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Understanding Breast Health Awareness in the Kingdom of Saudi Arabia: A Systematic Review of the Literature

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Abstract: Breast cancer (BC) is a critical health concern in the Kingdom of Saudi Arabia (KSA). A major factor influencing its incidence is the large proportion of younger Saudi women presenting with BC at an advanced stage. This systematic review aimed to explore health care providers' and women's experiences and perspectives of breast health awareness in KSA. Electronic data databases: MEDLINE, PubMed, CINAHL and the Web of Science were searched from inception (1946) to February 2017. A systematic search using breast cancer or breast health headings and index terms was conducted. Papers were included if they focused on Saudi women and health care providers (HCPs), breast cancer and breast health awareness. This systematic review was guided by PRISMA guidelines and all relevant studies were individually assessed by the researcher using Critical Appraisal Skills Programme and Milton Keynes Primary Care Trust checklists and reviewed by all authors. Thematic synthesis of data was used to present the results. 56 studies inform this systematic review. There are no national breast cancer education programs or screening programs in KSA. The findings demonstrated a very limited evidence base related to breast health awareness. This limited evidence suggests that the combination of inadequate awareness among women and a reluctance to conduct breast screening and provide education to health care providers has attributed to the absence of screening programs. Breast education and screening programs need to be embedded in KSA. Empirical studies are required to rigorously assess women and HCPs knowledge and awareness towards BC in order to help inform policy and breast cancer education and screening programs. The findings are likely to resonate with countries in the Eastern world where breast education and screening services are under developed.

Key words: Barriers • Breast Cancer • Breast Self-Examination • Clinical Breast Examination • Health Care Providers • Mammograms and Screening

INTRODUCTION

Breast cancer (BC) is the most common cancer among women in the Kingdom of Saudi Arabia (KSA) [1, 2]. Significantly, the incidence of BC has risen remarkably in the Arab world including KSA in the last decade [2, 3]. The increase in BC incidence can be attributed to increased urbanisation, longer life expectancy and a rise in reduced and delayed fertility [1, 4]. In comparison to western patterns, KSA has a remarkably high incidence and mortality of cancer at a young age [4-6]. The Saudi Cancer Registry (SCR) reported that BC constitutes 29.1 % of all cancer cases in women in KSA and the highest rate is in the 30-44 year-old age group [2]. There is a difference between BC cases in the KSA and U.S. and UK in terms of age, incidence and type of BC tumour and mortality rates (Table 1). The incidence of BC cases in KSA has rapidly increased over the last decade with an annual percentage incidence of malignant breast cancer steadily increased by 4.8%, from an annual rate of 23.5% in 2000 to 47.2% in 2007 [7]. This would suggest a significantly greater increase in incidence when compared to the UK (7%) [8] and the U.S. which has remained static [9]. Invasive BC accounts for 78.2% of all morphological BC variants in KSA [10]. While non-invasive BC accounts for 83% of all BC cases in the UK [10] and for about 1 out of every 5 new BC cases in the U.S. [9, 11]. BC presentation at a young age and an advanced stage with high mortality rates in KSA [10, 12-14]. In comparison, BC is considered as an older age disease and most patients

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BC cases features	KSA	U.S.	UK
The incidence and mean age of BC cases	 The annual percentage incidence of malignant breast cancer steadily increased by 4.8%, from an annual rate of 23.5% in 2000 to 47.2% in 2007⁷. -46.9 years^{12,14}. (Age <50 years: 57.5%)¹³. 	 Overall BC incidence rates have remained relatively stable in the last decade⁹. The incidence of BC is increased dramatically with age and the average age of BC patient is about 63 years in the U.S¹². (age <50 years: 12.5%)¹³. 	 BC incidence of BC increased dramatically with age. The incidence rates have increased by 7% in the last decade⁸. The average of 80% of BC cases are diagnosed in the over 50s and around 24% are diagnosed in women aged 75 and over¹⁴.
Common type of BC	-Invasive ductal carcinoma (IDC) or infiltrating duct carcinoma (ICD-O-3, 8500) accounts for 78.2% of all morphological BC variants ¹⁰ .	-Non-invasive breast cancer: Ductal carcinoma in situ (DCIS), around 60, 000 cases/year, accounting for about 1 out of every 5 new BC cases ^{9, 11} . -Invasive breast cancer: Invasive ductal carcinoma (IDC) or infiltrating ductal carcinoma. Around 85 % of all invasive BC cases are invasive ductal carcinomas ^{9, 11} .	 Non-invasive breast cancer: the majority of in situ breast carcinomas are ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS). An average 83% of cases were DCIS and 9% were LCIS⁸. Invasive breast cancer: Around 1 in 10 breast cancers diagnosed (10%) are invasive lobular carcinoma⁸.
Grade of the tumour and its feature	 Grade III tumoursA tumour size >2.5 cm was found in 61.1% of patients¹². The median tumor size is 9 cm^{10,14}. Axillary nodal metastasis was present in 57.1% and lymphovascular invasion in 64.1% of Saudi patients who underwent axillary nodal dissection¹. Patients present with an aggressive form of BC associated with poor outcome, high incidence of local recurrence and pulmonary metastases¹⁴. BC tends to be estrogen/progesterone receptor negative. Tumor size has an important impact on outcome¹⁴. Localized disease: 28.6%¹³. 	-Localized disease: 61.2% ¹³ .	-The majority of BC cases are diagnosed at ar early stage (83% diagnosed at stage I or II) than an advanced stage (17% diagnosed at stage III or IV) ⁸ .
Mortality	- BC Presentation at a young age and an advanced stage with high mortality rates ^{12, 13, 10} .	- Most patients who die as a result of BC in the U.S. are now aged ≥65 years and presented with other health problems such hypertension and mild dementia ^{9, 11} .	 -Most BC cases are diagnosed at an early stage BC in situ is the most common type of BC among cases⁸. - Around three-quarters of BC deaths in the UK are in women aged 60 and over⁸.

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Table 1: Comparison between breast cancer cases in the KSA and the U.S.

present with localized disease in the U.S. and UK [8, 9, 11]. The decline in mortality in the US and UK can be attributed to several factors, including early detection by following health behaviours, utilizing breast cancer screening (BCS) and improvements in the use of systemic therapies [15]. However, this improvement in survival rates has not been observed in less developed countries due to other significant health care issues such as the absence of national breast cancer education and screening programs and poor breast health awareness [4].

Breast cancer education for woman is a routine occurrence in many western countries [4]. BC preventive programmes aim is to create breast health awareness through the promotion of education concerning selfchecks, customary medical check-ups and healthy lifestyles. Such education is vital since it gives women the information to detect early BC signs thus staying healthy. Consequently, reducing incidences of BC morbidity and mortality as well as the presentation of late stages tumours [4]. National screening exercises coupled with education that is focused on adoption of healthy lifestyles, adherence to BC screening, control of symptoms and rehabilitation are deemed effective [4, 15]. Conversely, these dimensions are rarely applied in KSA. Although there is an effort to develop full breast cancer detection guidelines for the KSA [10] including searches for information about patients' values and preferences and cost for screening and resources use specific to the Saudi context [10] information concerning self-breast checks or national screening are non-existent.

According to studies conducted in KSA, general BC risk factors such as sedentary lifestyle, age at menarche, duration of breast feeding, age at first pregnancy, number of children, history of oral contraceptive use, nulliparity, hormonal therapy, passive and active smoking and genetics could lead to the high rate of BC among Saudi women [1, 16-21]. The early marriage could be a potential risk factor for BC among Saudi BC cases. In Islamic countries including KSA, any sexual activity without marriage is illegal and basically prohibited [18]. While there is no specific age for marriage, either for male and female, the Saudi Ministry of Justice prohibited marriage for females under the age of 14 and set 15 years as a minimum age for brides in KSA [18].

In addition, higher fat mass and fat intake and increased oestrogen levels are significantly associated with Saudi BC cases [22-24]. Some biomedical changes that are consistent with an activated stress response possibly caused by obesity and type 2 diabetic mellitus also lead to a higher risk of developing BC among Saudi cases recently diagnosed with BC [25-26]. Poor health can be linked to lack of national BC education programs and screening in Eastern countries [2, 4]. The majority of the population in KSA reside in remote rural areas which are underdeveloped in terms of infrastructure including health facilities. Poor breast health awareness and culture and social barriers such as delays in seeking medical advice, lack of breast health knowledge and service provision may be blamed for the advanced stages of BC in KSA [3, 28-30]. This systematic review aimed to provide a comprehensive overview of breast health awareness in KSA and to explore the nature and extent of Saudi women's and HCPs (Health care providers) perspectives and experiences of breast health awareness. The evidence and information obtained from the selected studies was collected and analysed to emphasize the themes which most commonly occurred in the literature. There is no literature review can be found to provide a comprehensive overview regarding the nature and extent of Saudi women's and health care providers' perspective and experiences of breast health awareness and the early diagnosis of breast cancer. This paper identified gaps in the literature and highlights requiring empirical evidence.

MATERIALS AND METHODS

Search Strategy: A systematic search using breast cancer or breast health heading and index terms was conducted. Electronic data databases: MEDLINE, PubMed, CINAHL and the Web of Science were searched from inception of the database until February 2017. The key terms were developed with the assistance and a subject librarian and included: breast cancer, breast health awareness, breast self-examination, heath screening, health education, incidence, mammogram, attitude*, knowledge, practice*, perception, health care providers, physician*, doctor*, nurse*, primary care center*, Saudi Arabia, health promotion, health behaviour*, breast, mammary, breast cancer neoplasm, tumour*, tumor* cancer*, malignancy*, awareness, prevention and clinical breast examination. The search was focused on advanced searches using Boolean logic with the logical operators 'AND' and 'OR' [31]. Google scholar was also searched for grey literature. The reference list of all papers for relevant studies was also searched. Reflection has also been implemented in this review to assist the researcher to use reflexivity to reduce researcher/reviewer bias. All the articles selected for this review were examined with the help of CASP and MKPCT appraisal tools to ascertain the credibility, objectivity and significance of the studies considered in this review.

Inclusion and Exclusion Criteria: Studies were included if they were published in a peer reviewed journal, written in English and focused on Saudi women or health care providers, breast cancer and breast health awareness. Studies were excluded if it focused on other forms of cancer, treatment intervention studies; Systemic Anticancer therapy (SACT) or were conducted outside the Kingdom of Saudi Arabia (Table 2).

Search Outcome

Searching of the Databases Yielded 392 Papers (Fig. 1): The researcher screened the title, abstract and full papers. Articles were exported into Refworks and duplicates were removed. There were 234 articles remaining after duplicates were removed. The titles of the remaining papers were screened for relevance. Abstracts were read and a further 183 articles were excluded based on the World J. Nursing Sci., 3 (1): 18-32, 2017

Table 2: Exclusion and inclusion criteria



Adopted from PRISMA 2009 Flow Diagram (Moher et al., 2009).

exclusion criteria. The abstracts of the remaining articles were re-read and re- judged to identify 69 potentially relevant papers for which 57 full text articles were obtained and 56 informed the review. Sample sizes ranged from 33 [29] to 1697 participants [30]. 54 studies were quantitative and 2 were review papers while no qualitative studies meeting the eligibility criteria were found.

Quality Appraisal: Selected studies were scrutinised using the Critical Appraisal Skills Programme (CASP) and Milton Keynes Primary Care Trust (MKPCT) to draw conclusive evidence from the selected studies results [32, 33]. Focus was placed on CASP and MKPCT criteria for individual papers and then totalled to give each study a score based on the CASP and MKPCT check list for each study. All studies were included irrespective of their scores because they had been conducted in KSA, but some had low scores as they did not use valid questionnaires and many studies suffer from several limitations. The Supervisory team assisted the researcher to critically appraise the relevant papers and resolve any difficulties or areas of ambiguity. The evidence and information obtained from these studies were analysed using the thematic framework [34].

Fig. 1: Flow diagram of the literature search

Data Abstraction and Synthesis: Data were extracted based on the aim of the review, search strategies, settings, participants and inclusion and exclusion criteria. Due to heterogeneity of measurement it was not possible to conduct a meta-analysis. Quantitative empirical study and review papers were synthesised according to the key themes which emerged from the literature search [34, 35].

RESULTS

Two overarching themes were identified, the first articulating Saudi women's experiences and perspectives of experiences with breast health awareness and BC early detection methods in KSA. Subthemes include: i) lack of knowledge and ii) barriers to performing breast cancer screening. The second overarching theme relates to the experiences of HCPs'. The findings are limited as knowledge and empirical study related to this topic is minimal.

Experiences and Perspectives of Breast Health Awareness and Breast Cancer Early Detection Methods among Saudi Population: Studies assessed women's knowledge and attitudes toward BC, its risk factors and its early detection methods (BSE, clinical breast examination and mammograms). Studies included cross sectional studies (n=42), quasi-experimental studies (n=4) and intervention study (n=1) with participant numbers ranging from 33 to 1697 in addition to two review studies. They include mainly affluent regions where education is of a high standard. Only two rural regions were included in four studies thus, we knew very little about rural experiences and perspectives. Poor breast health awareness cuts across different settings and groups in the KSA. For example, medical and nursing students [29, 36-42] university students [30, 43-47] secondary and high school students [48-50] and female teachers and works at school [51-53] as well as in public occupations [54-81] in addition to review studies [3, 28]. Subthemes are now discussed:

Lack of Knowledge: This literature review uncovers low breast health awareness among Saudi nationals, irrespective of their demographic characteristics across the KSA [36, 46, 48, 51, 55]. Ravichandran *et al.* [74] mentioned a Saudi public survey (n= 1407) which reported that around 86% of participants denied knowledge of cancer warning signals while 27% believed that cancer means imminent death. Although 80% believed that some cancer can be cured if detected early, the majority (74%) believed cancer would appear overnight. The practice of BCS is very low among Saudi women who often do not realize the importance of BSE and clinical breast examination and mammograms due to a knowledge deficit related to this topic and lack of national breast cancer screening programmes [27, 30, 37, 39, 40, 44, 50, 54, 59, 60, 65, 69, 73, 78, 79]. Several survey studies highlighted an absence of national BCS programs and standard health information and a lack of health education in relation to the signs, symptoms and risks of BC as well as its early detection methods among Saudi societies [39, 42, 51, 52, 68, 70, 72, 75]. Thus, the practice of BCS is low among Saudi women [59, 72] and decreases with increased age [54]. There is lack of awareness of BC and its symptoms [58, 74]. In one study, 70% of participants had information about BC symptoms and mammograms, but only 40.5% were aware that a breast mass is a symptom of BC [63]. Many women were unable to identify BC symptoms such as abnormal growth [65]. Many had never heard of BSE [78] while others believed that the frequency for performing a BSE was biannual when this is encouraged on a monthly basis [46]. Few women had heard about mammography as an early detection method [59, 72]. Nemenqani et al.'s survey [39] reported that although many women recognized the potential health benefits of BSE, only 17% practiced BSE monthly. Many women performed BSE incorrectly [44, 46]. However, some Saudi women were keen to receive information about their breast health and breast health awareness programs seem to have a positive impact on women's health behaviour [27, 40, 44, 42]. They also express high interest in genetic testing for BC risk despite their poor awareness [71].

Barriers to Performing Breast Cancer Screening: Very little is known about barriers to performing BCS in KSA but they include: fear of finding an abnormality; embarrassment or modesty; a lack of assurance about BSE; lack of knowledge, time, motivation and privacy; falling to see the need; forgetfulness and absence of symptoms [27, 29, 46, 55, 65]. In one study 92.3% of Saudi women believed they needed a physician's recommendation to practice and perform BCS. That said, 78% believed that health education programmes should be conducted in existing PHCCs and clinics [72]. Poor breast health awareness coupled physicians feeling uncomfortable about carrying out BCS in KSA has resulted in reduced breast examinations for women [46, 82]. Moreover, HCPs may also not be fully informed on the correct way to proceed when carrying out BCS, heightening their unease [83, 84]. Women report fear and a lack of knowledge about mammograms and the risk they impose. This may make HCPs even less likely to encourage women to partake in BCS [82-85]. AbdelHadi's medical review study [76] found that many Saudi women with BC postponed seeking medical advice because of inherited misconceptions which tend to override knowledge. While many women were willing to seek medical advices if they had breast lump [79]. So, they linked seeking medical advices with having BC symptoms. BC in KSA may be a stigmatised and many people do not name it explicitly for fear of catching the disease or it affecting a member of one's family. Thus, Saudi women with BC continue to present at an advanced stage of the disease [76-79].

Health Care Providers' Experiences and Perspectives of **Experiences with Breast Health Awareness and BC Early** Detection Methods in KSA: There are few studies which assess knowledge level among HCP's in primary health care centres (PHCCs) and their experience with women regarding BC in KSA. Only four survey studies conducted in the KSA have investigated physicians' experiences and attitudes toward breast health education and examination of breasts in hospital [82] or PHCCs [83-85]. None of these studies investigated the experiences of nurses or other health care providers. Another three surveys assessed the level of knowledge of BC, its risk factors and early detection methods among HCPs and reported that the level of breast health awareness was low among HCPs and only few of them performed BSE monthly [86-88]. The participant numbers ranged from 75 to 490 and they included mainly affluent regions. The results of these studies showed that physicians are unlikely to perform clinical breast examination, prescribe mammography, or view health education as part of their role, either in hospital or in PHCC settings [82-85]. The results also illuminate reasons which prevent HCPs discussing breast health with Saudi women: although many physicians believe that BC is a critical health concern in the KSA [84] many do not view health promotion and education as an essential part of the HCPs' role [82, 86]. In addition, their lack of interest alongside social and cultural barriers prevents open discussion of their role in BCS [84, 85]. Only one survey was conducted in KSA to explore the potential role of nurses in providing breast cancer awareness [86]. Al Darweesh's survey [86] reported that although nurses had a key role in developing breast cancer awareness programme, their limited knowledge did deter them from delivering breast health education. Interestingly, many

physicians working in Saudi are not from Saudi. Even if they have previously carried out BCS outside KSA they are often reluctant to carry out this role when in Saudi, perhaps because of a belief or knowledge that Saudi women would be embarrassed. Stereotyping of Saudi women prevents further discussions [82]. Saeedi et al. 's survey [84] found that although the majority of physicians working in PHCCs were aware of the importance of mammography as a BC screening method, few requested a mammogram as a screening tool for women ≥40-years-old. Physicians are reluctant to incorporate mammograms and clinical breast examination and provide breast health education to their practices within KSA [84]. They attribute this to several reasons including: lack of guidelines and recommendations for BCS; embarrassment; fear of the women's response; refusal because there are no guidelines regarding examination of the breast; time pressures; lack of training and facilities; poor communication skills and a lack of cooperation and trust from women [82-85].

DISCUSSION

This literature review demonstrated that breast health awareness is poor in KSA while the incidence of BC among Saudi women has increased over the time [2, 55, 56]. All studies had been conducted in KSA reiterated, the lack national breast cancer screening programs in KSA and the lack of breast health awareness among Saudi population. A variety of reasons contribute to this including lack of knowledge and motivation [59, 72] ignorance [82] and emotional reactions such as fear, discomfort or embarrassment when discussing topics related to the breast [52, 65, 68, 79]. People within KSA irrespective of their demographic characteristics find it challenging to talk about BC due to a lack of knowledge coupled with a fear of discussing a subject that may cause upset and distress [52, 65, 68, 77]. Studies conducted within Arab populations illuminate differing perspectives related to the concept of being healthy compared to people from Western society. Some Arab women including Saudi women irrespective of their educational level do not perform BSE, postpone seeking professional care for breast issues, use self-prescribed medications and home/herbal treatments and may not use preventive and educational service due to gendered socio-cultural roles, obligations, health beliefs, geographical familial inaccessibility to health centres and financial affordability [76, 89, 90]. Therefore, academic education alone is not enough to ensure that recommended health behaviour will be adopted [81]. A lack of knowledge, motivation and the inaccessibility of health services may contribute to poor health awareness [72]. BC cases continue to present at an advanced stage of disease [76, 79].Indeed, the referral process within health system in KSA is quite long [76, 91] and the quality of BC care might be below the acceptable international standards due to lack of facilities on site and the absence of local guidelines [92]. Saudi BC patients might experience more pain and suffering and experience deterioration in their health before they reach a cancer centre and access appropriate health care services [76, 92] and morbidity and mortality rates are high [3].

Globally, emotional discomfort such as fear, anxiety and embarrassment may prevent women performing or undergoing BCS [89, 90& 93]. Worldwide, women may not fully understand BCS and understanding and attitudes toward BC are variable and often inaccurate [94]. There is a conflict about the advantage of routine BCS, some women believing this may do more harm than good by exposing women to unnecessary concerns and medical investigations [95]. Similar to some women in countries such as the UK [96] and Australia [97] Saudi women may view themselves at low risk of BC and voice uncertainty and doubt over breast health awareness and appraising non-lump BC symptoms. Across the globe women have similar uncertainties but in KSA there is a dearth of services to address these problems. Most work conducted in the West demonstrates that many women are well informed about BC signs and symptoms, it risk factors and early detection methods. There are programmes to support early detection methods of BC [98] and campaigns to help women and improve their breast health awareness [52]. Work conducted in KSA highlights a lack of knowledge about BC, its risk factors and early detection methods [39, 47, 68& 75]. Tu et al. [99] assessed the practice level of BSE among women in the U.S. and found that 75% of participants (n=27241) conducted BSE. In contrast, Jahan et al. [78] assessed the practice level of BSE among women in the in KSA and found approximately 70% of participants (n=300) had never heard of BSE. This study highlighted that only 18.7% practiced BSE and many did this irregularly even though all women included in this study had achieved a good level of education. Clinical breast examination and mammogram are globally recommended for women over 50 years of age [100]. However, El-Bcheraoui et al. 's survey [61] examined the practice of BCS among Saudi women (n=1135) aged \geq 50 years and reported that about 89% of participants had not had clinical breast examination in the past year and 92% had never had a mammogram.

In KSA, women may not seek medical advice if they have no symptoms [29, 72]. Some women have misconceptions about mammograms [29, 59, 81]. For example, some women believe that there is no need to have a mammogram if a BSE has been performed, while many believe mammograms cause BC [29]. The evidence reviewed suggests there is a lack of trust between women and HCPs within KSA regarding knowledge and performance of BCS in women where there are no symptoms. Poor communication skills and training hinders the development of trusting relations between the HCPs and women in clinical environments [83, 85].

Saudi women need to know about BC, early detection methods and related significance to health. HCPs should be actively engaged in providing breast health education and performing BCS for women. This could be achieved if HCPs were to receive adequate education and training courses and recognize public health promotion and education as crucial aspects of their professional work. It is vital that Saudi women learn and understand how to care for their breasts and cultural barriers have to be overcome if the provision of better health information and motivation towards breast care is initiated. This could help women to realize the importance of BCS and change their concept of being healthy and lead them to prioritize their health and to adopt a healthy lifestyle. This cannot be achieved if HCPs themselves do not realize the importance of engaging actively in this public health agenda and addressing the barriers for BCS as a public health imperative. Strategies targeting the promotion of screening of BC should therefore focus on the groups that are most at risk. Additionally, the strategies should be part of national comprehensive policies that ascertain accessibility and applicability.

Search strategies would have under-represented non-English language studies and authors cannot be certain that they identified all relevant and all unpublished studies. The results of included studies that have been conducted in KSA must be viewed in light of the studies' limitations. All studies are quantitative in nature and a key limitation is that no study used valid questionnaires. It is not possible to evaluate the validity and generalizability of these studies due to limited information concerning inclusion and exclusion criteria, sampling procedures, power calculations, psychometric tests and the validity and reliability of the questionnaire's content. Therefore, validity and generalisability of these studies are poor.

CONCLUSIONS

The main objective of BC preventive programmes was to promote breast health awareness through the promotion of education on self-checks, customary regular medical check-ups and healthy lifestyles. In KSA, HCPs offer little health information either verbal or written to women and do not prescribe any form of standardized screening breast health awareness programs or educational programs in relation to BC risks, signs and symptoms. The dearth of qualitative evidence related to breast cancer may confirm that breast cancer is a taboo subject in KSA, not easily discussed. Qualitative research is required to explore experiences and understand the totality of the illness experiences of BC and its early detection methods within primary care which is the first point of contact for women. This will help to inform policy and practice to word suitable and applicable screening and education breast programs for all Saudi women and to alleviate physical and psychological pain resulting from a late breast cancer diagnosis. Policy changes are required to improve the overall breast health screening and education of HCPs.

Abbreviations: BC: breast cancer; BCS: breast cancer screening; CASP: Critical Appraisal Skills Programme; HCPs: health care providers; KSA: Kingdom of Saudi Arabia; PHCCs: primary health care centres; SCR: Saudi Cancer Registry; UK: United Kingdom; U.S. United States.

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Complains with Ethical Standards:

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