues; Black women sampled in these studies appeared relatively affluent, 58-92% had health insurance. Work of others, including Schneider, demonstrates clearly both the coexistence of socioeconomic factors and ethnicity and their impact on cancer staging and outcomes [43]. However, it is important to note that outside the US socioeconomic factors may be more or less associated with ethnicity. They may also impact differently on time to presentation with breast cancer in differing healthcare systems.

Evidence from the sole UK study indicated that poor knowledge of breast cancer and its associated symptoms, and both practical and financial issues, may act as barriers to early presentation with breast cancer in Black African and Black Caribbean women. However, this study alone is insufficient to enable conclusions to be drawn on factors impacting delayed diagnosis with breast cancer in Black women living in the UK. Further, it grouped all Black women together in the analysis. This would suggest that Black women are a homogenous group; it is very likely that attitudes, help-seeking intention and help-seeking behaviours will vary considerably within and between Black African and Black Caribbean women in the UK and possibly between first and second generation migrants. Merely labeling women as 'Black' may mask diverse attitudes and behaviours and lead researchers to overlook important nuances [44]. Further research is needed in the UK to explore factors impacting early diagnosis with symptomatic breast cancer and to study in detail similarities and differences by ethnic group.

Unfortunately, whilst we aimed to compare in detail barriers to early presentation with symptomatic breast cancer between different groups of Black women in the US and UK this proved impossible due to paucity of UK studies and poor level of reporting in many of the published US studies. Consequently, the specific nuances between different ethnic groups of Black women could not be determined. However, it is striking that so many of the beliefs, taboos, and fears were similar among Black women, irrespective of their country of residence. These factors are clearly not genetic which suggests cultural factors are durable over many generations.

There was some evidence that some barriers to early diagnosis had lessened during the period of this review. This suggests that awareness-raising campaigns may have been successful in raising the importance of early presentation and overcoming practical challenges and personal concerns. Equally, the findings could reflect the time that Black women migrating to developed countries had spent there. Arguably, migrants' views will change over time as they adapt to their surroundings and become influenced by new cultures and health systems [45]. There was also some evidence of differences between women with and without cancer, suggesting a distinction between what women say they would do if they discovered a symptom, versus what they do with the onset of symptoms.

Further high quality research is needed to better understand barriers to early presentation and diagnosis with breast cancer in Black ethnic groups living outside the US. In particular, studies of, and comparisons between, ethnic groups in the UK are needed to determine influences on delay in presentation and their possible contribution to the poorer survival of Black African and Black Caribbean women in the UK [3]. Researchers need to compare stage at diagnosis and cancer survival between ethnic groups after stratifying for tumour prognostic and biological factors. This would allow the relative influence of cancer biology, women's delay and system delay on outcomes to be determined. Findings of this review have several implications for policy and practice. Our review indicates that Black women should feature more prominently in media campaigns, and educational materials to prevent breast cancer being perceived as a 'white women's' disease. Information about the risk of breast cancer and its early symptoms, concerns about breast checking, surgery, and the side-effects of treatment also need to be addressed in ways that are culturally sensitive to Black women [46, 47]. Vulnerable women, who fear partner abandonment and who may be reluctant to have treatment for breast cancer as a result, need to be identified and supported by healthcare professionals. Further, enhancing women's experiences of being diagnosed and treated for breast cancer, and encouraging engagement and discussion regarding the disease, may help to address stigma and taboo, promote disclosure and allay women's fears; factors believed to impact positively on early presentation and diagnosis.

ACKNOWLEDGEMENTS AND FUNDING
This article was funded by the National Awareness and Early Diagnosis Initiative (NAEDI).

ETHICS COMMITTEE APPROVAL

As this article describes a systematic review of the literature, no ethical approval was needed for the study.

COMPETING INTERESTS

None

EXCLUSIVE LICENCE STATEMENT

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APPENDIX 1: BREAKDOWN OF EXCLUDED STUDIES (WEB ONLY FILES)

Reason for exclusion on preliminary screening	Number of studies
Aetiology	17
Barriers to, or uptake of, cancer screening	126
Clinical Studies	105
Duplicates	253
Incidence, prevalence and survival studies	71
Methods studies	11
Not about barriers to presentation and diagnosis	137
Not cancer, not Black African or Black Caribbean participants, or not conducted in Western countries	98
Not research	13
Risk factors	13
Unpublished material	5
TOTAL	**849**

Reason for exclusion on data extraction	Number
Data not reported separately for men and women and/or ethnic groups	22
Not Black African or Black Caribbean participants	3
Did not explore barriers	12
Investigated knowledge, attitudes and beliefs and their relationship to cancer screening utilisation	10
Study >20 years	1
Investigated stage at presentation and cancer detection methods	4
Investigated perceptions of risk factors	1
Investigated factors/barriers to treatment	1
Investigated association between socioeconomic status and race in cancer stage, treatment, survival and/or cancer screening uptake	4
Did not report findings for breast cancer separately	5
TOTAL	**63**

Studies retrieved	Studies excluded on preliminary screening	Studies excluded on data extraction	Studies included
930	849	63	18

APPENDIX 2: QUANTITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Description of study design:	
Setting	
Country	
ELIGIBILITY CRITERIA	
Exclusion criteria	
SAMPLING	
Sampling procedure	
PARTICIPANTS	
Total no. of eligible participants	
Number of participants recruited	
Number of surveys and/or	

participants included in the analysis	
What was the response rate?	
Mean age (standard deviation)	
Age range	
Females n (%)	
Males n(%)	
Ethnicities (provide breakdown, n (%))	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
OUTCOMES (please include data)	
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	
Barriers to early diagnosis (include both patient and provider related factors)	
Other outcomes/findings	
Measurement scales/units used: **Were they: investigator designed/tools with already established reliability and validity?**	
Timing of outcomes measured. When were measures taken?	
Other important outcome information	
Key conclusions as reported by authors:	
Key issues with the study:	

QUALITY APPRAISAL		
		Additional comments
Was the study design suitable?	Yes No Unclear	
Was the sampling method appropriate?	Yes No Unclear	
Were the tools suitable to measure study outcomes?	Yes No Unclear	
Were the tools used psychometrically sound?	Yes No Unclear	
Was the sample appropriate?	Yes No Unclear	
Were the measurements justified?	Yes No Unclear	
Which tests were performed? Were they suitable to satisfy study aims?	Yes No Unclear	
What were the confounding variables? Were there other factors that impacted on the results?		
Were confounding variables adequately controlled for? How were they controlled for in the analysis?	Yes No Unclear	
Was sensitivity to ethical concerns demonstrated? How?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: Evidence generated is strong, unbiased and generalisable		
B - Some flaws: unlikely to affect the reliability and validity of study findings greatly		

C - Many flaws: likely to impact on the reliability and validity of study findings	
D - Highly flawed study, data generated are likely to be biased and lacking reliability and validity	

REVIEWER'S COMMENTS		
Include		
Exclude		
Needs checking by another reviewer (please specify why)		
Contact author for further information (please specify which information)		

APPENDIX 3: QUALITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION
Reviewer:
Endnote reference no:
Title:
Author(s):
Year:
Journal:
Volume:
Issue:
Pages:

STUDY DESIGN	
Aim(s) of study:	
Setting	
Country	
Sampling procedure	
Inclusion criteria	
Exclusion criteria	
Data collection methods	
Data analysis approach/ procedure	
PARTICIPANTS	
Total no. participants	
Age range	
Females n	
Males n	
Ethnicities (provide breakdown, n)	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
FINDINGS OF INTEREST	**(please include data)**
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	

Barriers to early diagnosis (include both patient and provider related factors)				
Other findings:				
Key conclusions as reported by authors:				
Key issues with/limitations of the study:				
QUALITY APPRAISAL				
				Additional comments
Research design				
Was a qualitative methodology appropriate?	Yes	No	Unclear	
Was the method/design apparent, and consistent with research intent?	Yes	No	Unclear	
Was the data collection strategy apparent and appropriate?	Yes	No	Unclear	
Sampling strategy				
Was the sample and sampling method appropriate?	Yes	No	Unclear	
Analysis				
Was the analytic approach appropriate?	Yes	No	Unclear	
Was there evidence of data saturation?	Yes	No	Unclear	
Were deviant case/contradictory findings discussed? What were they?	Yes	No	Unclear	
Was there evidence of member checking and/or independent analysis of data by more than one researcher?	Yes	No	Unclear	
Presentation and interpretation of findings				
Was the context described and taken	Yes	No	Unclear	

account of in interpretation?		
Were appropriate quotes used in the presentation of findings and discussion of findings?	Yes No Unclear	
Was the interpretation of findings justified by the data that are presented?		
Reflexivity		
Was researcher reflexivity demonstrated?	Yes No Unclear	
Ethical considerations		
Was sensitivity to ethical concerns demonstrated?	Yes No Unclear	
Relevance and transferability		
Is relevance and transferability evident generally about the study?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: The study credibility, transferability, dependability, and confirmability is high		
B - Some flaws, unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study		
C - Some flaws, which may affect the credibility, transferability, dependability, and/or confirmability of the study		
D - Significant flaws, which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study		

APPENDIX 4: RESULTS OF INDIVIDUAL STUDIES (WEB ONLY FILE)

Reference	**Findings**
16	Women who are fearful more likely to delay (OR: 0.50, 95% CI: 0.27-0.92) No statistically significant evidence that financial barriers relate to delay (Unadjusted 1.06, 95% CI, 0.59-1.91) System barriers not significantly related to delay (Unadjusted 0.54, 95% CI, 0.59-1.00) Women with health insurance not significantly more likely to be diagnosed within 90 days (Unadjusted: 0.85, 95% CI, 0.44-1.63) Perceived discrimination not related to delay (data not provided)
17	Would rather know they had cancer:17% Agreed cancer treatments worse than cancer itself: 57% Believed cancer is curable: 74%
18	Believed death is imminent if someone is diagnosed with breast cancer: 1.6% Believed it is too late to do anything if someone is diagnosed with breast cancer: 3.9% Logistic regressions to determine impact of religiosity, spirituality and fatalism on time to presentation determined income is a significant indicator of time to seek medical care in these models: - Religiosity: (OR: 0.79, 95% CI: 0.68-0.92) - Spirituality: (OR: 0.77, 95% CI: 0.65-0.90) - Fatalism: ((OR: 0.78, 95% CI, 0.67, 0.92) Income is a significant indicator of time to seek medical care (OR: 0.77-0.79, 95% CI: 0.65-0.92) (higher the income, the more likely women were to seek medical care promptly) Disclosure reduces delay (OR: 0.25, 95% CI: 0.11- 0.57) Religiosity & spirituality in themselves do not affect delay (OR:1.00, 95% CI: 0.98-1.03) (OR: 1.06, 95% CI: 0.99-1.13)
19	Recognised 5 or more non-lump symptoms of breast cancer: 16% Black, 22% White Knew that a 70 yr old was at a higher risk of breast cancer than younger women: 13% Black, 12% White Was fairly or very confident about noticing change in breasts: 50% Black, 55% White Reported breast checking at least once a month: 18% Black, 28% White Barriers to help-seeking Worried about what a doctor might find: White 44%; Black 46% Too embarrassed to go and see the doctor: White 31%; Black 30% Lacked confidence to talk about symptoms: 19% White; Black 24% Too scared to go and see doctor: White 29%; Black 20% Too many other things to worry about: White 37%; Black 31% Too busy to make time to go to the doctor: White 35%; Black 34% Find it difficult to arrange transport: White 16%; Black 14% Find doctor difficult to talk to: White 23%; Black 23% Worried about wasting doctor's time: White 53%; Black 21% Find it difficult to make an appointment: White 36%; Black 30%
20	AA more likely than White women to: believe men would not want to know about cancer (3.1, 95% CI: 2.0-4.6), not go to doctor if lump not bothersome (6.0, 95% CI: 2.3-15), believe surgery would be the worst thing (1.6, 95% CI: 1.1-2.2), have a belief in herbal remedies (2.6, 95% CI: 1.7-4.1), over the counter medicines (2.0, 95% CI: 1.3-2.9) and chiropractic regimens (3.0, 95% CI: 1.8-5.2) as treatments for cancer AA less likely than White women to: have a belief in surgery (0.5, 95% CI: 0.3-0.9) and believe if a woman has cancer it increases the risk for daughter (0.6, 95% CI: 0.5-0.8)
21	More Black than White women attributed system- oriented delays to scheduling delays (no figures provided)
22	Racism (r=-0.08) independent of help-seeking Intention Childcare, employment, partnership (r=-0.48) and healthcare access (r=0.49) associated with help-seeking intention Fear of cancer has weak association with help-seeking intention (r=0.11)

	Income associated with seeking help (r=0.32) Perceived negative consequences of delay associated with more timely presentation (r=0.443)
23	Believed death is outcome of cancer: 13% AA, 16% White Believed early diagnosis increases chance of cure: 83% AA, 96% White Felt at risk of developing breast cancer: 25% AA, 44% White
24	Black women more likely to delay if they reported personally experiencing prejudice in healthcare delivery (P <0.001) than White women
25	Being AA is primary predictor of belief in religious intervention in place of treatment rather than religious intervention with treatment (p<0.0001)
26	No relationship between worry and delay No relationship between sociodemographic variables and delay
27	Afraid to conduct breast self-examination due to fear Advertising aimed at White women Lack confidence to breast check (e.g. unsure of symptoms) Lack time/family support to conduct breast self-examination
28	AA women: Concerned about substandard, aggressive or experimental care Fear of partner abandonment - inhibits help-seeking Lack knowledge to identify symptoms Religiosity does not constrain help-seeking
29	Felt at low risk Fear of physical examinations due to sexual abuse in past Breast self-examination low priority Mistrust of medical professionals Symptoms misinterpreted
30	Cancer is stigmatised Fear partner will abandon if cancer diagnosis is shared Very few women with experience or knowledge of breast cancer knew other women who had survived it Belief that breast cancer is primarily a white women's disease
31	Caring obligations were not barriers to presentation Fear and anxiety (e.g. of treatment) can lead to delay Lack of knowledge not always reason for delay Dismissal of lump led to delay Previous benign diagnosis by health professional led to delay Fear of partner abandonment may inhibit help-seeking Other symptoms(e.g. feeling unwell) prompt help-seeking
32	Believed breast cancer is a White woman's disease Lack of adequate information about risk factors/symptoms Cancer is taboo

33	Felt fear on symptom discovery: 32% Fear may be influenced by whether women believe in God (1 woman) Made own decision to seek care rather than being influenced by others: 65% Confrontive coping (confronting/dealing with cancer directly) correlated with shorter delays (r=-0.32, no p value provided) Denial associated with longer delays (r=0.36), p<0.05) Fear not correlated with delay Affordability and accessibility of healthcare not correlated with delay Tolerate pain until it worsens (1 woman)

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Study >20 years	1
Investigated stage at presentation and cancer detection methods	4
Investigated perceptions of risk factors	1
Investigated factors/barriers to treatment	1
Investigated association between socioeconomic status and race in cancer stage, treatment, survival and/or cancer screening uptake	4
Did not report findings for breast cancer separately	5
TOTAL	**63**

Studies retrieved	Studies excluded on preliminary screening	Studies excluded on data extraction	Studies included
930	849	63	18

APPENDIX 2: QUANTITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Description of study design:	
Setting	
Country	
ELIGIBILITY CRITERIA	
Exclusion criteria	
SAMPLING	
Sampling procedure	
PARTICIPANTS	
Total no. of eligible participants	
Number of participants recruited	
Number of surveys and/or participants included in the analysis	
What was the response rate?	
Mean age (standard deviation)	
Age range	
Females n (%)	
Males n(%)	
Ethnicities (provide breakdown, n (%))	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
OUTCOMES (please include data)	
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	
Barriers to early diagnosis (include both patient and provider related factors)	
Other outcomes/findings	

Measurement scales/units used: **Were they: investigator designed/tools with already established reliability and validity?**		
Timing of outcomes measured. When were measures taken?		
Other important outcome information		
Key conclusions as reported by authors:		
Key issues with the study:		
QUALITY APPRAISAL		
		Additional comments
Was the study design suitable?	Yes No Unclear	
Was the sampling method appropriate?	Yes No Unclear	
Were the tools suitable to measure study outcomes?	Yes No Unclear	
Were the tools used psychometrically sound?	Yes No Unclear	
Was the sample appropriate?	Yes No Unclear	
Were the measurements justified?	Yes No Unclear	
Which tests were performed? Were they suitable to satisfy study aims?	Yes No Unclear	
What were the confounding variables? Were there other factors that impacted on the results?		
Were confounding variables adequately controlled for? How were they controlled for in the analysis?	Yes No Unclear	
Was sensitivity to ethical concerns demonstrated? How?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: Evidence generated is strong, unbiased and generalisable		
B - Some flaws: unlikely to affect the reliability and validity of study findings greatly		
C - Many flaws: likely to impact on the reliability and validity of study findings		
D - Highly flawed study, data generated are likely to be biased and lacking reliability and validity		
REVIEWER'S COMMENTS		
Include		
Exclude		
Needs checking by another reviewer (please specify why)		

Contact author for further information (please specify which information)	

APPENDIX 3: QUALITATIVE DATA EXTRACTION FORM (WEB ONLY FILE)

BACKGROUND INFORMATION	
Reviewer:	
Endnote reference no:	
Title:	
Author(s):	
Year:	
Journal:	
Volume:	
Issue:	
Pages:	
STUDY DESIGN	
Aim(s) of study:	
Setting	
Country	
Sampling procedure	
Inclusion criteria	
Exclusion criteria	
Data collection methods	
Data analysis approach/ procedure	
PARTICIPANTS	
Total no. participants	
Age range	
Females n	
Males n	
Ethnicities (provide breakdown, n)	
Other demographic details (e.g. employment status, location) – please include data from tables/figures	
FINDINGS OF INTEREST	**(please include data)**
Knowledge or attitudes	
Barriers to early presentation (include both patient and provider related factors)	
Barriers to early diagnosis	

(include both patient and provider related factors)		
Other findings:		
Key conclusions as reported by authors:		
Key issues with/limitations of the study:		
QUALITY APPRAISAL		
		Additional comments
Research design		
Was a qualitative methodology appropriate?	Yes No Unclear	
Was the method/design apparent, and consistent with research intent?	Yes No Unclear	
Was the data collection strategy apparent and appropriate?	Yes No Unclear	
Sampling strategy		
Was the sample and sampling method appropriate?	Yes No Unclear	
Analysis		
Was the analytic approach appropriate?	Yes No Unclear	
Was there evidence of data saturation?	Yes No Unclear	
Were deviant case/contradictory findings discussed? What were they?	Yes No Unclear	
Was there evidence of member checking and/or independent analysis of data by more than one researcher?	Yes No Unclear	
Presentation and interpretation of findings		
Was the context described and taken account of in interpretation?	Yes No Unclear	
Were appropriate quotes used in the presentation of findings and discussion of findings?	Yes No Unclear	
Was the interpretation of findings justified by the data that are presented?		
Reflexivity		
Was researcher reflexivity demonstrated?	Yes No Unclear	
Ethical considerations		
Was sensitivity to ethical concerns demonstrated?	Yes No Unclear	
Relevance and transferability		
Is relevance and transferability evident generally about the study?	Yes No Unclear	
QUALITY SUMMARY SCORE IN LIGHT OF THE APPRAISAL ABOVE	**(please select one and outline your reasons why)**	
A - No or few flaws: The study credibility, transferability, dependability, and confirmability is high		
B - Some flaws, unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study		

C - Some flaws, which may affect the credibility, transferability, dependability, and/or confirmability of the study	
D - Significant flaws, which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study	

APPENDIX 4: RESULTS OF INDIVIDUAL STUDIES (WEB ONLY FILE)

Reference	**Findings**
16	Women who are fearful more likely to delay (OR: 0.50, 95% CI: 0.27-0.92) No statistically significant evidence that financial barriers relate to delay (Unadjusted 1.06, 95% CI, 0.59-1.91) System barriers not significantly related to delay (Unadjusted 0.54, 95% CI, 0.59-1.00) Women with health insurance not significantly more likely to be diagnosed within 90 days (Unadjusted: 0.85, 95% CI, 0.44-1.63) Perceived discrimination not related to delay (data not provided)
17	Would rather know they had cancer:17% Agreed cancer treatments worse than cancer itself: 57% Believed cancer is curable: 74%
18	Believed death is imminent if someone is diagnosed with breast cancer: 1.6% Believed it is too late to do anything if someone is diagnosed with breast cancer: 3.9% Logistic regressions to determine impact of religiosity, spirituality and fatalism on time to presentation determined income is a significant indicator of time to seek medical care in these models: - Religiosity: (OR: 0.79, 95% CI: 0.68-0.92) - Spirituality: (OR: 0.77, 95% CI: 0.65-0.90) - Fatalism: ((OR: 0.78, 95% CI, 0.67, 0.92) Income is a significant indicator of time to seek medical care (OR: 0.77-0.79, 95% CI: 0.65-0.92) (higher the income, the more likely women were to seek medical care promptly) Disclosure reduces delay (OR: 0.25, 95% CI: 0.11- 0.57) Religiosity & spirituality in themselves do not affect delay (OR:1.00, 95% CI: 0.98-1.03) (OR: 1.06, 95% CI: 0.99-1.13)
19	Recognised 5 or more non-lump symptoms of breast cancer: 16% Black, 22% White Knew that a 70 yr old was at a higher risk of breast cancer than younger women: 13% Black, 12% White Was fairly or very confident about noticing change in breasts: 50% Black, 55% White Reported breast checking at least once a month: 18% Black, 28% White Barriers to help-seeking Worried about what a doctor might find: White 44%; Black 46% Too embarrassed to go and see the doctor: White 31%; Black 30% Lacked confidence to talk about symptoms: 19% White; Black 24% Too scared to go and see doctor: White 29%; Black 20% Too many other things to worry about: White 37%; Black 31% Too busy to make time to go to the doctor: White 35%; Black 34% Find it difficult to arrange transport: White 16%; Black 14% Find doctor difficult to talk to: White 23%; Black 23% Worried about wasting doctor's time: White 53%; Black 21% Find it difficult to make an appointment: White 36%; Black 30%
20	AA more likely than White women to: believe men would not want to know about cancer (3.1, 95% CI: 2.0-4.6), not go to doctor if lump not bothersome (6.0, 95% CI: 2.3-15), believe surgery would be the worst thing (1.6, 95% CI: 1.1-2.2), have a belief in herbal remedies (2.6, 95% CI: 1.7-4.1), over the counter medicines (2.0, 95% CI: 1.3-2.9) and chiropractic regimens (3.0, 95% CI: 1.8-5.2) as treatments for cancer AA less likely than White women to: have a belief in surgery (0.5, 95% CI: 0.3-0.9) and believe if a woman has cancer it increases the risk for daughter (0.6, 95% CI: 0.5-0.8)
21	More Black than White women attributed system- oriented delays to scheduling delays (no figures provided)
22	Racism (r=-0.08) independent of help-seeking Intention Childcare, employment, partnership (r=-0.48) and healthcare access (r=0.49) associated with help-seeking intention Fear of cancer has weak association with help-seeking intention (r=0.11) Income associated with seeking help (r=0.32) Perceived negative consequences of delay associated with more timely presentation (r=0.443)
23	Believed death is outcome of cancer: 13% AA, 16% White Believed early diagnosis increases chance of cure: 83% AA, 96% White

	Felt at risk of developing breast cancer: 25% AA, 44% White
24	Black women more likely to delay if they reported personally experiencing prejudice in healthcare delivery (P <0.001) than White women
25	Being AA is primary predictor of belief in religious intervention in place of treatment rather than religious intervention with treatment (p<0.0001)
26	No relationship between worry and delay No relationship between sociodemographic variables and delay
27	Afraid to conduct breast self-examination due to fear Advertising aimed at White women Lack confidence to breast check (e.g. unsure of symptoms) Lack time/family support to conduct breast self-examination
28	AA women: Concerned about substandard, aggressive or experimental care Fear of partner abandonment - inhibits help-seeking Lack knowledge to identify symptoms Religiosity does not constrain help-seeking
29	Felt at low risk Fear of physical examinations due to sexual abuse in past Breast self-examination low priority Mistrust of medical professionals Symptoms misinterpreted
30	Cancer is stigmatised Fear partner will abandon if cancer diagnosis is shared Very few women with experience or knowledge of breast cancer knew other women who had survived it Belief that breast cancer is primarily a white women's disease
31	Caring obligations were not barriers to presentation Fear and anxiety (e.g. of treatment) can lead to delay Lack of knowledge not always reason for delay Dismissal of lump led to delay Previous benign diagnosis by health professional led to delay Fear of partner abandonment may inhibit help-seeking Other symptoms(e.g. feeling unwell) prompt help-seeking
32	Believed breast cancer is a White woman's disease Lack of adequate information about risk factors/symptoms Cancer is taboo
33	Felt fear on symptom discovery: 32% Fear may be influenced by whether women believe in God (1 woman) Made own decision to seek care rather than being influenced by others: 65% Confrontive coping (confronting/dealing with cancer directly) correlated with shorter delays (r=-0.32, no p value provided) Denial associated with longer delays (r=0.36), p<0.05) Fear not correlated with delay Affordability and accessibility of healthcare not correlated with delay Tolerate pain until it worsens (1 woman)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	4
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	4-5
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	4
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	4
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	4-5, 22
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	5, 22-9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	n/a
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	5-6
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2 for each meta-analysis.	6

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	n/a
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	n/a
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	6
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8-9, 30-32
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	8-9
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	30-32
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	10-14
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	15-17
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	3, 15-17
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	15-17
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	17

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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