

Research Article

Breast cancer awareness among Indonesian women at moderate-to-high risk

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Abstract

In this descriptive cross-sectional study, we examined awareness of breast cancer among Indonesian women at moderate-to-high-risk of developing breast cancer. Data were obtained from 87 eligible participants using the Modified Breast Cancer Awareness Measure. The International Breast Cancer Intervention Study model was used to identify women at moderate-to-high risk of developing breast cancer. The data were analyzed using descriptive statistics. The results showed that none of the participants had knowledge of age-related risk (0%). Other domains that indicated low awareness were knowledge of lifetime risk (31%), followed by knowledge of risk factors, in particular the item regarding menstruation at an early age (12.6%). These results indicated that increasing awareness of breast cancer risks is highly needed, in particular among women at moderate-to-high risk of developing breast cancer in Indonesia.

Key words

breast cancer, high risk, Indonesia, moderate risk, risk factor.

INTRODUCTION

Breast cancer is the most common cancer and cause of cancer-related deaths among women, accounting for 1.67 million (25.2%) new cases and 521,907 (14.7%) deaths worldwide (Ferlay *et al.*, 2015). Similarly, in Indonesia, breast cancer has become a great burden. It accounts for 30.5% of all cancers diagnosed and 21.5% of cancer-related deaths among females (Ferlay *et al.*, 2013). Moreover, breast cancer in Indonesia is mostly diagnosed in the advanced stages of the cancer (Ng *et al.*, 2011; Rahmatya *et al.*, 2015), with increasing rates of mortality (Ministry of Health Republic of Indonesia, 2015b).

Delayed presentation among women with breast cancer has resulted in increased mortality, poor prognoses, and decreased survival rates, which can be associated to low awareness of breast cancer, as well as non-adherence to recommended screening (Stapleton *et al.*, 2011; Iskandarsyah, 2013; McIntosh, 2015). However, in general, a high awareness of cancer has been reported to play a significant role in promoting and increasing cancer-prevention practice (Wakimizu *et al.*, 2015). As the greatest benefit from cancer prevention comes from the management of women who are at increased risk of this disease, addressing this issue among at-risk women is important (Linsell *et al.*, 2010; Cadiz *et al.*, 2013). In particular, women with a family history of breast cancer, who are at a moderate-to-high risk of developing breast cancer, have a 15% or more lifetime risk of developing breast cancer (American Cancer Society, 2014).

However, evidence from previous studies regarding breast cancer awareness has indicated that the majority of women at increased risk of developing breast cancer have a lack of awareness regarding breast cancer (Linsell *et al.*, 2008; Subramanian *et al.*, 2013). Given the high number of Indonesian women diagnosed in the advanced stages of breast cancer, to date, little evidence has been found regarding the status of breast cancer awareness within the context of Indonesia, in particular among women at moderate-to-high risk of developing breast cancer. Therefore, an understanding of this situation in Indonesia is needed.

LITERATURE REVIEW

Breast cancer awareness is viewed as knowledge on various aspects of breast cancer, as well as confidence and skills in detecting a breast change (Linsell *et al.*, 2008; Forbes *et al.*, 2010). In accordance with the literature, knowledge regarding breast cancer consisted of: (i) breast cancer symptoms, which included 11 lump and non-lump symptoms; (ii) age-related risk; (iii) lifetime risk; and (iv) risk factors. The confidence and skills to detect a breast change consisted of: (i) the frequency of breast checking, done at least every month, which involved looking at and feeling the breasts to identify or interpret what was normal or abnormal; and (ii) the confidence to notice any changes in the breasts.

A number of previously-published studies on breast cancer awareness have been conducted. A low proportion of women reported being aware of five or more of the non-lump symptoms of breast cancer, the frequency of breast checking, risk factors, lifetime risk, and age-related risk (Forbes *et al.*, 2010; Subramanian *et al.*, 2013; Nurleli *et al.*, 2014). However, limited evidence has been found regarding breast cancer awareness

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among women at a moderate-to-high risk of developing breast cancer, in particular in Indonesia, where most breast cancer patients present in the late stages of cancer.

STUDY AIMS

The aims of this study were to describe the knowledge of breast cancer symptoms, age-related risk, lifetime risk, and risk factors, as well as the frequency of breast checking and the confidence to detect a breast change among Indonesian women at moderate-to-high risk of developing breast cancer. The results are part of a main study examining breast cancer awareness and adherence to the screening program among Indonesian women at moderate-to-high risk.

METHODS

Design

A descriptive, cross-sectional study was employed to examine breast cancer awareness among Indonesian women at moderate-to-high risk of developing breast cancer. The cross-sectional design was suitable, as it involved the analysis of data collected from a population or a representative subset at one specific point in time (Polit & Beck, 2012).

Setting

This study was conducted at the oncology clinic, chemotherapy unit, and at three general inpatient wards of Dharmais Hospital National Cancer Center, Jakarta, Indonesia, from February to March 2016. This hospital serves as a top referral cancer hospital, as well as a major research and education facility for medical doctors and nurses in Indonesia.

Participants

The participants were first-degree relatives (mother, sister, or daughter) of breast cancer patients recruited from the study hospital using the purposive sampling technique. The inclusion criteria were: (i) first-degree relative of a breast cancer patient; (ii) aged ≥ 40 years; (iii) available and willing to be interviewed face to face or by telephone; (iv) not diagnosed with breast cancer; (v) at moderate-to-high risk of developing breast cancer determined by having a 15% or more lifetime risk of developing breast cancer based on the International Breast Cancer Intervention Study (IBIS) Breast Cancer Risk Evaluation Tool; (vi) able to speak Indonesian; and (vii) willing to participate in the study.

The sample size was estimated and calculated using power analysis. The effect size was 0.31, as determined from a previous study (Subramanian *et al.*, 2013). The sample size was 85, the significant criterion was 0.05, and the power was equal to 0.80. In accordance with Subramanian *et al.* (2013), to allow for a 5% attrition rate, 90 eligible women were recruited to this study. However, three participants were excluded due to not completing the interview. Finally, 87 eligible Indonesian women participants were included in the study.

Ethical considerations

This study was granted ethical committee review and approval from both the Nursing Faculty Ethics Committee, Prince of Songkla University, Hat Yai, Thailand (approval no. MOE 0521.1.05/3312) and the committee of Medical Research Ethics of the Dharmais Hospital National Cancer Center, Jakarta, Indonesia (approval no. KEPK/005/I/2016). Permission to access the breast cancer patients and participants was granted from the Director of Dharmais Hospital National Cancer Center, Indonesia (approval no. LB.02.01/1/318/2016). Informed consent was received from each breast cancer patient and her first-degree relative following the standard informed consent procedure, and the principles of respect for autonomy, anonymity, confidentiality, and privacy of the participants were adhered to. The participants were treated with respect, and were informed of their right to freely decide to participate in the study, and if so, their right to withdraw any time without penalty (Robley, 1995; Orb *et al.*, 2001).

Data collection

Data collection was sequentially conducted. The head and staff nurses were informed of the study by the researcher, and the breast cancer patients were then identified from the medical records in each setting. Next, each breast cancer patient was approached and asked for permission to introduce her first-degree relatives to participate in this study. After that, the recruitment process commenced by contacting and asking each first-degree relative to participate in the study. At the time of the appointment, the potential participants were assessed for their eligibility to participate in the study. Finally, the researcher started collecting the data by interviewing each eligible participant either face to face or via telephone.

The structured questionnaire used for data collection consisted of three parts: (i) the IBIS Breast Cancer Risk Evaluation Tool version 7.02 (Cuzick *et al.*, 2013); (ii) the Personal Characteristics and Health-Related Questionnaire; and (iii) the Modified Breast Cancer Awareness Measure (Modified Breast-CAM). The original version of the Breast-CAM was developed by Cancer Research UK, Kings College London, and University College London, and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer in 2009 in the UK (Cancer Research UK, 2009). In this study, the Breast-CAM was modified and translated into Indonesian. Permission was given to use the Breast-CAM and IBIS Breast Cancer Risk Evaluation Tool version 7.02. The validity of each questionnaire was approved by three experts from Prince of Songkla University. The internal consistency reliability of the Modified Breast-CAM was 0.78. According to Lance *et al.* (2006), this result was acceptably reliable.

Data analysis

Data obtained from the study results were entered, recoded, cross-checked, and analyzed using SPSS for Windows (version 20.0; IBM Corp., Armonk, NY, USA) for descriptive statistics, including frequency, percentage, mean, and standard deviation (SD).

RESULTS

Demographic characteristics of the study population and risks of breast cancer

The mean age of the participants was 48.74 years (SD = 5.87). Most of the participants were married (87.4%), lived in an urban area (74.7%), were homemakers (59.8%), and came from diverse ethnic groups. There was a relatively high number of Javanese participants (34.5%). Nearly half of the participants had completed college or university study (43.7%). Most had health insurance (72.4%), with a medium family income (50.6%). More than half of the participants had received information on breast self-examination (BSE) (64.4%) and breast cancer symptoms (58.6%). However, less than half had received information on breast cancer risk (46%). In this study, the healthcare provider was the major source of information (41.2%), followed by the Internet and media (32.9%), and family members (17.7%). The mean lifetime risk of breast cancer based on the IBIS model of the participants was 22.14% (SD = 6.18). Based on risk classification, 52.9% of the participants were at high risk, while 47.1% were at moderate risk of developing breast cancer.

Knowledge of breast cancer symptoms

More than half of the participants (52.9%) correctly identified at least five non-lump symptoms (Table 1). An additional data analysis of each symptom was done to identify the proportion

Table 1. Breast cancer awareness based on the response of each item among Indonesian women at moderate-to-high risk ($n = 87$)

Variable	N	%
Knowledge of symptoms		
>5 non-lump symptoms [†]	46	52.9
1–4 non-lump symptoms	20	23.0
Do not know	21	24.1
Frequency of breast checking		
At least once a week or once a month [†]	49	56.3
At least once every 6 months	3	3.4
Rarely or never	35	40.2
Confidence to detect a breast change		
Fairly-to-very confident [†]	53	60.9
Slightly-to-not at all confident	31	35.6
Do not know	3	3.4
Knowledge of age-related risk		
A 70 year old woman [†]	0	0
A 30 year old woman	27	31.0
A 50 year old woman	15	17.2
A women at any age	43	49.4
Do not know	2	2.3
Knowledge of lifetime risk		
1 in 8 women [†]	27	31.0
1 in 3 women	10	11.5
1 in 100 women	26	29.9
1 in 1000 women	9	10.3
Do not know	15	17.2

[†]Aware of breast cancer.

of participants who could recognize each potential breast cancer symptom (Table 2).

Knowledge of each potential breast cancer symptom

The majority of participants recognized a lump in the breast (74.7%) or a discharge from the nipple (62.1%) as a potential symptom of breast cancer (Table 2). However, less than half recognized a lump under the armpit (43.7%), change in nipple position (43.7%), nipple rash (42.5%), redness of breast skin (41.4%), or puckering of breast skin (39.1%) as potential symptoms of breast cancer.

Frequency of breast checking and confidence to detect a breast change

More than half of the participants (56.3%) checked their breast at least once a week or once a month, but almost half (40.2%) rarely or never checked their breasts. In addition, nearly two-thirds reported being fairly-to-very confident in their ability to detect a breast change (60.9%), whereas 35.6% were slightly to not at all confident in their ability to detect a breast change (Table 1).

Knowledge of age-related and lifetime risks

None of the participants correctly identified “a 70 year old woman” as an age-related risk or most likely to get breast cancer (0%). Almost half identified “a woman at any age” as most likely to get breast cancer (49.4%). In addition, only 31% of participants correctly identified that “one in eight women” will develop breast cancer in her lifetime (Table 1).

Knowledge of risk factors

The participants were considered to have knowledge of risk factors in developing breast cancer if they answered “strongly agree” or “agree”. The data analysis was done for each item individually, as displayed in Table 3.

Approximately two-thirds answered “strongly agree” or “agree” for having certain benign breast disease (65.5%) and having a past history of breast cancer (64.4%) as risk factors

Table 2. Indonesian women at moderate-to-high risk who were aware of each potential breast cancer symptom ($n = 87$)

Variable	N	%
Change in nipple position	38	43.7
Pulling in of nipple	44	50.6
Pain in one of the breasts or in armpit	46	52.9
Puckering or dimpling of breast skin	34	39.1
Discharge or bleeding from nipple	54	62.1
A lump on or thickening in the breast	65	74.7
Nipple rash	37	42.5
Redness of breast skin	36	41.4
A lump or thickening under an armpit	38	43.7
Change in the shape of the breast or nipple	46	52.9
Change in the size of the breast or nipple	49	56.3

Table 3. Indonesian women at moderate-to-high risk who were aware of breast cancer risk factors ($n = 87$)

Variable	N	%
Past history of breast cancer	56	64.4
Certain benign breast disease	57	65.5
An exogenous hormone	35	40.2
Drinking alcohol	41	47.1
Being overweight	22	25.3
Having a close relative with breast cancer	45	51.7
Having children later on in life or not at all	32	36.8
Menstruating at an early age	11	12.6
Late menopause	16	18.4
Low level of moderate physical activity	30	34.5

for developing breast cancer (Table 3). More than half of the participants were aware that having a close relative with breast cancer was an increased risk factor for breast cancer (51.7%), whereas only one-quarter of participants (25.3%) answered “strongly agree” or “agree” that being overweight was a risk factor for breast cancer. Furthermore, only 18.4% and 12.6% of participants strongly agreed or agreed that late menopause and menstruating at an early age were risk factors for breast cancer, respectively.

DISCUSSION

Knowledge of breast cancer symptoms, frequency of breast checking, and confidence to detect a breast change

The majority of Indonesian women participants in this study were aware of five or more of the non-lump symptoms of breast cancer (52.9%), whereas only 18% and 5% of the participants in previous UK and Indonesian studies were aware, respectively (Forbes *et al.*, 2010; Nurleli *et al.*, 2014). Similarly, previous studies conducted among adult Iranian women and Chinese women revealed that women with a family history of breast cancer were more likely to have greater awareness of breast cancer warning signs and symptoms (Tazhibi & Feizi, 2014), as well as a general awareness of breast cancer (Liu *et al.*, 2014).

More than half (56.3%) of the Indonesian women in this study were aware that they needed to check their breasts at least once a week or once a month. Similarly, a previous study conducted among Indonesian women at risk of developing breast cancer reported that 52.3% of women had a BSE every month (Desanti *et al.*, 2010), whereas a study conducted among Indonesian breast cancer patients revealed that only 21.2% had a BSE (Nurleli *et al.*, 2014).

Being fairly-to-very confident in detecting a breast change in the majority of Indonesian women participants in this study was consistent with previous studies (Linsell *et al.*, 2008; Forbes *et al.*, 2010). Being fairly-to-very confident in detecting a breast change could be because the majority of women were aware of breast cancer symptoms and the frequency of BSE. Increased knowledge enhanced their perception of the benefits of breast checking, which in turn improved BSE and strengthened their confidence to detect a breast change (Karayurt *et al.*, 2009).

Because the Indonesian women participants in this study were the first-degree relatives of breast cancer patients, raising awareness of breast cancer symptoms, the frequency of breast checking, and the confidence to detect a breast change were probably derived from their first-hand experience of encountering or taking care of family members with breast cancer. As mentioned previously, healthcare providers and family members were reported by the participants in this study as the two major sources of information, which is in agreement with a previous study (Wakimizu *et al.*, 2015). As seen, the majority of the participants in this study received information regarding breast cancer symptoms and BSE.

In the Indonesian hospital context, family members are generally involved, and they assist in sharing information about health education with the patients (Effendy *et al.*, 2015). The traditional role of being the main care provider for family members who are unwell is often the responsibility of Indonesian women (Do-Le & Raharjo, 2002). In addition, the majority of the Indonesian participants in this study had senior high school and college or university levels of education (75.9%). According to Linsell *et al.* (2008) and Liu *et al.* (2014), women with a higher level of education are more likely to have breast cancer awareness.

Discussing the breast cancer care situation of a first-degree relative diagnosed with breast cancer with healthcare providers could increase awareness of breast cancer symptoms, the frequency of breast checking, and the confidence to detect a breast change in the majority of the Indonesian participants in this study, who also had a high level of education.

Knowledge of age-related risk, lifetime risk, and risk factors

The results of this study revealed that all of the Indonesian women participants lacked awareness of the age-related risk of developing breast cancer. Likewise, previous studies revealed that most of the women participants were not aware that women at an older age have a greater risk of developing breast cancer (Moser *et al.*, 2007; Nurleli *et al.*, 2014).

Similar to a study conducted by McMenamin *et al.* (2005), only one-third of the participants in this study were aware of the lifetime risk. Consistent with previous studies, women were overly optimistic regarding a woman's lifetime risk of developing breast cancer, with the majority believing that the risks were less than 1 in 100 (Grunfeld *et al.*, 2002; Linsell *et al.*, 2008).

The Indonesian women participants were mostly aware that having a certain benign breast disease, a past history of breast cancer, and a close relative with breast cancer were risks for developing breast cancer. Similarly, previous studies revealed that the majority of women with a family history of breast cancer reported family history as a risk factor for developing breast cancer (Al-Dubai *et al.*, 2011; Subramanian *et al.*, 2013; Tazhibi & Feizi, 2014). Direct experience with breast cancer care of a first-degree relative diagnosed with breast cancer, as discussed previously, could be vital for raising their awareness of risk factors. However, awareness of other lifestyle, reproductive, and hormonal-related risk factors, in particular menstruating at an early age and late menopause, were still low in this study.

Currently, information regarding age-related risk, lifetime risk, and the overall risk factors for developing breast cancer is not included in the general breast cancer prevention education program provided by healthcare providers, particularly in the primary healthcare context (Bustan, 2007; Ministry of Health Republic of Indonesia, 2015a). As mentioned previously, less than half of the Indonesian women participants in this study received information regarding breast cancer risks. Furthermore, the media and television broadcasts in Indonesia frequently present unhealthy lifestyles and foods as causes of breast cancer in young women, but knowledge of age-related risk, lifetime risk, and the overall risk factors are not included. Therefore, knowledge of age-related risk, lifetime risk, and the overall risk factors for developing breast cancer might not be common for Indonesian women.

Limitations of the study

This study used the IBIS Breast Cancer Risk Evaluation Tool, which was developed for a Western context, and there are no published data of its use in the Indonesian context. Therefore, some items were not feasible for Indonesian women, including items of genetic testing and the country rate, as the age-standardized incidence of breast cancer in Indonesia is lower than that of Western countries. This raises the question of the sensitivity of implementing this tool in the Indonesian context. In this study, however, according to the opinion of a breast cancer surgeon specialist, this tool could still be used without providing genetic testing information since genetic testing is not commonly used in countries other than Western countries, and Indonesia is no exception.

CONCLUSION

In particular, this study highlights the low awareness with regard to age-related risk and certain reproductive, hormonal, and lifestyle risk factors, as well as the lifetime risk of developing breast cancer. As the ultimate goal was to disseminate and utilize the study findings to raise awareness of breast cancer, the following implications and recommendations are drawn for nursing practice and future nursing research in the field of breast cancer care that is focused on breast cancer awareness.

First, raising breast cancer awareness among women with a family history, who are at a moderate-to-high risk of developing breast cancer, is important. In particular, awareness of age-related risk, lifetime risk, and the risk factors for developing breast cancer should be emphasized in the national breast cancer education and prevention program. Furthermore, family members should be involved in the education sessions. Individual counselling by healthcare providers, in particular, primary healthcare providers, is also beneficial for women with a family history of breast cancer. In addition, improving media content and increasing the number of sources for breast cancer education are needed so that Indonesian women have easy access to information on breast cancer awareness.

Second, an intervention study should be conducted to develop an effective strategy or program to promote breast cancer awareness, in particular, among women with a family

history, who are at a moderate-to-high risk of developing breast cancer.

Lastly, the interval or ratio scale of measurement for breast cancer awareness should be considered for application in future studies to evaluate the intervention. In addition, reliability testing of the IBIS Breast Cancer Risk Evaluation Tool for application among the Asian population should be examined further.

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CONTRIBUTIONS

Study Design: APM, KM, HS

Data Collection and analysis: APM, KM, HS

Manuscript Writing: APM, KM, HS

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