



**Breast Cancer Awareness and Adherence to Screening Program
among Indonesian Women at Moderate to High Risk**

Aira Putri Mardela

**A Thesis Submitted in Partial Fulfillment of the Requirements for the
Degree of Master of Nursing Science (International Program)**

Prince of Songkla University

2016

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Thesis Title Breast Cancer Awareness and Adherence to Screening Program among Indonesian Women at Moderate to High Risk

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Author	Miss Aira Putri Mardela
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ABSTRACT

Raising the awareness of breast cancer plays a vital role for the success of screening program to reduce the mortality of breast cancer. This descriptive correlational study was conducted to describe the awareness regarding breast cancer, adherence to screening program, and to determine the relationship between these two variables among Indonesian women at moderate to high risk of developing breast cancer.

The data were obtained from 87 eligible first-degree relatives of breast cancer patients at Dharmais Hospital National Cancer Center, Jakarta, Indonesia, from February to March, 2016. Breast cancer awareness was measured using the Modified Breast Cancer Awareness Measure (Modified Breast-CAM) and the adherence to screening program was measured using the Modified Personal History and Screening Questionnaire (Modified PHSQ). The International Breast Cancer Intervention Study (IBIS) model was used to identify the women at moderate to high risk of developing breast cancer. The reliabilities of the Modified Breast-CAM and the Modified PHSQ were .78 and .86, respectively. The data analysis was done using descriptive statistics and Fisher exact test for hypothesis testing.

The highest awareness was regarding knowledge of screening program for the item about breast self-examination (BSE) frequency (75.8%). Other domains that indicated high awareness were knowledge of risk factors for the item about having certain benign breast disease (65.5%), followed by confidence to detect a breast change (60.9%), frequency of breast checking (56.3%), perceived heightened risk (55.2%), and knowledge of symptoms (52.9%).

The lowest awareness was regarding knowledge of age-related risk (0%). Other domains that indicated low awareness were knowledge of lifetime risk (31%), followed by knowledge of screening program for the item about mammography frequency (12.9%), and knowledge of risk factors for the item about starting the periods at an early age (12.6%).

A significant lack of adherence to screening program was concluded. The adherence rates to clinical breast-examination (CBE) and mammography screening were 4.6 percent and 3.4 percent, respectively. Having no appearance of symptoms (36.5%), not having enough time (19%), and fear (17.5%) were the common reasons for not having a CBE and mammography screening.

Overall, there were no significant relationships between breast cancer awareness and the adherence to a CBE and mammography screening. An association was found between the awareness regarding knowledge of risk factors for the item about having children later on in life or not at all and the adherence to CBE screening ($p = .02$). Other associations were found between the knowledge of screening program for the item about age of first BSE and the adherence to a CBE ($p = .01$) and mammography screening ($p = .03$). The discrepancies found in this study raised the concern that awareness alone might not be enough to increase adherence to screening program.

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CONTENTS

	Page
ABSTRACT.....	v
ACKNOWLEDGEMENTS.....	vii
CONTENTS.....	viii
LIST OF TABLES.....	xiii
LIST OF FIGURES.....	xvi
CHAPTERS	
1. INTRODUCTION.....	1
Background and Significance of the Problem	1
Objectives of the Study	4
Research Questions.....	5
Conceptual Framework of the Study.....	5
Research Hypothesis.....	10
Definition of Terms.....	10
Scope of the Study.....	11
Significance of the Study.....	12
2. LITERATURE REVIEW.....	13
Introduction.....	14
An Overview of Breast Cancer.....	14
Breast Cancer in Indonesia.....	18
An Overview of Breast Cancer Screening.....	19
Breast Cancer Screening in Indonesia	25

CONTENTS (Continued)

	Page
Women at Moderate to High Risk of Developing Breast Cancer.....	31
An Overview of Breast Cancer Risks.....	31
Breast Cancer Risks Assessment.....	33
Breast Cancer Awareness.....	38
Concept of Breast Cancer Awareness.....	38
Factors Contributing to Breast Cancer Awareness.....	47
Measurement of Breast Cancer Awareness.....	48
Adherence to Breast Cancer Screening Program.....	50
Concept of Adherence to Breast Cancer Screening Program.....	51
Factors Contributing to Adherence to Breast Cancer Screening Program.....	53
Measurement of Adherence to Breast Cancer Screening Program.....	56
Relationship between Breast Cancer Awareness and Adherence to Screening Program.....	58
Summary of the Literature Review.....	58
3. RESEARCH METHODOLOGY.....	60
Research Design.....	60
Setting.....	60
Population and Samples.....	61
Population.....	61

CONTENTS (Continued)

	Page
Samples and Sampling Procedure.....	61
Sample Size.....	62
Instrumentations.....	62
Translation of the Research Instruments.....	71
Validity and Reliability of the Research Instruments.....	72
Validity of the Research Instruments.....	72
Reliability of the Research Instruments.....	72
Data Collection Procedure.....	73
Ethical Considerations.....	74
Data Analysis.....	77
4. RESULTS AND DISCUSSIONS.....	78
Results.....	78
Demographic Characteristics of the Study Population and Risks of Breast Cancer.....	78
Breast Cancer Awareness among Indonesian Women at Moderate to High Risk of Developing Breast Cancer	85
Adherence to Screening Program among Indonesian Women at Moderate to High Risk of Developing Breast Cancer	91
Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk of Developing Breast Cancer	96

CONTENTS (Continued)

	Page
Discussions.....	100
Demographic Characteristics of the Study Population and Risks of Breast Cancer.....	101
Breast Cancer Awareness among Indonesian Women at Moderate to High Risk of Developing Breast Cancer.....	106
Adherence to Screening Program among Indonesian Women at Moderate to High Risk of Developing Breast Cancer.....	112
Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk of Developing Breast Cancer.....	115
5. CONCLUSIONS AND RECOMMENDATIONS.....	119
Conclusions.....	119
Strengths and Limitations of the Study.....	121
Strengths of the Study.....	121
Limitations of the Study.....	121
Implications and Recommendations.....	122
REFERENCES.....	125
APPENDICES.....	150
A. IBIS Breast Cancer Risk Evaluation Tool.....	151
B. Personal Characteristic and Health Related Questionnaire.....	154
C. Modified Breast Cancer Awareness Measure.....	157

CONTENTS (Continued)

	Page
D. Modified Personal History and Screening Questionnaire.....	161
E. List of Translators.....	164
F. List of Experts.....	165
G. Patient's and First-degree Relative(s)' Information Form.....	166
H. Informed Consent Form.....	167
I. Approval Letters.....	171
J. Additional Analysis.....	175
VITAE.....	182

LIST OF TABLES

Table	Page
1. Comparison of the American Cancer Society Guideline and Indonesian Screening Program.....	28
2. Breast Cancer Risk Factors and Their Incorporation into Risk Assessment Models.....	33
3. Number and Percentage of the Respondents' Characteristics (N = 87).....	79
4. Number and Percentage of the Risk Statuses of the Respondents (N = 87).....	82
5. Number and Percentage of the Family History Risk Factors of the Respondents (N = 87).....	82
6. Number and Percentage of the Personal Risk Factors of the Respondents (N = 87).....	84
7. Number and Percentage of Breast Cancer Awareness of Indonesian Women at Moderate to High Risk (N = 87).....	86
8. Number and Percentage of Knowledge of Each Potential Breast Cancer Symptom of Indonesian Women at Moderate to High Risk (N = 87).....	87
9. Number and Percentage of Knowledge of Breast Cancer Risk Factors of Each Item of Indonesian Women at Moderate to High Risk (N = 87).....	89

LIST OF TABLES (Continued)

Table	Page
10. Number and Percentage of Knowledge of Breast Cancer Screening Program of Indonesian Women at Moderate to High Risk (N = 87).....	90
11. Number and Percentage of Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87).....	92
12. Number and Percentage of Time since Last CBE and Mammography Screening of Indonesian Women at Moderate to High Risk Based on Age Groups (N = 87).....	93
13. Number and Percentage of the Main Reasons for Having CBE and/or Mammogram.....	94
14. Number and Percentage of Reasons for Not Having CBE and/or Mammogram (N = 84).....	95
15. Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87).....	97
16. Relationship between Knowledge of Breast Cancer Risk Factors and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87).....	98
17. Relationship between Knowledge of Screening Program and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87).....	99

LIST OF TABLES (Continued)

Table	Page
18. Number and Percentage of Breast Cancer Awareness Based on Each Item's Response of Indonesian Women at Moderate to High Risk (N = 87).....	175
19. Relationship between Breast Cancer Awareness and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87).....	176
20. Relationship between Knowledge of Screening Program and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87).....	177
21. Relationship between Knowledge of Risk Factors and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87).....	178
22. Number and Percentage of Other Tests that the Respondents Ever Had (N = 87).....	180
23. Number and Percentage of Reasons for Having Other Tests (n = 5)	180
24. Number and Percentage of Who or What Encouraged to Have a CBE and/or Mammogram (n = 22).....	180
25. Number and Percentage of Supplementary of Respondents' Characteristic (N = 87).....	181

LIST OF FIGURES

Figure	Page
1. Conceptual framework.....	9
2. Flowchart of breast cancer early detection program in Indonesia....	26
3. IBIS Breast Cancer Risk Evaluation Tool version 7.02.....	153

CHAPTER 1

INTRODUCTION

This chapter presents the background and significance of the problem, objectives of the study, research questions, conceptual framework, research hypothesis, definition of terms, scope of the study, and significance of the study.

Background and Significance of the Problem

Breast cancer is the most common diagnosed cancer and cause of cancer-related deaths among women accounting for 1.67 million new cases and 521,907 deaths worldwide (Ferlay et al., 2015). In Indonesia, similar to the other less developed countries, breast cancer has been ranked as the topmost cancer accounting for 30.5 percent of all cancers diagnosed among females with higher increases in mortality rates (Ferlay et al., 2013). In Dharmais Hospital National Cancer Center of Indonesia, for instance, the number of new cases and deaths from breast cancer increased between 2010 and 2013, ranging from 711 to 819 cases and 93 to 217 deaths, respectively (Ministry of Health Republic of Indonesia, 2015c).

Nowadays, breast cancer screening has been evidenced to achieve down-staging, reduced morbidity and mortality as well as improved treatment outcomes and survival rates of breast cancer (American Cancer Society [ACS], 2014a; Badgwell et al., 2008; Carney et al., 2005; Coleman et al., 2008; Miller & Baines, 2011; Nelson et al., 2009). The international and national breast cancer screening programs have been developed and utilized for early detection of breast

cancer (Oeffinger et al., 2015).

In Indonesia, a national breast cancer screening program or early detection program, which includes a clinical breast examination (CBE) and a referral mammography, is a cost-free service under the national health insurance (JKN). This program is available at all levels of health care services allocated by government hospitals as well as non-governmental cancer institutions. However, mammography is only provided in tertiary cares and some private hospitals for certain women who have risk factors of developing breast cancer (Health and Social Security Agency, 2014; Kardinah, Anderson, Duggan, Ali, & Thomas, 2014; Kompasiana, 2015; Ministry of Health Republic of Indonesia, 2015b).

In addition, a variety of health education and media were released to increase the knowledge and awareness of Indonesian women to participate in the breast cancer screening and early detection program (Ministry of Health Republic of Indonesia, 2015c). However, the number of Indonesian women who adhere to the national breast cancer screening program is still low, particularly in mammography screening (Nurleli, 2013). Moreover, breast cancer in Indonesia is mostly diagnosed in the advanced stages of cancer (Ng et al., 2011; Rahmatya, Khambri, & Mulyan, 2015). Here, increased accessibility to early detection and the breast cancer screening program is not congruent with an increased adherence of Indonesian women.

Adherence to the breast cancer screening program was established as one of the cornerstones of a successful screening program (Caleffi et al., 2010). A number of factors contributed to individual adherence to the screening program (Iskandarsyah, 2013). Among those, awareness of breast cancer was significantly correlated and improved women's adherence to breast cancer screening (Audrain-McGovern, Hughes, & Patterson, 2003; Hajian, Vakilian, Najabadi, Hosseini, &

Mirzaei, 2011). Women with higher awareness of breast cancer were more likely to have higher attendance or adherence to breast cancer screening (Desanti, Sunarsih, & Supriyati, 2010; Tazhibi & Feizi, 2014).

On the other hand, a lack of breast cancer awareness was reported as a significant barrier to breast cancer screening adherence in developing countries (Agarwal et al., 2009; Ahmadian & Samah, 2012). Therefore, low awareness of breast cancer led to delayed presentation of symptomatic breast cancer and resulted in increased poor prognoses and decreased survival rates (Ramirez et al., 1999). However, evidence from previous studies regarding breast cancer awareness revealed that the majority of women at increased risk of developing breast cancer had a lack of awareness of the signs and symptoms of breast cancer, risks of developing breast cancer, and screening program (Adelekan & Edoni, 2012; Audrain-McGovern et al., 1995; Elobaid, Aw, Grivna, & Nagelkerke, 2014; Linsell, Burgess, & Ramirez, 2008; Subramanian, Oranye, Masri, Taib, & Ahmad, 2013). From this, raising the awareness of breast cancer plays a vital role in improving cancer survival, in particular among women who have risks of developing breast cancer (Linsell et al., 2010).

According to the American Cancer Society (ACS, 2014a), having a family history of breast cancer is one of the most important risk factors for developing breast cancer. In accordance with ACS (2014a), women with a positive family history of breast cancer among their first-degree relatives (mother, sister, or daughter) are twice at risk of developing breast cancer. Additionally, the risk of developing breast cancer is found among women with a positive family history of more than one relative or at a younger age of diagnosis (Amir, Freedman, Seruga, & Evans, 2010; Walker, Chiarelli, Knight, et al., 2013). Fortunately, the risks of developing breast cancer can be identified and managed by life style changes, risk-reduction surgery,

chemoprevention (Antill et al., 2006), and breast cancer screening (Oeffinger et al., 2015). Preventing and treating women at moderate to high risk of developing breast cancer is therefore important (Cadiz et al., 2013).

Under the dramatically increased accessibility to the Indonesian breast cancer screening program, evidence regarding the importance and status of breast cancer awareness and adherence to breast cancer screening program as well as the high number of Indonesian women diagnosed at advanced stages of breast cancer reflected the need to understand this situation in Indonesia, in particular in Indonesian women with moderate to high risk of developing breast cancer.

To date, while there have been a number of studies explaining breast cancer awareness and adherence to breast cancer screening programs, little evidence has been found within the context of Indonesia. This lack of evidence reflected the need to develop this study to describe the awareness of breast cancer, the adherence to screening program, and the relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.

Objectives of the Study

The objectives of this study were to:

1. Describe the breast cancer awareness among Indonesian women at moderate to high risk of developing breast cancer;
2. Describe the adherence to the breast cancer screening program among Indonesian women at moderate to high risk of developing breast cancer; and

3. Determine the relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.

Research Questions

The research questions of this study were:

1. How many percentages of Indonesian women at moderate to high risk of developing breast cancer are aware of breast cancer?
2. How many percentages of Indonesian women at moderate to high risk of developing breast cancer do adhere to the breast cancer screening program?
3. Is there a relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer?

Conceptual Framework of the Study

This study was conducted based on three vital concepts of (1) breast cancer awareness, (2) adherence to screening program, and (3) the relationship between breast cancer awareness and adherence to screening program derived from literature review as follows.

1) Breast cancer awareness

In this study, breast cancer awareness was viewed in terms of knowledge regarding breast cancer, confidence and skills to detect a breast change, as well as the perceived heightened risk of developing breast cancer (Audrain-McGovern

et al., 1995, 2003; Cancer Research UK, 2009; Forbes, Atkins, Ramirez, Haste, & Layburn, 2010; Grunfeld, Ramirez, Hunter, & Richards, 2002; Linsell et al., 2008, 2010).

Knowledge regarding breast cancer

Knowledge regarding breast cancer consisted of (1) breast cancer symptoms, (2) age-related risk, (3) lifetime risk, (4) risk factors, and (5) screening program (Forbes et al., 2010; Grunfeld et al., 2002; Linsell et al., 2008, 2010).

Knowledge of breast cancer symptoms

Knowledge of breast cancer symptoms is the recognition of lump and non-lump symptoms of breast cancer including change in nipple position, pulling in of nipple, nipple rash, discharge or bleeding from a nipple, pain in a breast or armpit, puckering or dimpling in breast skin, redness of breast skin, change in the size and shape of the breast or nipple (non-lump symptoms); a lump or thickening in the breast, a lump or thickening under an armpit (lump symptoms) (Linsell et al., 2008, 2010).

Confidence and skills to detect a breast change

The confidence and skills to detect a breast change consisted of (1) the frequency of breast checking performance by looking at and feeling the breasts to identify or interpret as normal or abnormal which is done at least every month and (2) the confidence in noticing any changes in the breasts (Linsell et al., 2008, 2010).

Knowledge of age-related risk and lifetime risk

Knowledge of age-related risk is knowing that the risk of breast cancer increases with advancing age. In addition, knowledge of lifetime risk is knowing that one out of eight (1/8) women will develop breast cancer during their lifetime (Cancer

Research UK, 2009; Grunfeld et al., 2002; Linsell et al., 2008, 2010).

Perceived heightened risk of developing breast cancer

In addition to knowledge of age-related risk and lifetime risk, the perception of heightened risk was one important awareness among women at moderate to high risk of developing breast cancer (Audrain-McGovern et al., 1995, 2003). According to the American Cancer Society (ACS, 2014a), women at moderate to high risk were women with a positive family history of breast cancer, including women with a lifetime risk of 15 percent or more according to the risk assessment tools.

The perception of heightened risk refers to the individual perception or belief regarding the elevated risk of developing breast cancer as compared to other women who do not have a family history of breast cancer (Audrain-McGovern et al., 1995, 2003).

Knowledge of risk factors

Knowledge of risk factors refers to the recognition of 10 established and probable risk factors: positive family history of breast cancer, previous history of breast cancer, having certain benign breast disease, taking exogenous hormones (such as hormone replacement therapy [HRT], oral contraceptives), having no children or having children at late age, starting menarche earlier, having late menopause, drinking alcohol, being overweight, and doing less physical activity (Cancer Research UK, 2009; Grunfeld et al., 2002; McPherson, Steel, & Dixon, 2000; Subramanian et al., 2013).

Knowledge of breast cancer screening program

Knowledge of breast cancer screening program consists of knowing the existence of breast cancer screening program, the age women are first invited to

attend screening program; the age of starting a clinical breast examination (CBE), mammography, and breast self-examination (BSE); and the recommended frequency of CBE, mammography, and BSE (Forbes et al., 2010; Subramanian et al., 2013). In this study, the knowledge of the breast cancer screening program was in accordance with the Ministry of Health Republic of Indonesia (2015b). This program includes inviting women since age 30 to attend a screening program and providing recommendations to start monthly BSE at age 20, annual CBE at age 30, as well as biennial and annual mammography at age 40 and after age 50, respectively (Ministry of Health Republic of Indonesia, 2015b).

2) Adherence to screening program

The adherence to the breast cancer screening program in this study was conducted based on “Adherence to Breast and Ovarian Cancer Screening” proposed by Campitelli and colleagues (2011) and Indonesian breast cancer screening proposed by the Ministry of Health Republic of Indonesia (2015b). Accordingly, adherence to breast cancer screening requires women aged 30 or older to attend a CBE every year and a mammography every two years for women aged 40 to 50 and every year after aged 50 with a reason for screening purpose. From this, the adherence was identified if the individual followed or participated as scheduled in the screening program with a reason for screening purpose (Campitelli et al., 2011; Ministry of Health Republic of Indonesia, 2015b).

3) The relationship between breast cancer awareness and adherence to screening program

Participation in the screening program was evidenced associated with a number of factors, including awareness of breast cancer. Previous studies have shown the evidence that women were more likely to participate in the screening program if

they had higher awareness or knowledge of breast cancer screening, risk factors, and symptoms (Elobaid et al., 2014; Hajian et al., 2011; Shieh et al., 2012; Tazhibi & Feizi, 2014). In addition, women who had knowledge of breast cancer risk factors were more likely to attend breast cancer screening (Tazhibi & Feizi, 2014; Subramanian et al., 2013). Furthermore, according to Audrain-McGovern and colleagues (2003), women at increased risk of developing breast cancer were more likely to participate in breast cancer screening if they perceived at higher risk than women in the general population. Moreover, women who had performed monthly self-breast checking were more likely to have a clinical breast exam screening (Dahlui, Ng, Sadat, Ismail, & Bulgibal, 2011). Also, women's confidence to detect breast change via breast self-exam improved likelihood of receiving breast cancer screening (McIntosh, 2015). In consequence, it is worth studying the relationship between breast cancer awareness and adherence to screening program in the particular group of women.

The knowledge derived from the literature review provided the basis to develop the conceptual framework to underpin this study (Figure 1).

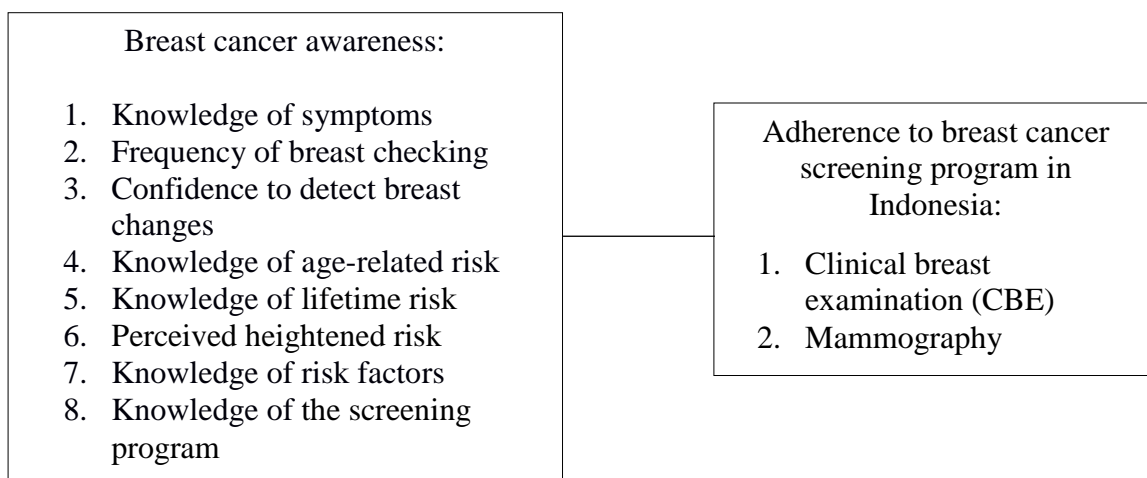


Figure 1. Conceptual framework

Research Hypothesis

There is a relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.

Definition of Terms

Breast Cancer Awareness

Breast cancer awareness refers to the knowledge or understanding based on information or experience about five or more of the non-lump symptoms of breast cancer, the skill or the reported frequency of breast checking for at least once a month, the confidence or being certain of the ability to detect a breast change, the knowledge or understanding about age-related risk and lifetime risk, the perception or belief about the heightened risk of developing breast cancer, as well as the knowledge or understanding about breast cancer risk factors and screening program. In this study, breast cancer awareness was measured by the modification of the Breast Cancer Awareness Measure which was originally proposed by Cancer Research UK, King's College London and University College London (Cancer Research UK, 2009).

Adherence to Breast Cancer Screening Program

Adherence to breast cancer screening program refers to the extent to which a woman has attended a CBE and mammography screening with a reason for screening purpose in accordance with the Indonesian breast cancer screening program proposed by the Ministry of Health Republic of Indonesia (2015b). The adherence to

breast cancer screening program in this study was measured by a self-reported questionnaire modified from Personal History and Screening Questionnaire (PHSQ) proposed by Ontario Familial Breast Cancer Registry (OFBCR) for the items regarding breast examination (Campitelli et al., 2011).

Women at Moderate to High Risk

Women at moderate to high risk of developing breast cancer in this study refers to women who were identified as having at least a 15 percent lifetime risk of developing breast cancer based on the International Breast Cancer Intervention Study (IBIS) model (Tyrer, Duffy, & Cuzick, 2004). The computerized program of IBIS Breast Cancer Risk Evaluation Tool version 7.02 developed by Cuzick, Tyrer, and Brentnall (2013) was used in identifying women at moderate to high risk of developing breast cancer.

Scope of the Study

This study focused on examining breast cancer awareness and adherence to screening program, and the relationship between these two variables among Indonesian women at moderate to high risk of developing breast cancer. The respondents involved in this study were women at moderate to high risk of developing breast cancer recruited from first-degree relatives of breast cancer patients in the oncology clinic, chemotherapy unit, and three general inpatient wards of Dharmais Hospital National Cancer Center, who met the inclusion criteria of the study. The data was collected from February to March, 2016.

Significance of the Study

The results from this study can provide an understanding of the current status regarding breast cancer awareness and adherence to screening program among Indonesian women as well as women in the Asian context. Knowledge derived from this study can also be used to develop future studies, in particular among women at moderate to high risk of developing breast cancer.

Furthermore, the study results provide evidence and room for improvement for the Indonesian government as well as others regarding the early detection of breast cancer and screening program. In addition, the results from this study will increase the awareness of nurses and other health care providers regarding the significance of early detection of breast cancer. Consequently, the mortality rates of breast cancer should decrease as well as will increase the survival rates and the quality of life among the women in this group.

CHAPTER 2

LITERATURE REVIEW

This literature review section presents a review of the literature related to the overview of breast cancer and breast cancer screening, women who are at a moderate to high risk of developing breast cancer, breast cancer awareness, adherence to breast cancer screening program, the relationship between breast cancer awareness and adherence to screening program and a summary of the literature review. The contents are sequentially presented in the following.

1. Introduction
 - 1.1 An Overview of Breast Cancer
 - 1.2 Breast Cancer in Indonesia
 - 1.3 An Overview of Breast Cancer Screening
 - 1.4 Breast Cancer Screening in Indonesia
2. Women at Moderate to High Risk of Developing Breast Cancer
 - 2.1 An Overview of Breast Cancer Risks
 - 2.2 Breast Cancer Risks Assessment
3. Breast Cancer Awareness
 - 3.1 Concept of Breast Cancer Awareness
 - 3.2 Factors Contributing to Breast Cancer Awareness
 - 3.3 Measurement of Breast Cancer Awareness
4. Adherence to Breast Cancer Screening Program
 - 4.1 Concept of Adherence to Breast Cancer Screening Program

4.2 Factors Contributing to Adherence to Breast Cancer Screening Program

4.3 Measurement of Adherence to Breast Cancer Screening Program

5. Relationship between Breast Cancer Awareness and Adherence to Screening Program

6. Summary of the Literature Review

Introduction

An Overview of Breast Cancer

Breast cancer is the topmost cancer and the leading cause of cancer death among women worldwide. Importantly, in less developed regions, the incidence and mortality rates of breast cancer have been increasing (Ferlay et al., 2015). This might be relevant to the increasing life expectancy, urbanization and adoption of western lifestyles (World Health Organization [WHO], 2015). In 2012, the number of new cases worldwide of breast cancer was approximately 1.67 million cases while the mortality rate was about 521,907 cases which represented 25.2 and 14.7 percent of all cancers among women, respectively (Ferlay et al., 2015).

Breast cancer is a malignant tumor resulting from the uncontrolled growth of abnormal cells. The most common type of breast cancer is ductal carcinoma, which begins in the cells of the ducts and also begins in the cells of the lobules and in other tissues in the breast. Invasive breast cancer is cancer that has spread from the origin to surrounding tissue and distant areas of the body (American Cancer Society [ACS], 2014a).

Currently, the cause of breast cancer is still not yet exactly known. Many risk factors may increase an individual's chances of developing breast cancer such as gender, age, menstrual period, personal history of breast cancer, family history, which includes genetic risk factors. Women whose first degree relatives (mothers, daughters, or sisters) have had breast cancer have twice the risk of developing cancer (ACS, 2014a).

Breast cancer is diagnosed from medical history, physical examination, breast imaging test, or other tests such as nipple discharge examination, or biopsies of suspicious areas. The imaging tests consist of mammogram, breast ultrasound, and breast magnetic resonance imaging (MRI). A diagnostic mammogram is used when women have breast symptoms or an abnormal result on a screening mammogram, which will include more images of the area of concern. A biopsy will be needed if the result from the diagnostic mammogram, ultrasound, or breast MRI shows the abnormal area is more likely to be cancerous. In addition, even if no tumor is found, but there is a lump felt by a medical doctor, a biopsy will be done to exclude cancer (ACS, 2014a).

Similarly with other types of cancer, the TNM staging system has been used to determine the stages of breast cancer (ACS, 2014a). According to the TNM staging system, the staging of breast cancer is classified based on the size, spread or extent of a tumor (T), the involvement of the lymph nodes (N), and the absence or presence of distance metastasis (M). Breast cancer consists of five stages from stage 0 to IV as described by the American Cancer Society (2014a) as follows.

Stage 0: Stage 0 is a non-invasive breast cancer, including a pre-cancer of the breast; ductal carcinoma in situ (DCIS), lobular carcinoma in situ (LCIS); and Paget's disease of the nipple.

Stage I: Stage I is invasive breast cancer, which is divided into stages IA and IB.

Stage IA is the invasive breast cancer with the tumor size at 2 centimeters or less across (T1) and has no lymph nodes spread (N0) or distant organ metastasis (M0).

Stage IB is the invasive breast cancer with tumor size 2 centimeters or less across or no tumor found in the breast (T1 or T0), with micro metastasis in one to three axillary lymph nodes, or the cancer cells in the lymph nodes is greater than 0.2 millimeter across and/or more than 200 cells but is not larger than 2 millimeters (N1mi). Also, there is no metastasis to a distant site (M0).

Stage II: Stage II is divided into two categories, stage IIA and stage IIB.

Stage IIA is the invasive breast cancer with the tumor size at 2 centimeters, or less across, or no tumor found in the breast (T1 or T0), and either it has spread to one to three axillary lymph nodes, with the cancer in the lymph nodes larger than 2 millimeters across (N1a), or a small amount of cancer cells are found in the internal mammary lymph nodes or sentinel lymph node biopsy (N1b), or the cancer has spread to one to three lymph nodes under the arm and to internal mammary lymph nodes which are found by sentinel lymph node biopsy (N1c). Furthermore, it can be the tumor is larger than 2 centimeters but not larger than 5 centimeters across (T2) with no lymph node spread (N0). Also, the cancer has not spread to distant organs (M0).

Stage IIB is the invasive breast cancer with the tumor size larger than 2 centimeters but less than 5 centimeters across (T2), no lymph node spread (N0), and no metastasis to distant sites (M0). Also, this stage describes the tumor size is larger

than 5 centimeters across, but it does not grow into the chest wall or skin (T3), and there is no spread to the lymph nodes (N0). Also, there is no distant metastasis (M0).

Stage III: Stage III is divided into stage IIIA, IIIB, and IIIC.

Stage IIIA is the invasive breast cancer where the tumor size is not larger than 5 centimeters across, or no tumor can be found (T0 to T2), which has spread into four to nine axillary nodes, or to internal mammary nodes (N2). However, the cancer has not spread to distant sites (M0). It also can be a stage IIIA if the tumor is larger than 5 centimeters across, but it does not grow into the chest wall or skin (T3). It has spread to one to nine axillary nodes, or to internal mammary nodes (N1 or N2). However, the cancer has not spread to distant sites (M0).

Stage IIIB is the invasive breast cancer in which the tumor has grown into the chest wall or skin (T4), including one of the following conditions: the cancer has not spread to lymph nodes (N0); the cancer has spread to one to three axillary lymph nodes and/or small amounts of cancer are found in internal mammary lymph nodes on a sentinel lymph node biopsy (N1); it has spread to four to nine axillary lymph nodes, or it has enlarged the internal mammary lymph nodes (N2). Furthermore, the cancer has not spread to distant sites (M0). Also, inflammatory breast cancer which makes the skin of the breast become swollen, and inflamed, with a pitted appearance, and has any tumor size growing into the chest wall or skin (T4d) is included in stage IIIB.

Stage IIIC is the invasive breast cancer in which there is no tumor found on the breast, or if there is a tumor, it can be any size, with one of these following conditions: cancer has spread to 10 or more lymph nodes, or spread to the lymph nodes under or above the clavicle, involving the axillary lymph nodes and has engorged the internal mammary lymph nodes, or spread to four or more axillary

lymph nodes, and a small amount of cancer cells are found in the internal mammary lymph nodes by a sentinel lymph node biopsy (N3). However, the cancer has not spread into distant organs or sites (M0).

Stage IV: Stage IV is the advanced stage of breast cancer in which the cancer has spread to distant parts of the body. This stage is invasive breast cancer with any tumor size (any T), and may or may not have lymph node spread (any N). It also has metastasized to lymph nodes far from the breast, or to distant organs (M1), of which the most common metastasize to the bone, liver, brain, and lung.

Since the TNM cancer staging system represents the size of the cancer and the level of metastases, the staging of breast cancer at the time of diagnosis becomes the most important predictors of the prognosis of women with breast cancer (ACS, 2014a). From this, the early detection of breast cancer using breast cancer screening program has long been accepted as one of the most effective strategies to increase breast cancer survivors (Hofvind, Ursin, Tretli, Sebuødegård, & Møller, 2013; Venturini et al., 2013).

Breast Cancer in Indonesia

In Indonesia, breast cancer was the topmost common cancer among Indonesian women (Ferlay et al., 2013) with an increasing number of breast cancer patients diagnosed at a later stage (Ng et al., 2011; Rahmatya et al., 2015). In Dharmais Hospital National Cancer Center of Indonesia, breast cancer was the top cancer between 2010 and 2013. The number of new cases and deaths from breast cancer increased between 2010 and 2013, ranging from 711 to 819 cases, and 93 to 217 deaths, respectively. Among 34 provinces in Indonesia, Jakarta is the fourth

province where the prevalence of breast cancer is above the national average, which is about 0.8 per thousand women (Ministry of Health Republic of Indonesia, 2015c).

Moreover, until now, the majority of Indonesian breast cancer patients were diagnosed in the advanced stage of cancer. A study conducted by Ng and colleagues (2011) with 637 women with breast cancer in Dharmais Cancer Center, the top referral cancer hospital for Indonesia, revealed that 63 percent of breast cancer patients were diagnosed in stage III or IV. Likewise, a study conducted with 46 breast cancer patients by Rahmatya and colleagues (2015) found that 69.9 percent of the newly diagnosed breast cancer patients in Dr. M. Djamil Hospital in 2012 were in the advanced stages of cancer.

Consequently, patients presenting in the late stage of breast cancer in Indonesia leads to poor outcomes and prognosis (Ng et al., 2011; Rahmatya et al., 2015). The increasing incidence of cancer and the presentation in advanced stages of cancer among Indonesian patients has resulted in increasing high costs for diagnoses and treatment. In Indonesia, the amount spent on cancer treatment is relatively high, and is the second highest cost among all diseases. In 2014, the cost increased 3-fold compared to that in 2012 (Ministry of Health Republic of Indonesia, 2015c).

An Overview of Breast Cancer Screening

Breast cancer screening has been evidenced to achieve down-staging, reduce morbidity and mortality as well as improve treatment outcomes and the survival rates of breast cancer, in general (ACS, 2014a; Badgwell et al., 2008; Caleffi et al., 2010; Carney et al., 2005; Coleman et al., 2008; Elobaid et al., 2014; Miller & Baines, 2011; Nelson et al., 2009; Shieh et al., 2012).

According to ACS (2014a), cancer screening refers to the tests and examinations used to find out cancer or disease among asymptomatic people. From this, the screening program helps to early detect and diagnose breast cancer in an asymptomatic phase (Nelson et al., 2009). The duration of an asymptomatic phase of breast cancer has long periods which can be from one to several years until symptoms present, depending on women's ages and breast density (Canadian Breast Cancer Foundation, 2009).

In addition, according to the American Cancer Society (2014a), breast cancer that is found after the presentation of any symptoms is more likely to be larger and tends to have already spread outside the breast. In contrary, breast cancer detected during screening examinations is more likely to be smaller and still restricted to the breast. Thus, the American Cancer Society recommends routine screening before the symptoms develop to detect breast cancer at the early stage.

In this regard, breast cancer screening has been reported to reduce morbidity and mortality as well as improve the survival rates of breast cancer patients (ACS, 2014a; Nelson et al., 2009). The reduction of mortality due to breast cancer is the main advantages of early detection through screening. The other benefits also include reducing or avoiding the possible negative outcomes related to a diagnosis of advanced breast cancer. This may include more aggressive surgery (mastectomy, or lumpectomy), and chemotherapy; years of disability, reduced years of life and the loss for relatives or friends of those patients who die from breast cancer, as well as the high cost of breast cancer treatment for patients and families if treatment is unsuccessful. All these benefits could improve the quality of life of breast cancer patients (Myers et al., 2015).

Generally, breast cancer screening includes breast self-examination, clinical breast examination, and a mammography. In addition, magnetic resonance imaging (MRI) screening along with annual mammograms have been recommended for certain high risk women (Saslow et al., 2007). The details for each screening method together with their benefits, limitations and practices among women are described in the following.

Breast self-examination

Breast self-examination (BSE) is a highly accessible method of breast cancer screening for women from the age of 20. BSE is a simple screening method as it can be performed independently, in comfort, and privately by women at any age in their home. Practicing BSE involves a systematic step-by-step approach to examine the look and feel of the breasts to detect any changes earlier (Smith et al., 2014). Women who perform regular BSE have a higher rate of benign breast biopsies as compared with those who do not perform regular BSE (Thomas et al., 2002).

BSE also plays a vital role in increasing the awareness of a normal breast composition resulting in raising the awareness of any changes that may be detected during the practice of BSE or at other times. Practicing BSE encourages women to get familiar with their own breasts every month, looking and feeling for any changes, and reporting any obvious changes promptly (Yoo, Choi, Jung, & Jun, 2012). Also, it should be emphasized to women that the regular performance of BSE does not mean that breast cancer can be with certainty self-detected during a formal BSE procedure. However, it can be detected incidentally, proposing that there is an increased body awareness of any symptoms in addition to the self-performed physical or breast examination (Smith et al., 2003). In addition, women should be informed about the benefits and limitations of BSE, and the importance of reporting any breast

symptoms to a health professional earlier should be emphasized (ACS, 2014a; Smith et al., 2014).

Nowadays, there has been a paradigm shift from BSE to breast awareness in breast cancer early detection. The evolution toward breast awareness is a concept of a woman being familiar with her own breasts so that she notices any change that might develop and bring this to the attention of her health care provider promptly. This concept of breast awareness has the same goals with BSE which is to encourage women to be familiar with their own breasts and to report promptly any changes (Mac Bride, Pruthi, & Bavers, 2012).

Clinical breast examination

Clinical breast examination (CBE) is the examination of the breast allocated by a health care professional. CBE is important for women who do not screen regularly by mammography, either due to not being recommended for a mammography (such as those women aged less than 40) or due to not screening for a mammography regularly with recommended guidelines (Saslow et al., 2004). According to the American Cancer Society (2014a), CBE is recommended for average risk asymptomatic women preferably at least every three years for those aged 20 and 30 years, and annually for those aged 40 years or over. Although the current American Cancer Society guideline does not recommend CBE for women at any age, CBE still becomes an important choice for breast cancer screening in low and middle income countries (Oeffinger et al., 2015).

CBE should take place during periodic health examinations, and ideally prior to a mammography for women aged 40 years or over so that any suspicious palpable tumors or abnormalities can be detected during the examination. While performing CBE, health care professionals should inform the women or discuss

information related to breast cancer screening and breast cancer risks such as family history. Health care professionals or clinicians should regularly investigate the family history of breast and ovarian cancers in the first degree or second degree relatives on both the maternal and paternal side of three generations in a family and describe the effect of family history on breast cancer risk. In addition, clinicians also should emphasize the importance of breast cancer awareness and of seeking consultation earlier (Smith et al., 2014).

CBE has been reported to reduce the mortality of breast cancer, accounting for an 11 percent reduction in breast cancer deaths (Miller & Baines, 2011). Furthermore, the combination of CBE and mammography screening has been reported to lower the mortality of breast cancer. In addition, it is reported that CBE detected some cancers which were not detected by mammography (Smith et al., 2003).

Mammography

Mammography screening is the widely employed imaging test for breast cancer screening, which can detect breast cancer before it shows any symptoms. It is a sensitive (77% to 95%) and specific (94% to 97%) screening method for breast cancer, with a strong evidence of benefits for women aged 40 to 74 years (Nelson et al., 2009). Mammography can be done by using either plain film or digital mammogram. Usually, it takes two views of each breast. From this, the mammography is used to look for breast disease in women who have no sign or symptoms of breast problems (ACS, 2014a).

The current American Cancer Society guideline recommends annual mammography screening for average risk women aged 45 to 54 years, and women aged 55 years and older should transition to biennial screening or have the

opportunity to continue screening annually. Women also should have the opportunity to begin annual screening between the ages of 40 to 44 years, and women at 45 years old should begin annual screening. The mammography screening should be continued as long as the overall health of the woman is good and her life expectancy is of 10 years or longer (Oeffienger et al., 2015). Women should be informed about the benefits, and the limitations of an annual mammography, as well as the importance of adhering to a schedule of regular screening (Smith et al., 2014).

Mammography screening has been evidenced to reduce mortality and increase survival rates of breast cancer patients (Smith et al., 2014; Weedon-Fekjær, Romundstad, & Vatten, 2014). A previous study revealed that women aged 40 to 74, who attended mammography screening was associated with 15 to 20 percent reduction of breast cancer mortality (Nelson et al., 2009). Moreover, regular mammography screening in older women is associated with the diagnosis of earlier stages of breast cancer and also lower breast cancer mortality (Badgwell et al., 2008).

The limitations of mammography screening, however, have been evidenced. These include the potential for false-positive results and over diagnosis. False-positive results can increase suspicion for breast cancer and lead to further testing including additional imaging or a biopsy, but does not lead to a cancer diagnosis (Hubbard et al., 2011; Smith et al., 2014). In addition, the risk of false positives may increase when screening is started at a younger age (Pace & Keating, 2014).

Breast magnetic resonance imaging

Breast magnetic resonance imaging (MRI) is a highly sensitive test in high risk asymptomatic and symptomatic women (Kuhl et al., 2005; Leach et al., 2005; Warner et al., 2004). In addition to a yearly mammography, breast MRI was

recommended by the American Cancer Society for certain women at high risk for developing breast cancer (Saslow et al., 2007). Also, breast MRI is sometimes also used in other situations, such as to better examine suspicious areas found by a mammogram or to look more closely at the breast in someone who has already been diagnosed with breast cancer (ACS, 2014a).

False positive findings from breast MRI screening however, require further tests and/or biopsies for confirmation. From this, breast MRI is not recommended for women at average risk of breast cancer, as it would result in unneeded biopsies and other tests in a large portion of these women, resulting in high costs (ACS, 2014a).

Breast Cancer Screening in Indonesia

In order to decrease the incidence or the burden of breast cancer as well as the high number of patients presenting in advanced stages of breast cancer, the Indonesian government has implemented the early detection program. The target population of the program is the women from the age of 20, focusing on women aged between 30 and 50 years old. This program aims to increase women's awareness and attention in controlling breast cancer through early detection. It is expected that 50 percent of the target women will be attending this program in 2019 (Ministry of Health Republic of Indonesia, 2015b).

This program serves for both routine screening for asymptomatic persons and early diagnosis for symptomatic persons (Ministry of Health Republic of Indonesia, 2015b). In accordance with the Ministry of Health Republic of Indonesia (2015b) and the Health and Social Security Agency (2014), the flowchart of the breast cancer early detection program in Indonesia is established as displayed in Figure 2.

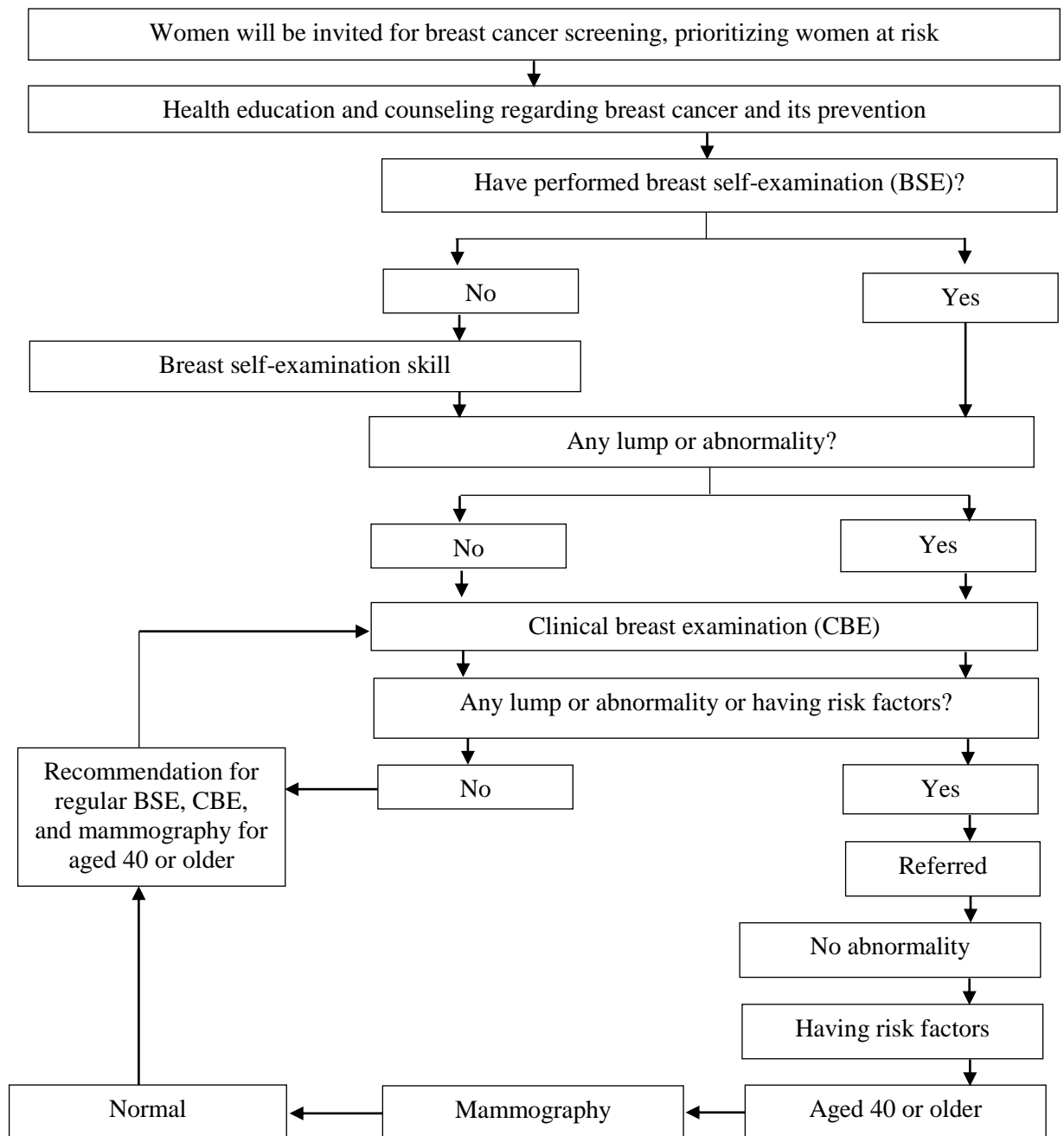


Figure 2. Flowchart of breast cancer early detection program in Indonesia. Adapted from Practical Guideline for Screening by Health and Social Security Agency, 2014. Act of Ministry of Health Republic of Indonesia Number 34 Year of 2015 about Technical Guideline of Breast and Cervical Cancer Prevention by Ministry of Health Republic of Indonesia, 2015b.

As seen in Figure 2, the Indonesian breast cancer screening program consists of providing health education, teaching breast self-examination skills, clinical breast examination screening for women aged 30 years or older, and recommending mammography screening for women aged 40 years or older, as well as allocating a referral mammography screening for women aged 40 years or older who have breast cancer risk factors (Health and Social Security Agency, 2014; Ministry of Health Republic of Indonesia, 2015b). In addition, according to the Ministry of Health Republic of Indonesia (2015b), the opportunistic breast cancer screening program is allocated to individuals or clients that come to visit a health care provider based on the client's initiative or awareness.

The clinical breast examination (CBE) is the first option for breast cancer screening in Indonesia (Kardinah et al., 2014). A referral mammography or further specific tests and treatment will be employed only for women who have abnormal findings detected from the CBE or have risk factors of developing breast cancer (Health and Social Security Agency, 2014; Kompasiana, 2015; Ministry of Health Republic of Indonesia, 2015b). In accordance with the Health and Social Security Agency (2014), a mammography is currently included in the Indonesian national health insurance (JKN). However, according to the Ministry of Health Republic of Indonesia (2015b), mammography screening is only provided in tertiary care or private hospitals in large cities, as well as in major cancer centers.

In accordance with the Indonesian breast cancer early detection program, women should undergo CBE every three years starting at the age of 30, and then every year from the age of 40. While those women who have risk factors of developing breast cancer should undergo CBE every year (Ministry of Health Republic of Indonesia, 2015b). In addition, for these women who have risk factors, or

who have any abnormal findings from CBE, they will be allocated for a referral mammography screening and recommended to continue breast self-exam (BSE), CBE and mammography regularly. In Indonesia, women are recommended to undergo a mammography every two years starting at the age of 40 and every year after the age of 50, in general (Ministry of Health Republic of Indonesia, 2015b).

To date, the clinical breast-exam (CBE) is an optimal optional for breast cancer screening program in Indonesia with the referral mammography. Although the current American Cancer Society guideline does not recommend CBE for women at any age, CBE is reported to benefit women at high risk of breast cancer, in particular in low and middle income countries (Kardinah et al., 2014; Oeffinger et al., 2015; Sankaranarayanan, 2014).

The comparison of the current American Cancer Society guideline and Indonesian screening program is presented in Table 1.

Table 1

Comparison of the American Cancer Society Guideline and Indonesian Screening Program

Screening modalities	American Cancer Society guideline	Indonesian screening program
CBE	<ul style="list-style-type: none"> ▪ CBE is not recommended among average risk women at any age (qualified recommendation) 	<ul style="list-style-type: none"> ▪ Recommends and allocates CBE screening; every three years starting at age 30, and every year starting at age 40 for average risk women ▪ Recommends and allocates CBE screening; every year starting at age 30 for women having risk factors

Table 1 (Continued)

Screening modalities	American Cancer Society guideline	Indonesian screening program
Mammography	<p>Recommends mammography screening as follows:</p> <ul style="list-style-type: none"> ▪ Start at age 45 years, women should undergo regular mammography screening (strong recommendation) ▪ Between ages 40 and 44 years, women should have the opportunity to begin annual screening (qualified recommendation) ▪ Women aged 45 to 54 should be screened annually (qualified recommendation) ▪ Women age ≥ 55 should undergo biennial screening or have the opportunity to continue screening annually (qualified recommendation) <p>Women should continue mammography screening as long as their overall health is good and have a life expectancy of 10 years or longer (qualified recommendation)</p>	<p>Recommends mammography screening for average risk women, as well as allocates a referral mammography screening for women having risk factors; every two years starting at age 40, and every year after age 50</p>
Breast MRI	<ul style="list-style-type: none"> ▪ Recommend annual breast MRI for women at high risk 	<ul style="list-style-type: none"> ▪ No recommendation

Note. Adapted from “Breast Cancer Screening for Women at Average Risk 2015 Guideline Update from the American Cancer Society” by K. C. Oeffinger and colleagues, 2015, *Journal of the American Medical Association*, 314, p. 1599-1614. “American Cancer Society Guidelines for Breast Screening with MRI as An Adjunct to Mammography” by D. Saslow and colleagues, 2007, *A Cancer Journal for Clinicians*, 57, p. 75-89. Act of Ministry of Health Republic of Indonesia Number 34 Year of 2015 about Technical Guideline of Breast and Cervical Cancer Prevention by Ministry of Health Republic of Indonesia, 2015b.

As seen in Table 1, the American Cancer Society (ACS) guideline for breast cancer screening provides the recommendation for women at high risk of developing breast cancer that they might benefit from additional screening strategies beyond those offered to women of average risk. The recommendation of breast cancer screening for women at high risk of breast cancer according to the ACS guideline includes earlier initiation of mammography screening starting at aged 30 or younger, shorter screening intervals, such as every six months or an addition of annual MRI

screening as an adjunct to a mammography and physical examination (Saslow et al., 2007; Smith et al., 2003). In Indonesia, women who have risk factors for developing breast cancer are recommended to have an annual CBE. However, a referral mammography screening is occasionally recommended based on the judgment of a health care provider, which does not follow the guideline.

The implementation of the breast cancer early detection program in Indonesia has been supported by the National Health Insurance (JKN) under the Health and Social Security Agency (BPJS) (2014) with free of charge. In cooperation with the Ministry of Health Republic of Indonesia, the BPJS also provides health screening services including CBE and a referral for a mammography for women at increased risk of developing breast cancer (The Jakarta Post, 2015). Women have to register as a member of the BPJS and complete the screening form provided by the BPJS. Then, the women with increased risk will be invited for breast cancer screening through the primary health service (Health and Social Security Agency, 2014).

In Indonesia, the implementation of breast cancer screening program also involves the village health volunteers in the community. The village health volunteers are the key persons to effectively implement the breast cancer screening program in the community as they are familiar with the women in the community. The health care provider and the village health volunteer will invite women to undergo breast cancer screening in the community.

The report from the national breast cancer early detection program in Indonesia from 2007 to 2014 revealed that 904,009 (2.45%) Indonesian women attended the breast cancer screening program and 2,368 breast tumors were found (2.6 per 1,000 women) (Ministry of Health Republic of Indonesia, 2015c). In addition, the report from Dharmais Hospital National Cancer Center revealed that there was a

15.77 percent increase in the number of Indonesian women who attended a breast cancer early detection program between 2013 and 2014 (Ministry of Health Republic of Indonesia, 2015c).

As mentioned earlier, the majority of Indonesian patients with breast cancer however, still come to visit or consult a medical doctor in the very late stages of cancer. Because of this, early detection by improving awareness and adherence to breast cancer screening, in particular among women at moderate to high risk of developing breast cancer is, therefore, important in Indonesia.

Women at Moderate to High Risk of Developing Breast Cancer

An Overview of Breast Cancer Risks

In general, one out of eight (1/8) women is at risk of developing breast cancer during their lifetime (ACS, 2014b; Cancer Research UK, 2015b). In addition, other risk factors of developing breast cancer include age, family history, hormonal and reproductive factors, and clinical factors such as history of proliferative breast disease, and breast density (Amir et al., 2010). In accordance with Amir and colleagues (2010) and the American Cancer Society (2014a), among these factors, the family history of breast cancer is evidenced as the most important risk factor for developing breast cancer.

A number of definitions and strategies have been studied to identify or categorize the level of risk of developing breast cancer. The American Cancer Society developed risk assessment tools based on the family history of breast cancer to categorize the level of risk of developing breast cancer (ACS, 2014a). According to the American Cancer Society (2014a), women at moderate risk are those who have a

lifetime risk of 15 to 20 percent. While women who have a lifetime risk of breast cancer at about 20 percent or more are defined as at high risk of developing breast cancer. In addition, according to the American Cancer Society, normal risk is a lifetime risk of less than 15 percent.

Whereas, according to the National Institute for Health and Care Excellent (NICE) in the UK and other European countries, women at moderate and low risk have a lifetime risk of 17 to 29 percent and less than 17 percent, respectively (Cadiz et al., 2013). High risk is also defined as a lifetime risk of 30 percent or more, and these women have an eight percent or more risk of developing breast cancer at the ages of 40 to 50 years (Armstrong & Evans, 2014). Women with a 20 percent or more chance of carrying a breast cancer susceptibility gene (BRCA1 or BRCA2), or tumor protein 53 (TP53) mutation are also classified as high risk (Cadiz et al., 2013).

The International Consensus Conference on Breast Cancer Risk, Genetics, and Risk Management in 2007 suggested four risk categories which consist of high, very high, moderate, and average risk. The high risk is defined as women with 5 to 10 percent of relative risk (RR – risk compared to average women in the women's age group). This includes women with lobular carcinoma in situ (LCIS), atypical ductal hyperplasia (ADH), and atypical lobular hyperplasia (ALH), and women with two first-degree relatives with breast cancer but no mutation. For women whose RR is more than 10 percent due to either a high penetrance gene mutation (BRCA1, BRCA2, phosphatase and tensin homolog [PTEN] or TP53) or those likely to harbor such a mutation, or a personal history of irradiation to breast or chest wall prior to the age of 30, such as for Hodgkin disease, are categorized as a very high risk group. Whereas, moderate risk is women with risk that is more than average for their

age group but the RR is less than 5 percent, while average risk is the female population at large (Cadiz et al., 2013; Schwartz et al., 2009).

As mentioned above, a number of definitions and strategies have been used to identify or categorize the level of risk of developing breast cancer. This study however, used the definitions and categorization proposed by the American Cancer Society (2014a) as they are used accordingly with the risk assessment tool used in this study as discussed in the following section.

Breast Cancer Risks Assessment

A number of risk assessment tools have been developed to identify the level of risk of developing breast cancer, in particular at moderate to high risks over a specific time and or over the lifetime risk (Amir et al., 2010). To date, the common breast cancer risk assessment tools include the Gail model, Claus model, International Breast Cancer Intervention Study (IBIS) or Tyrer-Cuzick model, Berry-Parmigiani-Aguilar (BRCAPRO) model, The Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) model, and the Jonker model (Afonso, 2009; Amir et al., 2010) which are summarized in Table 2.

Table 2

Breast Cancer Risk Factors and Their Incorporation into Risk Assessment Models

Risk Factors	Gail	Claus	BRCAPRO	IBIS	BOADICEA	Jonker
Personal information						
Age	Yes	Yes	Yes	Yes	Yes	Yes
Body mass index	No	No	No	Yes	No	No
Alcohol intake	No	No	No	No	No	No
Hormonal and reproductive factors						
Age at menarche	Yes	No	No	Yes	No	No

Table 2 (Continued)

Risk Factors	Gail	Claus	BRCAPRO	IBIS	BOADICEA	Jonker
Age at first live birth	Yes	No	No	Yes	No	No
Age at menopause	No	No	No	Yes	No	No
Hormone replacement therapy use	No	No	No	Yes	No	No
Oral contraceptive pill use	No	No	No	No	No	No
Breast feeding	No	No	No	No	No	No
Plasma estrogen level	No	No	No	No	No	No
Personal history of breast and/or ovarian cancer						
Breast biopsies	Yes	No	No	Yes	No	No
Atypical ductal hyperplasia	Yes	No	No	Yes	No	No
Lobular carcinoma in situ	No	No	No	Yes	No	No
Breast density	No	No	No	No	No	No
Family history of breast and/or ovarian cancer						
First-degree relatives with breast cancer	Yes	Yes	Yes	Yes	Yes	Yes
Second-degree relatives with breast cancer	No	Yes	Yes	Yes	Yes	Yes
Third-degree relatives with breast cancer	No	No	No	No	Yes	No
Age of onset of breast cancer in a relative	No	Yes	Yes	Yes	Yes	Yes
Bilateral breast cancer in a relative	No	No	Yes	Yes	Yes	Yes
Ovarian cancer in a relative	No	No	Yes	Yes	Yes	Yes
Male breast cancer	No	No	Yes	No	Yes	Yes

Note. Adapted from “Assessing Women at High Risk of Breast Cancer: A Review of Risk Assessment Models” by E. Amir, O. C. Freedman, B. Seruga, and D. G. Evans, 2010, *Journal of the National Cancer Institute*, 102, p. 680-691.

In choosing the risk assessment models to assess breast cancer risk, it is important to consider that the model is based on epidemiologic data from a specific population as the models yield different results when applied to other populations (Cadiz et al., 2013). Currently, the available risk assessment models have been used and validated in large study populations as well as different populations (Amir et al.,

2010). In Indonesia, however, there is no risk assessment model specifically designed and validated for Indonesian women. The details of the risk assessment models are as follows.

Gail model

The Gail model is one of the most widely known and used models for breast cancer risk assessment. This model includes six risk factors of breast cancer as shown in Table 2. In addition, this model predicts women's probability to have a breast cancer diagnosis within the next five years and within her lifetime (Afonso, 2009; Amir et al., 2010). In accordance with Amir and colleagues (2010), the Gail model has been validated in three large population-based databases and they reported that this model was well calibrated. However, this model has some limitations since it does not include the paternal family history, second-degree relatives, or the age at the onset of the affected relatives, as well as having limited discriminatory accuracy. According to Amir and colleagues, this limitation is the probable reason for the poor individualized risk assessment of this model when testing in higher-risk populations, such as patients enrolled in family history clinics or women with atypical hyperplasia.

Claus model

The Claus model estimates the woman's probability to develop breast cancer based on her family history. It is more extensive than the Gail model since it includes affected first- and second-degree relatives and the age at which cancers in those relatives were diagnosed, but excludes other risk factors. This model can be used only for women who have at least one female first- or second-degree relative with breast cancer (Afonso, 2009). Also, this model does not include nonhereditary risk factors such as hormonal and reproductive factors. In addition, the more discrep-

ancies were seen in women with nulliparous, multiple benign breast biopsies, and a strong paternal or first-degree family history (Amir et al., 2010).

Berry-Parmigiani-Aguilar model

The Berry-Parmigiani-Aguilar (BRCAPRO) model analyzes the likelihood of carrying a breast cancer susceptibility gene (BRCA) mutation and calculates an overall breast cancer risk. The calculations are based on Bayes rules of determination of the probability of a mutation, and given family history (Afonso, 2009). The advantage of this model is that it includes information on both affected and unaffected relatives. However, this tool does not include nonhereditary risk factors which will lead to underestimated risks in breast cancer only families (Amir et al., 2010).

Jonker model

The Jonker model is an extension of the Claus model combined with the BRCAPRO model. In this model, the familial clustering is explained by three genes; the breast cancer susceptibility gene (BRCA 1, BRCA 2), and a hypothetical third gene called BRCAu. The BRCAu was modeled to explain all familial clustering which is not accounted for by BRCA 1 or BRCA 2. The parameters of the model were estimated using published population incidence and relative risk estimates. However, this model does not include personal breast cancer risk factors. Furthermore, it is also has inability to estimate risk in women with complex family histories (Amir et al., 2010).

Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm model

The Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) model was designed with the use of segregation

analysis in which susceptibility is explained by gene mutations of BRCA 1 or BRCA 2 and a polygenic component. This model incorporates family history of breast, ovarian, prostate, and pancreatic cancer. This model predicts both the BRCA mutation probabilities and cancer risk in individuals with a family history (Amir et al., 2010; Saslow et al., 2007).

International Breast Cancer Intervention Study model

The International Breast Cancer Intervention Study (IBIS) model is the most comprehensive model that has integrated all the variables of all models, including the family history, endogenous estrogen exposure, and benign breast disease. This model is based on a dataset from the International Breast Cancer Intervention Study (IBIS) and other epidemiological data. In addition, this model allows the presence of multiple genes of differing penetrance, which are not included in Claus or BRCAPRO models. Furthermore, the IBIS model is similar with the Joker model in that its algorithm includes BRCA 1 and BRCA 2 mutations while allowing for a lower penetrance of BRCAu (Amir et al., 2010).

Three studies have compared the accuracy of the risk assessment models and found that the IBIS model is the most consistently accurate model for predicting breast cancer risk in women with a family history of breast or ovarian cancer (Amir et al., 2003, 2010; Jacobi, de Bock, Siegerink, & van Asperen, 2009). Therefore, based on the literature review, the IBIS model seems to be the most comprehensive model to assess breast cancer risk, as it incorporates family history and other risk factors. From this, the IBIS model was selected and used to assess the women at moderate to high risk of developing breast cancer in the Indonesian population in this study.

Breast Cancer Awareness

The review of breast cancer awareness in this study consists of the evidence of the relevant concept of breast cancer awareness from the previous studies, the factors contributing to breast cancer awareness, and the measurement related to breast cancer awareness.

Concept of Breast Cancer Awareness

Breast cancer awareness is viewed as knowledge on various aspects of breast cancer, perceptions or beliefs of the heightened risk of developing breast cancer, as well as confidence and skills in detecting a breast change (Al-Dubai et al., 2011; Audrain-McGovern et al., 1995, 2003; Dey, Mishra, Govil, & Dhillon, 2014; Forbes et al., 2010; Linsell et al., 2008, 2010; Tazhibi & Feizi, 2014).

In regard to breast cancer awareness, Linsell and colleagues (2008, 2010) examined women's knowledge regarding breast cancer symptoms, age-related risk, lifetime risk, and the confidence and skills to detect for a breast change. The confidence and skills to detect a change in a breast include the frequency of breast checking which needs to be performed for at least once a month, as well as the confidence to notice any breast changes in order to seek help promptly and reduce the risk of delay in presentation (Cancer Research UK, 2009; Forbes et al., 2010; Linsell et al., 2008). Furthermore, Forbes and colleagues (2010) proposed five domains of breast cancer awareness which are knowledge of breast cancer symptoms; confidence, skills, and behavior in relation to detecting a breast change; anticipated delay in contacting the doctor on discovering any symptoms; knowledge of age-related risk and lifetime risk of breast cancer; and knowledge of breast screening program.

The details of the eight domains of breast cancer awareness are presented as follows.

1) Knowledge of breast cancer symptoms

The knowledge of breast cancer symptoms, according to Linsell and colleagues (2008), consists of lump and non-lump symptoms. A lump or thickening in the breast is the most common symptom felt by women (Grundfeld et al., 2002; Linsell et al., 2008; Nurleli, 2013; Renganathan et al., 2014; Tazhibi & Feizi, 2014; Ukwanya, Yusufu, Nmadu, Garba, & Ahmed, 2008). A lump usually made women seek help or consult a medical doctor early (Kumari & Goonewardena, 2011; Ramirez et al., 1999).

The cancerous mass is more likely characterized as a hard and painless mass with irregular edges. However, breast cancer can be also tender, soft, or rounded (ACS, 2014a). In this regard, although the majority of women are aware of a breast lump, this may lead to misinterpreting other potential breast cancer symptoms and the misconception that a lump is the only symptom of breast cancer. Consequently, a delay in the presentation of a breast cancer patient, in particular among women with lower socioeconomic status could be evidenced (Rauscher et al., 2015).

The non-lump symptoms of breast cancer were reported to be more likely to cause a delay of presentation. The non-lump symptoms include a change in nipple position, pulling in of the nipple or turning inward, nipple rash, discharge or bleeding from a nipple, pain in a breast or armpit or heaviness, puckering or dimpling or skin irritation in breast skin, redness of breast skin, change in the size and shape of the breast or nipple (Linsell et al., 2008; Ramirez et al., 1999). Here, women who were knowledgeable in five or more of the non-lump symptoms of breast cancer were reported as being aware of breast cancer symptoms (Linsell et al., 2010).

A number of previous studies regarding breast cancer awareness in the knowledge of breast cancer symptoms have been conducted with inconsistent study results. A low proportion of women reported being aware of five or more of the non-lump symptoms of breast cancer (Forbes et al., 2010; Linsell et al., 2008; Nurleli, 2013). While previous studies have revealed that the majority of women were aware of discharge from a nipple and pain as the initial symptoms of breast cancer (Al-Dubai et al., 2014; Dey et al., 2015).

However, the other non-lump symptoms, including change in nipple position, nipple rash, redness of breast skin, and puckering of breast skin were reported as the least aware among women (Al-Dubai et al., 2014; Grundfeld et al., 2002; Montazeri et al., 2008; Renganathan et al., 2014; Tazhibi & Feizi, 2014). In addition, most women associated pain with the existence of cancer and paid no attention to the seriousness of a painless lump which contributed to a delay in seeking medical help (Ukwenya et al., 2008).

From this, the detail analysis of women's interpretation and perception regarding each potential breast cancer symptom is, therefore, important. Women also need clearer information regarding each breast cancer early warning sign and symptom to increase their awareness of early warning signs and symptoms. This could contribute to a higher attendance in screening and education programs (Tazhibi & Feizi, 2014).

2) Frequency of breast checking

Women who reported their frequency of breast checking of at least once a month are indicated as aware of breast cancer (Cancer Research UK, 2009; Linsell et al., 2008). In this regard, self-checking the breast enhances women's process of getting to know how their own breasts look and feel normally and become

familiar with their appearance, and the way that they will change throughout her life. Consequently, they gain confidence about noticing any change which might help to detect breast cancer early (National Health Service [NHS], 2006; Thornton & Pillarisetti, 2008) and receive a quick and an effective management of this disease (Grundfeld et al., 2002). Previous studies conducted in Asian countries, including in Korea, and Indonesia reported a low proportion of women who self-checked their breasts regularly, as 13.2 and 25 percent, respectively (Nurleli, 2013; Yoo et al., 2012). In contrast, previous studies in the United Arab Emirates, India, and Malaysia reported higher numbers of women who performed breast self-examination, however these figures were less than 50 percent (Dey et al., 2014; Elobaid et al., 2014; Subramanian et al., 2013).

3) Confidence to detect a breast change

The confidence to detect for a breast change indicates one awareness of breast cancer (Linsell et al., 2008). A number of previous studies regarding confidence to detect a breast change have been conducted with inconsistent study results. A previous study in the UK revealed that nearly one third of older women was not confident in noticing a breast change and did not check their breasts on a monthly basis (Forbes et al., 2010). In addition, in accordance with Linsell and colleagues (2008), Asian women in the UK had low breast cancer awareness regarding the confidence to detect breast changes.

4) Knowledge of age-related risk

Increasing age is one of the strongest risk factors for developing breast cancer (ACS, 2014a). The risk of breast cancer increases doubling every 10 years until menopause (McPherson et al., 2000). A previous study in the UK revealed that women lacked knowledge regarding increasing age as a risk factor of breast cancer

(Linsell et al., 2008). Only one percent of women were aware that women of older ages were at the greatest risk of developing breast cancer (Moser, Patnick, & Beral, 2007). Similarly, a study conducted in Indonesia also reported that very few women were aware of the age-related risk of developing breast cancer (Nurleli, 2013).

5) Knowledge of lifetime risk

Knowledge of lifetime risk indicates that women have to know that one out of eight (1/8) women have a lifetime risk of developing breast cancer during their lifetime (ACS, 2014b; Cancer Research UK, 2015b). Previous studies reported that women were overly optimistic regarding the lifetime risk of developing breast cancer (Grundfeld et al., 2002; Linsell et al., 2008; Webster & Austoker, 2006). As a consequent, women were ill-equipped in decision making which led to delayed presentation as well as poor survival (Ramirez et al., 1999).

6) Perceived heightened risk

Perceived heightened risk indicates that women with a family history of breast cancer are aware about their heightened risk of developing breast cancer as compared to other women who do not have risk factors (Audrain-McGovern et al., 1995, 2003). In accordance with Audrain-McGovern and colleagues (1995, 2003), around one quarter to one third of women perceived their risk as lower.

7) Knowledge of risk factors

Knowledge of risk factors is identified according to the risk factors of breast cancer. A number of risk factors in developing breast cancer have been evidenced which include a family history of breast cancer, personal history of breast cancer, certain benign breast diseases, earlier menarche and late menopause, nulliparity and a late age at first birth, and hormone replacement therapy (HRT) as follows (McPherson et al., 2000; ACS, 2014a).

Family history of breast cancer

A family history of breast cancer is one of the important factors which placed women at a high risk for developing breast cancer. Having a first-degree relative as such a mother, sister, or daughter, with breast cancer doubles the risk for developing breast cancer. Having two first-degree relatives with breast cancer will increase the risk approximately 3-fold (ACS, 2014a).

First-degree relatives share around half of their genes, while second-degree relatives share around a quarter of their genes (National Health Service [NHS], 2015). In addition, having a father or brother diagnosed with breast cancer also increases the risk for developing breast cancer. However, it have been reported that most women who have breast cancer do not have a family history of breast cancer (ACS, 2014a).

The features of family history which increase the risk for breast cancer include two or more first-degree relatives (parent, sibling, or child) or second-degree relatives (grandmother, granddaughter, aunt, niece, half-sibling) with breast or ovarian cancer; breast cancer which occurs before 50 years of age (premenopausal) in a close relative; one first degree female relative (parent, brother or sister, or child) diagnosed with breast cancer younger than 40 years old; family history of both breast and ovarian cancer; one or more relatives with breast and ovarian cancer or two independent breast cancers; male relatives with breast cancer; and two breast cancer susceptibility genes have recently been identified (BRCA1 and BRCA2) (Afonso, 2009; National Institute for Health and Care Excellent [NICE], 2015).

Furthermore, the Ministry of Health Republic of Indonesia (2015b) also describes the features of the family history of breast and ovarian cancer which increase the risk for breast cancer. These include three or more family members with

breast or ovarian cancer, two or more family members with breast or ovarian cancer younger than 40 years old, a family member with breast or ovarian cancer, and a family history of bilateral breast cancer (Ministry of Health Republic of Indonesia, 2015b).

Personal history of breast cancer

A woman with a personal history of breast cancer in one breast has a 3 to 4-fold increased risk for developing a new cancer in the other breast, or in another part of the same breast (ACS, 2014a).

Certain benign breast diseases

The risk of breast cancer increases in women with certain benign breast diseases. Based on how the benign breast diseases affect breast cancer risk, there are three groups of benign breast diseases, including non-proliferative lesions, proliferative lesions without atypia, and proliferative lesions with atypia, including lobular carcinoma in situ as follows (ACS, 2014a).

Non-proliferative lesions

These types of lesions have a little extent in affecting breast cancer risk, and commonly are not associated with an overgrowth of breast cancer. These conditions include fibrosis and/or simple cysts, mild hyperplasia, adenosis (non-sclerosing), ductal ectasia, a single papilloma, fat necrosis, phyllodes tumor (benign), periductal fibrosis, epithelial-related calcifications, squamous and apocrine metaplasia, other benign tumors (lipoma, hamartoma, hemangioma, neurofibroma, adenomyoepithelioma) (ACS, 2014a).

Proliferative lesions without atypia

These type of lesions increase the risk of breast cancer slightly (1.5 to 2 times), as these conditions show the excessive growth of cells in the ducts or lobules

of breast tissue. These type of lesions include usual ductal hyperplasia (without atypia), fibroadenoma, sclerosing adenosis, several papillomas (called papillomatosis), and radial scar (ACS, 2014a).

Proliferative lesions with atypia

While proliferative lesions with atypia, which include atypical ductal hyperplasia (ADH) and atypical lobular hyperplasia (ALH), have a stronger risk for breast cancer, 3.5 to 5 times higher than normal. These conditions show the overgrowth of cells in the ducts or lobules of the breast tissue, with some of the cells no longer appearing normal. Also, the risk of breast cancer is higher for women with a family history of breast cancer and either hyperplasia or atypical hyperplasia (ACS, 2014a).

Lobular carcinoma in situ

Women with lobular carcinoma in situ have a high risk of developing invasive cancer in either breast, around 7 to 11-fold (ACS, 2014a; Afonso, 2009). According to ACS (2014a), in this condition, the cells which look like cancer cells are growing only in the lobules of the breast, and are not growing into the wall of lobules.

Earlier menarche and late menopause

Women with more menstrual cycles have an increased risk of developing breast cancer. This could be because the women who have an onset of earlier menstruation (before the age of 12) and have menopause later in life (after 55 years of age) have a longer exposure time to the hormones estrogen and progesterone (ACS, 2014a).

Nulliparity and late age at first birth

Women who had their first child after the age of 30 or have had no children have a slightly higher breast cancer risk. The risk of breast cancer is

increased two fold more than women who have had their first child at a younger age. On the other hand, having pregnancies and becoming pregnant at a young age reduce breast cancer risk (ACS, 2014a).

Hormone replacement therapy

Among current users of HRT and for those who have used HRT for one to four years previously, the relative risk of breast cancer is increased by a factor of 1.023 for each year of use. HRT increases breast cancer density and reduces the sensitivity and specificity of breast cancer screening (McPherson et al., 2000).

Alcohol consumption

The use of alcohol increases the risk of developing breast cancer. The risk is increased 1.5 fold for those who have two or five drinks daily as compared with women who do not consume alcohol (ACS, 2014a).

Overweight

Being overweight or obese (BMI > 25) in post-menopausal women increases breast cancer risk two fold (McPherson et al., 2000). Women who have more fat tissue after menopause can increase their breast cancer risk because of raising estrogen levels (ACS, 2014a).

The statuses of knowledge of breast cancer risk factors

Previous studies have been conducted regarding the awareness of knowledge of breast cancer risk factors. A poor understanding of breast cancer risk factors was revealed among women, even though the women were aware of breast cancer in general (Washbrook, 2006). In addition, a study conducted among first-degree relatives of breast cancer patients in Malaysia revealed that the majority of the women were aware that having a family history of breast cancer increases the chance of developing breast cancer (Subramanian et al, 2013). Similarly with the findings of

other studies conducted among women in Asian countries, it was found that women were aware of family history as a risk factor for breast cancer, however the awareness of other risk factors related to reproductive and hormonal factors were found to be poor (Al-Dubai et al., 2011; Tazhibi & Feizi, 2014).

8) Knowledge of screening program

Knowledge of breast cancer screening program consists of knowing the existence of breast cancer screening program, the age that women are first invited to attend a screening program; the age of starting CBE, mammography, and BSE; and the recommended frequency of CBE, mammography, and BSE (Forbes et al., 2010; Subramanian et al., 2013).

Previous studies have shown a lack of awareness in women regarding the age of first attending the breast cancer screening program among women in the UK, even though these women were aware of the existence of breast cancer screening programs (Forbes et al., 2010). In addition, another study in Malaysia among first-degree relatives revealed women were aware of mammography and BSE as screening modalities (Subramanian et al., 2013). The breast cancer screening modalities available in Indonesia consist of breast self-examination, clinical breast examination, and a referral mammography, with specific recommendations for each screening as described previously. Therefore, raising awareness of each of these screening modalities is important.

Factors Contributing to Breast Cancer Awareness

Women's personal characteristics and participation in screening and public educational programs have contributed to the awareness of breast cancer. The personal characteristics including age, educational qualification, marital status, family

income, family and personal history of breast cancer were reported as factors contributing to the awareness of breast cancer among women (Linsell et al., 2008; Liu et al., 2014; Tazhibi & Feizi, 2014).

In accordance with Linsell and colleagues (2008) and Liu and colleagues (2014), women with higher levels of education were more likely to be aware of breast cancer symptoms and risk factors. In addition, Liu and colleagues reported that younger aged women (i.e., age 25 to 35) with higher family incomes were more likely to be more aware of breast cancer. Similarly, Al-Dubai and colleagues (2011) also reported that women who were married and had high educational levels were more likely to be aware of breast cancer. Moreover, women with a positive family history and personal history of breast cancer were more likely to be aware of breast cancer (Liu et al., 2014; Tazhibi & Feizi, 2014). Furthermore, Tazhibi and Feizi (2014) also reported that women who participate or attend in screening and public educational programs were more likely to have high levels of awareness of breast cancer symptoms and risk factors.

Measurement of Breast Cancer Awareness

To date, the Breast Cancer Awareness Measure (Breast-CAM) is evidenced as a valid and reliable instrument to measure breast cancer awareness. This instrument was developed by Cancer Research UK, King's College London and University College London in 2009. This instrument was validated by Linsell and colleagues (2010) with 1035 women who attended the National Health Service (NHS) Breast Screening Program in South East London.

Breast-CAM consists of seven domains which are knowledge of breast cancer symptoms; confidence, skills and behavior in relation to detect breast change;

anticipated delay in contacting a medical doctor; barriers to seek medical help; knowledge of age-related risk and lifetime risk; knowledge of the NHS breast cancer screening program; and knowledge of risk factors (Cancer Research UK, 2009).

In accordance with Cancer Research UK (2009), the knowledge of breast cancer symptoms consists of 11 symptoms which are change in nipple position, pulling in of nipple, pain in a breast or armpit, puckering or dimpling in breast skin, discharge or bleeding from a nipple, a lump or thickening in the breast, nipple rash, redness of breast skin, a lump or thickening under an armpit, and change in the size and shape of the breast or nipple. On application, women are asked to identify the symptoms from a list of 11 symptoms (two lump and nine non-lump), which match their opinion of each potential breast cancer symptom (Cancer Research UK, 2009). The women have to identify at least five non-lump symptoms, which is more than a half, to get a one point score of breast cancer awareness (Linsell et al., 2010).

The knowledge of age-related risk and lifetime risk are recorded as correct or incorrect. The age-related risk response categories consist of a 30-year-old woman, a 50-year-old woman, a 70-year-old woman, and a woman at any age. To get a one point score, the women have to identify that a 70-year-old woman is most likely to get breast cancer (Cancer Research UK, 2009).

With regard to confidence and behavior to breast change, the response categories for breast checking behavior are rarely or never, at least every six months, at least once a month, and at least once a week. To get a one point score, the women had to report checking their breasts at least once a month or at least once a week (Cancer Research UK, 2009).

In addition, the confidence to detect breast change is recorded as correct (very confident/fairly confident) or incorrect (not confident at all/slightly

confident). Furthermore, the anticipated delay in contacting a doctor is recorded verbatim as correct or incorrect. Knowledge of risk factors could be recorded as correct (strongly agree/agree) versus incorrect (not sure/disagree/strongly disagree) to explore “knowledge” rather than the strength of agreement.

Finally, women are categorized as being aware of breast cancer if they can identify five or more of the non-lump symptoms, identify that women at the age of 70 are more likely to get breast cancer, and report checking their breasts at least once a month (Linsell et al., 2010).

The Breast-CAM has high readability, and the test-retest reliability was moderate to good (.42 to .70). It also had good construct validity with cancer experts achieving higher scores than non-medical academic (50% versus 6%, $p = .001$). Also, it has been reported to distinguish between cancer specialist (women known to have higher breast cancer awareness) and non-medical academic women (Linsell et al., 2010). Additionally, Breast-CAM can be employed with respondents through a face-to-face interview, over the telephone, on the internet, or can be self-administered (Cancer Research UK, 2009). From the aforementioned, the Breast-CAM was used in this study to determine breast cancer awareness of Indonesian women at moderate to high risk of developing breast cancer.

Adherence to Breast Cancer Screening Program

The review of adherence to breast cancer screening program in this study consists of the concept of adherence to breast cancer screening program, the factors contributing to the adherence to screening program, and the measurement of adherence to screening program as follows.

Concept of Adherence to Breast Cancer Screening Program

The term adherence was defined by the World Health Organization (WHO, 2003) as the extent to which a person's behaviors correspond with agreed recommendations. Adherence involves a wide range of health behaviors related to routine preventive health behavior (such as annual mammogram screening), recommendations, and on-going health maintenance (Uniformed Service University of Health Science, 2015). In this regard, breast cancer screening is health improvement activities, including breast self-examination (BSE), clinical breast examination (CBE), and mammography, which facilitate the early detection (Charkazi et al., 2013). Therefore, adherence to breast cancer screening is the extent to which a woman has attended and practiced recommended breast cancer screening.

According to Campitelli and colleagues (2011), the adherence to breast cancer screening requires women to follow or undergo recommended and standardized breast cancer screening, with a reason for screening purpose. Similarly, adherence was defined as women's behavioral action to perform or comply with breast cancer screening according to the recommended guideline (Charkazi et al., 2013; Elobaid et al., 2014; Hasnain, Menon, Ferrans, & Szalacha, 2014; Hui, Engelman, Shireman, & Ellerbeck, 2013; Mullen, 2010).

The adherence to breast cancer screening is one of the important keys for down staging breast cancer. The regular intervals between screenings should be shorter than the time allocated to assure the early detection of breast cancer (Caleffi et al., 2010). The adherence to regular screening helps to increase the chance for detecting breast cancer while the tumor is still small size and localized (Smith et al., 2014). Routine screening was contributing to better treatment, and increasing the quality of life of women with breast cancer (Shieh et al., 2012), as well as decreasing

mortality and improving the survival rate of breast cancer patients (Carney et al., 2005; Elobaid et al., 2014).

Particularly, mammography screening has been associated with a 15 to 20 percent reduction of breast cancer mortality (Nelson et al., 2009). In addition, regular mammography in older women is associated with earlier stages of breast cancer and lower breast cancer mortality (Badgwell et al., 2008). Moreover, monthly breast self-examinations (BSE) are effective in the early detection of breast cancer symptoms due to an increased awareness in women of any changes, and therefore, are useful for the early detection of breast cancer (Kim et al., 2011).

Previous studies in Western and Asian countries revealed that women in Asian countries had lower adherence to breast cancer screening than Western countries. A study among women at increased familial risk of breast cancer in Australia by Antill and colleagues (2006), found that 42.3 percent of women adhered to BSE practice, and almost half of them (49.5%) adhered to CBE. In addition, regarding mammography screening, it was found that 70.6 percent of high risk women adhered to mammography. On the contrary, in Asian countries, a study among high risk women in Malaysia revealed the poor practice of breast cancer screening among women with a positive family history, with only 19.1 percent of women having had a mammogram and only 35.9 percent of women having performed BSE, despite the awareness and beliefs regarding breast cancer screening (Subramanian et al., 2013). In addition, a study in Korea by Yoo and colleagues (2012) revealed that only 13.2 percent of women performed BSE monthly, with the practice being higher among women at 50 years of age. The factors contributing to the adherence to breast cancer screening are discussed in the following section.

Factors Contributing to Adherence to Breast Cancer Screening Program

A number of studies have been conducted to determine the factors contributing to the adherence to breast cancer screening program to increase the level of adherence. These factors are demographic factors, knowledge of breast cancer and screening programs, and psychosocial and cultural factors as follows.

Demographic factors

The demographic factors which include age, education, income, employment status, marital status, religion, family history, health insurance, and access to a healthcare provider were reported as factors contributing to breast cancer screening adherence (Ahmadian & Samah, 2012; Boxwala, Bridgemohan, Griffith, & Soliman, 2010). In accordance with Ahmadian and Samah (2012), women at older ages and less educated were less likely to have had a mammogram in the past two years. On the other hand, women with higher educational levels and income were more likely to have had a mammogram, including women at older ages and those who were married (Montazeri et al., 2008). Similarly, Boxwala and colleagues (2010) reported that women at a college education level were more likely to have a mammogram. In addition, a study conducted among Indonesian nursing students by Juanita, Jittanoon, and Boonyasopun (2012) reported that women with a family history of breast cancer, those who were married, and women with no history of breast illness were more likely to practice BSE.

Knowledge of breast cancer and screening program

Women's knowledge regarding breast cancer and screening program is a significant factor to strengthen women's participation in breast cancer screening or cancer preventive behavior (Ahmadian & Samah, 2012; Montazeri et al., 2008). Knowledge about warning signs and screening methods could enhance women to

attend breast cancer screening (Tazhibi & Feizi, 2014). A previous study among women with a family history of breast cancer revealed a significant relationship between mammogram use and knowledge of breast cancer risk factors as the more women knew of the risk factors, the higher performance of mammography use (Subramanian et al., 2013). Another study also found that the higher the awareness, the higher the willingness of attending breast cancer screening (Shieh et al., 2012).

On the other hand, lack of knowledge to perform BSE and to have a mammogram were associated with women who did not practiced BSE and/or have mammography (Chua, Mok, Kwan, Yeo, & Zee, 2005). Lack of knowledge on the risk factors could lead to develop misconceptions as a result of non-adherence to regular screening (Subramanian et al., 2013). In addition, Subramanian and colleagues (2013) revealed that women's knowledge about family history as a risk factor of breast cancer was not congruent with the number of women who adhered to regular breast cancer screening.

Parsa, Kandiah, Rahman and Zulkefli (2006) also reported that lower screening adherence among Asian women was also associated with their knowledge of preventive health measures. Knowledge of breast cancer screening guidelines was a major predictor of regular screening, in which women who had knowledge of mammography guidelines were ten times more likely to have regular mammograms. Also, knowledge is an important factor in mammography screening use and breast self-examination (Ahmadian & Samah, 2012).

Psychosocial and cultural factors

Psychosocial and cultural factors contributed to breast cancer screening behavior include beliefs towards breast cancer screening, self-efficacy, social

influence, perceived barriers of breast cancer screening, and cultural factors as follows.

Belief toward breast cancer and early detection

The belief in the benefit of early detection among Asian women was reported as a positive association with breast cancer screening (Ahmadian & Samah, 2012). The perception of women regarding the ineffectiveness of detecting breast cancer, no presentation of any problem, and the fear of detecting breast cancer were found as the important factors in the decrease of the number of women practicing BSE (Yoo et al., 2012). A result from a previous study revealed the belief of women that breast cancer can be detected early, and that early detection improves survival rates, and the belief in the significance of BSE influenced the practice of BSE (Al-Naggar, Bobryshev, & Al-Jashamy, 2012). From this, the belief toward breast cancer and early detection become one of the important factors influencing women's adherence to breast cancer screening.

Self-efficacy to perform breast cancer early detection practice

Self-efficacy has been reported as a significant factor influencing the use of mammography screening (Hasnain et al., 2014). The adherent group to mammography had more self-efficacy towards mammography uptake than the non-adherent group (Ahmadian & Samah, 2012).

Social influence on breast cancer screening

Influence from family, friends, or someone with breast cancer has significant influenced for screening participation (Ahmadian & Samah, 2012). A previous study revealed that women who did not adhere to screening guidelines reported having less social support (Katapodi, Facione, Miaskowski, Dodd, & Waters, 2002).

Perceived barriers of breast cancer screening

A perceived barrier involves an individual's own estimation of the obstacles to adapt or perform a new behavior (Graham, 2002). A perceived barrier is viewed as a salient factor that can affect breast cancer screening practice (Kissal & Beser, 2011). The most common perceived barriers were not taking care of oneself, lack of information, and fear (Garbers, Jessop, Foti, UribeLarrea, & Chiasson, 2003). Fear of cancer, pain, cost, travel and time were also reported as the most common barriers for mammography screening (Ahmadian & Samah, 2012).

Cultural factors

According to Ahmadian and Samah (2012), in Asian traditional cultures, the embarrassment of women prevents them to show their breasts to others, including to health care providers which is a barrier for Asian women in screening practice and in delaying access to health care services. This barrier includes women being concerned with maintaining her expectation of modesty and the attitude of her male sexual partner. A significant correlation was found between beliefs regarding touching the breasts by a technician, and the number of women who have a mammography (Ahmadian & Samah, 2012).

Measurement of Adherence to Breast Cancer Screening Program

To date, the self-reported Personal History and Screening Questionnaire (PHSQ) is recommended as the best available tool to measure adherence to a breast cancer screening program (Walker, Chiarelli, Mirea, et al., 2013). The PHSQ was developed by the Ontario Familial Breast Cancer Registry (Campitelli et al., 2011). The PHSQ consists of 36 questions regarding information on breast outcomes, use of breast cancer screening within the past 12 months

(mammography, CBE, BSE, breast MRI and ultrasound), genetic testing or counseling, behavioral characteristics and general health-related characteristics (Walker, 2014).

The PHSQ comprises of 12 questions regarding breast cancer screening use for women to give either the dates (month and year) of their breast examinations or their age at the time of their last examination. Furthermore, women are asked whether their breast examinations are for screening purposes (part of a regular check-up or due to a family history of breast cancer) or for non-screening purposes (examination due to a breast problem or symptom, follow-up of a previous breast problem, or participation in a research study). The time since the last breast examination and the reason for the examination were combined into a single variable to characterize a participant's breast screening behavior (Campitelli et al., 2011).

The PHSQ has been used through face to face interviews (Walker, Chiarelli, Knight, et al., 2013), and telephone interviews (Campitelli et al., 2011; Walker, 2014) among women with familial risk of breast cancer. The accuracy of a self-reported measurement of breast cancer screening adherence has been reported by Walker, Chiarelli, Mirea, and colleagues (2013). They stated that the self-reported screening mammogram used within a 12-month period is highly accurate (over 95%) in measuring adherence. Therefore, the PHSQ was used in this study to determine adherence to breast cancer screening program of Indonesian women at moderate to high risk of developing breast cancer.

Relationship between Breast Cancer Awareness and Adherence to Screening Program

A number of previous studies have been conducted to examine the relationship between breast cancer awareness and adherence to screening program which revealed a positive association. Breast cancer awareness was found to have an influence on increasing screening behavior (Elobaid et al., 2014; Iskandarsyah, 2013; Sadler et al., 2007; Subramanian et al., 2013). In addition, there is a positive association between high awareness about screening methods, risk factors, and early warning signs with participation in screening and educational programs (Tazhibi & Feizi, 2014). Also, the higher the awareness, the higher the willingness of attending a screening was also evidenced from previous studies (Shieh et al., 2012). Furthermore, Sobani and colleagues (2012) found a relationship between knowledge of BSE and the practice of CBE among Pakistani women.

The positive association from previous evidence led to the hypothesis of this study of “there is a relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.”

Summary of the Literature Review

The literature review highlights the importance of raising breast cancer awareness and adherence to screening program in reducing mortality and morbidity as well as improving the survival rates of breast cancer patients. Hence, Asian countries, including Indonesia, in which most breast cancer patients presented in the late stages

of cancer, need to address this problem to increase the awareness of and adherence to breast cancer screening. In this regard, breast cancer awareness reflects women's knowledge about breast cancer, including symptoms, age-related and lifetime risks, risk factors, and screening programs; women's confidence and skills to detect breast change; as well as women's perceived heightened risks. Accordingly, several studies reported that the awareness of breast cancer influences the screening behavior. As the highest benefit from cancer prevention comes from the management of women who are at increased risk of this disease, addressing this issue among women in the moderate to high risk group is important. Therefore, the gaps in the literature review demonstrated a need for conducting a study to examine the relationship between breast cancer awareness and adherence to screening program among women at moderate to high risk of developing breast cancer.

CHAPTER 3

RESEARCH METHODOLOGY

This chapter presents the details of research methodology which includes research design, setting, population and samples, instrumentations, translation of the research instruments, validity and reliability of the research instruments, data collection procedure, ethical considerations, and data analysis.

Research Design

The descriptive correlational study was employed to examine the relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.

Setting

This study was conducted in Dharmais Hospital National Cancer Center, Jakarta, Indonesia. This hospital has 350 inpatient beds and it serves as a top referral cancer hospital as well as a major research and education facility for undergraduate and postgraduate education for medical doctors and nurses in Indonesia. The data collection was conducted at the oncology clinic, chemotherapy unit, and at three general inpatient wards. In this hospital, the oncology clinic is provided for consultation and physical examination of all cancer patients, including breast cancer patients. The office hours of this clinic are from 8 a.m. to 4 p.m. on

weekdays. The chemotherapy unit is a day care unit allocated for patients receiving chemotherapy. The office hours of this unit are from 8 a.m. to 5 p.m. on weekdays. The inpatient wards are provided for cancer patients who need admission. The visiting hours are usually from 11 a.m. to 1 p.m. and in the late afternoon from 5 p.m. to 6 p.m. In this hospital, one relative is allowed to stay overnight with a patient.

Population and Samples

Population

The population in this study was the first-degree relatives (mother, sister or daughter) of breast cancer patients who had a moderate to high risk of developing breast cancer while attending the oncology clinic, the chemotherapy unit, or the three general inpatient wards of Dharmais Hospital National Cancer Center, Jakarta, Indonesia.

Samples and Sampling Procedure

The samples in this study were recruited using the purposive sampling technique. The women at moderate to high risk of developing breast cancer during the data collection who met the inclusion criteria were included. The inclusion criteria were (1) first-degree relative of a breast cancer patient, (2) aged 40 years or older, (3) available and willing to be interviewed via face-to-face or telephone call, (4) not being diagnosed with breast cancer, (5) have moderate to high risk of developing breast cancer determined by having a 15 percent or more of a lifetime risk of developing breast cancer based on the International Breast Cancer Intervention Study

(IBIS) Breast Cancer Risk Evaluation Tool, (6) able to speak Indonesian, and (7) willing to participate in this study.

Sample Size

The sample size of this study was estimated and calculated using power analysis (Polit & Beck, 2012). In accordance with Polit and Beck (2012), power analysis was employed to determine the sample size to reduce the risk of type II errors. In this study, the alpha level was .05 and the power was equal to .80. The effect size calculation was calculated from a previous study entitled “Breast Cancer Knowledge and Screening Behavior among Women with a Positive Family History: A Cross-sectional Study” which included 134 women who had a positive family history of breast cancer (Subramanian et al., 2013). Based on that study, the effect size was .31. According to Polit and Beck (2012, Table 17.7 on page 425), the sample size was 85, the significant criterion was .05, and the power was equal to .80. In accordance with Subramanian and colleagues (2013), to allow for a 5 percent attrition rate, 90 eligible women were recruited in this study. However, only 87 eligible women completed the whole interview of this study. Finally, with regard to the difficulty of accessing the respondents in this study (i.e., three respondents were excluded due to the unavailability of the respondents to complete the whole interview), 87 eligible Indonesian women respondents were included in this study.

Instrumentations

In this study, the data were collected by a structured questionnaire which consisted of four parts: 1) IBIS Breast Cancer Risk Evaluation Tool,

2) Personal Characteristic and Health-Related Questionnaire, 3) Modified Breast Cancer Awareness Measure (Modified Breast-CAM), and 4) Modified Personal History and Screening Questionnaire (Modified PHSQ).

Part I: IBIS Breast Cancer Evaluation Tool

The IBIS Breast Cancer Risk Evaluation Tool was used to identify the women who have moderate to high risk of developing breast cancer. This tool was developed by Cuzick and colleagues (2013) from Cancer Research UK, Centre of Epidemiology, Mathematics and Statistics, Wolfson Institute of Preventive Medicine. It consisted of personal factors and details of family history. The personal factors included women's age; age at menarche; parity and age of first child; information of any hyperplasia, atypical hyperplasia, lobular carcinoma in situ (LCIS), or ovarian cancer; height and weight; menopause information and age at menopause; as well as hormone replacement therapy (HRT) information, including length or duration of used and its type. The family history included the details of mother, sisters, daughters, paternal and maternal grand, paternal and maternal aunts, half-sisters, affected cousins, nieces, and genetic testing information (see Appendix A). Women with at least 15 percent of lifetime risk of developing breast cancer were categorized as moderate to high risk of developing breast cancer (ACS, 2014a).

Part II: Personal Characteristic and Health-Related Questionnaire

The Personal Characteristic and Health-Related Questionnaire was used to collect data regarding the demographics and personal characteristics, including the health-related characteristics. This questionnaire was developed by the researcher based on previous evidences (Ahmadian & Samah, 2012; Sunjorn, 2002).

It consisted of 15 items: ethnicity, religion, marital status, level of education, occupation, family monthly income, insurance status, place of residence, history of breast problems and time the breast problem occurred as well as the history of seeking medical help for the breast problem, history of breast cancer, information of regular contact with a health care provider; information received regarding breast cancer symptoms, risks, breast self-exam, clinical breast exam and mammography; sources of information, and information on invitations to breast cancer screening program (see Appendix B).

Part III: The Modified Breast Cancer Awareness Measure

The Modified Breast Cancer Awareness Measure (Modified Breast-CAM) was used to collect data regarding breast cancer awareness in this study. The original version of Breast-CAM proposed by the Cancer Research UK, King's College London and University College London (Cancer Research UK, 2009) was validated by Linsell and colleagues (2010) and was found to be a valid and reliable instrument to measure breast cancer awareness in women. It has high readability, and the test-retest reliability was moderate to good (.42 to .70). It also has good construct validity with cancer experts achieving a higher score than non-medical academics (50% versus 6%, $p = .001$).

The original version of Breast-CAM consisted of seven domains: (1) knowledge of symptoms, which consists of a list of 11 early warning signs and symptoms, (2) confidence, skills, and behavior in relation to breast change, (3) anticipated delay in contacting the doctor, (4) barriers in seeking medical help, (5) knowledge of age-related and lifetime risks, (6) knowledge of the NHS breast screening program, and (7) knowledge of risk factors that consists of nine risk factors.

In this study, the Breast-CAM was modified by the researcher for the appropriateness and feasibility in the Indonesian context to best fit with the study population in this study. The Modified Breast-CAM consisted of eight domains. Each domain had different types of questions as well as a specific data analysis and interpretation as follows.

Domain 1: Knowledge of breast cancer symptoms

This domain consisted of 11 items: two lump symptoms and nine non-lump symptoms. The respondents were asked to identify the symptoms by answering either “yes” or “no” which matched their opinions of breast cancer symptoms (see Appendix C). The answers yes were coded as “1”; while the answers no were coded as “0”.

In this study, the respondents who correctly identified at least five non-lump symptoms or having scores of the non-lump symptoms as 5 to 9 were categorized as aware of breast cancer symptoms (Linsell et al., 2010). An additional analysis was performed for each symptom to identify the proportion of respondents recognizing each potential breast cancer symptom.

Domain 2: Frequency of breast checking

This domain consisted of the question “how often do you check your breast?” which was modified into “how often do you self-check your breast?” in order to clarify self-breast checking. The respondents were asked to report their frequency of self-breast checking as rarely or never/at least once every 6 months/at least once a month/at least once a week.

The respondents who reported their frequency of self-breast checking as “at least once a week” or “once a month” were classified as aware of the frequency of breast checking (Linsell et al., 2010).

Domain 3: Confidence to detect a breast change

This domain consisted of one question. The respondents were asked to rate their confidence in noticing a breast change as very confident/fairly confident/slightly confident/not confident at all. The respondents who rate their confidence as “very confident/fairly confident” were classified as aware of confidence to detect a breast change (Cancer Research UK, 2009).

Domain 4: The knowledge of age-related risk

This domain consisted of one multiple choice question. The respondents were asked to correctly identify one answer of who is more likely to develop breast cancer. The respondents who correctly identified that “a 70-year-old woman” was more likely to develop breast cancer, were categorized as aware of age-related risk (Linsell et al., 2010).

Domain 5: The knowledge of lifetime risk

This domain consisted of one multiple choice question. The respondents were asked to correctly identify one answer of how many women will develop breast cancer during their lifetime. The respondents who correctly identified “1 in 8 women” will develop breast cancer during their lifetime were categorized as aware of lifetime risk (Cancer Research UK, 2009).

Domain 6: Perceived heightened risk

The respondents were asked to identify their chance of getting breast cancer as compared with other women who do not have a close relative with breast cancer, as lower/about the same/a little higher/much higher (see Appendix C). The respondents who correctly answered “a little higher/much higher” were classified as aware of perceived heightened risk (Audrain-McGovern et al., 1995).

Domain 7: Knowledge of risk factors

This domain consisted of 10 items of breast cancer risk factors. One risk factor “having certain benign breast disease” was added in accordance with McPherson and colleagues (2000) and ACS (2014a). Also, the term “1 unit” in one risk factor “drinking more than 1 unit of alcohol a day” was modified into “drinking more than ‘a small single glass (25 ml)’ of alcohol a day” (Cancer Research UK, 2015a).

The respondents were asked to identify their agreement of a list of 10 items as strongly disagree/disagree/not sure/agree/strongly agree that matched their opinion of the risk factors of developing breast cancer (see Appendix C). The respondents who identified strongly agree/agree on each risk factors were classified as aware of each of the risk factors (Cancer Research UK, 2009).

Domain 8: Knowledge of the breast cancer screening program

This domain consisted of eight questions, which was modified according to the Indonesian breast cancer screening program. The first question asked regarding the existence of the Indonesian breast cancer screening program. The respondents who answered yes to the question “Is there a breast cancer screening program in Indonesia?” were classified as aware of the existence of screening program (Forbes et al., 2010), and were further asked the remaining seven questions.

The second question was a multiple choice question which asked the age of first invitation of women to the breast cancer screening program. The respondents who correctly identified the age as “30 years old” were classified as aware of the age of first invitation. The third question was a multiple choice question about the age of first CBE. The respondents who correctly answered 30 years old

were classified as aware of the age of first CBE (Ministry of Health Republic of Indonesia, 2015b).

The fourth question was a multiple choice question about the frequency of the CBE. The respondents who correctly answered “at least every year” were classified as aware of the age of frequency for the CBE. The fifth question was a multiple choice question about the age of first mammography. The respondents who correctly answered “40 years old” were classified as aware of the age of first mammography (Ministry of Health Republic of Indonesia, 2015b).

The sixth question was a multiple choice question about the frequency of mammography. The respondents aged 40 to 50 years who correctly answered “at least every two years” and the respondents aged older than 50 years who correctly answered “at least every year” were classified as aware of the frequency of mammography. The seventh question was a multiple choice question about the age of first BSE. The respondents who correctly answered “20 years old” were classified as aware of the age of first BSE. The final question was a multiple choice question about the frequency of BSE. The respondents who correctly answered “at least every month” were classified as aware of the frequency of BSE (Ministry of Health Republic of Indonesia, 2015b).

Part IV: The Modified Personal History and Screening Questionnaire

The Modified Personal History and Screening Questionnaire (Modified PHSQ) was used to collect data regarding adherence to the breast cancer screening program in this study (see Appendix D). Since the original version of PHSQ was used to examine adherence to breast and ovarian cancer screening (Campitelli et al., 2011),

the researcher modified the questionnaire to best fit with the breast cancer screening program.

The original PHSQ consisted of questions regarding information on breast outcomes, use of breast cancer screening (mammography, CBE, BSE, breast MRI, ultrasound, and other tests), genetic testing or counseling, and behavioral and general health-related characteristics. In the original PHSQ, the questions related to breast cancer screening included 6 items: 1) whether the women ever had breast cancer screening, 2) the time since last breast examination: either the date (month and year), or age at each of the recent screenings, 3) the reason, whether the examinations were for screening purposes (part of a regular check-up or routine screening, part of Ontario breast cancer screening program, family history of breast cancer) or for non-screening purposes (breast problem or symptoms), or others; 4) reason of not having a breast examination, 5) who or what encouraged or inspired her to have the examination, and 6) whether she had other tests of breast cancer screening and for which reasons.

In this study, only the items related to adherence to the CBE and mammography screening were included in this study. The Modified PHSQ in this study consisted of two parts.

Part I: Adherence-related CBE and mammogram

The first part consisted of six adherence-related questions which included three questions for each of CBE and mammogram: 1) whether ever had CBE and mammogram, 2) the time since last CBE and mammogram, either the date (month and year), or the age at the last screening; 3) the reason for the last CBE and mammogram (see Appendix D).

In addition, modifications were made in the reasons to have a CBE and mammogram for screening purposes as “part of a regular check-up or routine screening, part of Indonesian breast cancer screening program, due to family history of breast cancer, due to age or old enough, due to the use of hormone therapy, due to lifestyle” or for non-screening purposes as “referred from health care provider due to breast problem or symptoms, cannot solve a problem with breast symptoms after waiting, doing self-care or looking the other way,” and others.

As mentioned earlier, the adherence to breast cancer screening program in this study consisted of adherence to the CBE and mammography. The time since the last CBE and/or mammogram and the reason for the last CBE and/or mammogram were combined into a single variable to characterize the respondents' adherences for each CBE and mammogram (Campitelli et al., 2011).

In this regard, the adherence was claimed based on two elements: 1) if the time since last CBE and/or mammogram was in accordance with the Indonesian national guideline proposed by the Ministry of Health Republic of Indonesia (2015b), and 2) if the reason of the last CBE and/or mammogram was for the screening purpose based on Campitelli and colleagues (2011) and the Ministry of Health Republic of Indonesia (2015b).

From this, the respondents who had a CBE during the past year (≤ 12 months) and with a reason for screening purpose were categorized as adherence to CBE. While the respondents who had a mammography screening in the past year (≤ 12 months) for women aged older than 50 or in the past two years (≤ 24 months ago) for women aged 40-50 and with a reason for screening purpose were categorized as adherence to mammography.

Part II: Additional questions of adherence-related CBE and mammogram

The second part of the Modified PHSQ consisted of an additional three questions related to screening: 1) reason of not having a CBE and/or mammography screening, 2) other tests of breast examination and the reason, and 3) what or who encouraged to have the CBE and/or mammography screening. In this part, the question “who or what encouraged you to have the screening” was modified according to Indonesian health care conditions by adding “nurse or midwife” and “village health volunteer.” Also, the reasons for not having the screening were modified according to the cultural beliefs of breast cancer screening in Indonesia that were derived from a previous study (Nurleli, 2013) by adding other reasons that included “nothing can be done to prevent or stop getting breast cancer,” “because it is fate and God’s will,” “detecting a small lump in breast is not serious and there is no need to hurry to seek help,” “females cannot expose their breasts and cannot be examined by a male doctor,” “no free time to visit a medical doctor due to the role as a mother and wife to take care of the children or family” (see Appendix D).

Translation of the Research Instruments

In this study, the questionnaires were initially developed in an English version. In order to ensure the equivalence of these instruments in the Indonesian language, the researcher used the back translation technique (Hilton & Skrutkowski, 2002) performed by Indonesian bilingual translators. In this study, the translators were English experts from the University of Padjadjaran and the Islamic State University of Sunan Gunung Jati Indonesia (see Appendix E). The questionnaires

were translated from the original English version into an Indonesian version by the first translator. Afterward, the Indonesian version questionnaires were translated back into an English version by the second translator. Thereafter, the two English versions were examined for comparability of language and similarity of interpretation as well as any discrepancies and differences between the original version and the back-translated version by the third translator. No major discrepancies were found between the two English versions.

Validity and Reliability of the Research Instruments

Validity of the Research Instruments

The instruments were evaluated for content validity, language suitability, and criteria scoring of the entire questionnaire by three experts from Prince of Songkla University (see Appendix F). Each item was evaluated for appropriateness with its related construct. Modifications and revisions of the instruments were made based on the experts' recommendations and suggestions under the thesis supervisory team.

Reliability of the Research Instruments

The approved revised versions of the questionnaires were initially tested on 20 first-degree relatives in the study hospital who met the inclusion criteria of the study in order to assess the reliability of the translated instruments. The reliability of the translated instruments of the Modified Breast-CAM and the Modified PHSQ were assessed for internal consistency using the Kuder-Richardson (*KR20*) coefficient. The results of reliability coefficients were .78 for the Modified Breast-

CAM and .86 for the Modified PHSQ. According to Lance, Butts, and Michels (2006), these results were acceptably reliable.

Data Collection Procedure

In this study, data collection was conducted among Indonesian women at moderate to high risk of developing breast cancer at Dharmais Hospital National Cancer Center, Indonesia. The data collection was sequentially conducted as follows.

First, the researcher well informed the head nurses and staff nurses in the oncology clinic, chemotherapy unit, and the three general inpatient wards of the objectives and methods in conducting this study, including the potential risks and benefits and ethical conduct.

Next, the researcher identified the lists of breast cancer patients from the medical records and the potential respondents in each setting. Prior to approach the breast cancer patients and the potential respondents, the researcher asked the staff nurses in each setting to introduce the researcher to the breast cancer patients and the potential respondents, and ask for permission to start the recruitment process. Importantly, the researcher ascertained from the nurses that the selected patients were informed of their diagnosis of breast cancer and disclosure to the potential respondents.

Then, the breast cancer patient was approached and asked for permission to introduce her first-degree relatives (mother, sister, or daughter) aged 40 years or older to participate in this study. Fully informed consent was obtained regarding the study and permission to contact her first-degree relatives was requested.

After the breast cancer patient agreed, the information of her first-degree relative(s) and her personal information were obtained (see Appendix G).

After that, the recruitment process was started by contacting each first-degree relative to ascertain their interest and willingness to participate in the study, either face-to-face or by a telephone call. The face-to-face interview was used when the respondents were available in the setting. While the telephone interview was optional used in case of the respondents were not available in the setting. Fully informed consent was used to inform the objectives of the study, the study procedures including the inclusion criteria for participating in this study, the benefits, risks, rights, and responsibilities, as well as the process of keeping the respondents' confidentiality (see Appendix H). The first-degree relatives interested in participating in the study were arranged for an appointment schedule to participate further in the study.

At the time of the appointment, the potential respondents were assessed for their eligibility to participate in the study including the moderate to high risk criteria using the IBIS Breast Cancer Risk Evaluation Tool.

Finally, the eligible respondents who had have at least a 15 percent of lifetime risk of developing breast cancer continued to participate in this study. Thereafter, the researcher started collecting the data by interviewing each respondent either face-to-face or via a telephone.

Ethical Considerations

In this study, concerning the rights of human respondents, the researcher requested and was granted an ethical committee review and approval from both the Institutional Review Board of the Faculty of Nursing, Prince of Songkla

University, Thailand and the committee of the Medical Research Ethics of the Dharmais Hospital National Cancer Center, Indonesia. Permission to access to the breast cancer patients and respondents was granted from the Director of Dharmais Hospital National Cancer Center, Indonesia. The data collection procedure was conducted after obtaining all approvals (see Appendix I).

In this study, informed consent was conducted based on the standard informed consent procedure and the principle of respect for autonomy of the respondents. According to Holloway and Wheeler (2002), respect for autonomy means that the respondents must be allowed to make a free, independent or the right of informed consent or refusal to take part, and informed choice without coercion. Informed consent is closely linked with promise of anonymity, confidentiality, and privacy of the respondents (Robley, 1995). Informed consent was given for each breast cancer patient and her first-degree relative. The objectives and the contributions of this study were explained to both of them. They were also informed that the results of this study may be used in publications and presentations. In addition, they were assured that their identity would be kept confidential and anonymous. Here, the researcher used codes and pseudonyms throughout the data collection as well as data analysis. Furthermore, throughout the study, privacy was maintained since the researcher was well aware of this issue both for breast cancer patients and their first-degree relatives. The researcher approached both the breast cancer patients and their first-degree relatives by avoiding of attracting the attention of others.

In this study, according to Orb, Eisenhauer, and Wynaden (2001), respondents were treated with respect, well-informed of their right to freely decide whether to participate in the study, and the right to withdraw any time without penalty. From this, it was explained to the respondents that their participation in this study was

entirely voluntary and they had the right to withdraw from the study at any time. There is no penalty to withdraw and it will not influence the service they and their family receive from the hospital. In addition, they were informed that there is no cost of payment to participate in this study.

Since the respondents in this study were the first-degree relatives of breast cancer patients, family-based recruitment was employed to recruit the respondents (Beskow et al., 2004). The breast cancer patients were asked to provide the contact information of their first-degree relatives and they gave permission for the researcher to contact their first-degree relatives. In this regard, both written and/or verbal informed consents were given to the breast cancer patients and to the first-degree relatives. In accordance with Beskow and colleagues (2004), the researcher informed the respondents of the reasons of being contacted, the way their personal information was obtained, and what would happen to that information if they decided not to participate.

The researcher also explained the study procedures including the screening process to include the eligible respondents who have moderate to high risk of developing breast cancer based on the risk assessment tool. In this regard, the respondents were asked for their permission and willingness to be screened for the moderate to high risk criteria and the researcher explained that if they are not eligible for moderate to high risk, their information would be deleted from the records of the study. According to Beskow and colleagues (2004), in the recruitment process, the researcher should be sensitive to the fact that some individuals from families at increased risk will have no prior knowledge of their risk status. From this, the researcher prepared to offer information of counseling resources as needed for the respondents (Beskow et al., 2004).

Data Analysis

Data obtained from the study results were entered, recoded, cross-checked, and analyzed using SPSS for Windows version 20.0 for both descriptive and inferential statistics.

1. Demographic characteristics were analyzed by using frequency and percentage. Among these, age and time of breast problem were also analyzed and interpreted as mean and standard deviation (*SD*), whereas family monthly income was analyzed and interpreted as median and interquartile range (*IQR*).

2. The risks of breast cancer were analyzed by using frequency and percentage. Among these, age at diagnosis, age at menarche, age at first child, and age at menopause were also analyzed and interpreted as mean and *SD*.

3. Breast cancer awareness and adherence to screening program were analyzed by using frequency and percentage.

4. The hypotheses testing to determine the relationship between breast cancer awareness and adherence to screening program was analyzed by using the non-parametric test since both variables were categorical data. Specifically, the Fisher exact test was used to test the relationship between these two variables since all cross tabulation indicated that more than 20 percent of cells had an expected count less than five. Statistical significance was determined at $p < .05$.

5. One domain of breast cancer awareness regarding knowledge of age-related risk was not included in the hypotheses testing since no variability of its response.

CHAPTER 4

RESULTS AND DISCUSSIONS

The results and discussions sections provide details on the study results and the discussions on the findings of this study. The research findings, the results of the research hypothesis testing, and the discussions of those findings, including demographic characteristics of the study population and risks of breast cancer are presented. The results and discussions are presented according to the objectives of this study as follows: demographic characteristics of the study population and risks of breast cancer, awareness of breast cancer, adherence to screening program, and the relationship between breast cancer awareness and adherence to screening program among Indonesian women at moderate to high risk of developing breast cancer.

Results

Demographic Characteristics of the Study Population and Risks of Breast Cancer

In this study, data were obtained from 87 eligible Indonesian women aged 40 years or older who had not been diagnosed with breast cancer but had a first-degree relative diagnosed with breast cancer, and had a 15 percent or more lifetime risk of developing breast cancer based on the International Breast Cancer Intervention Study (IBIS) Breast Cancer Risk Evaluation Tool. Sixteen demographic characteristics of the respondents were analyzed and the number and percentage in each demographic characteristic are presented in Table 3.

Table 3

Number and Percentage of the Respondents' Characteristics (N = 87)

Variable	<i>n</i>	%
Age (years)		
40 - 50	57	65.5
≥ 51	30	34.5
<i>M (SD) = 48.74 (5.87)</i>		
<i>Min = 40</i>		
<i>Max = 63</i>		
Ethnicity		
Betawi	6	6.9
Java	30	34.5
Sunda	25	28.7
Others	26	29.9
Religion		
Islam	74	85.1
Christian	12	13.8
Buddhist	1	1.1
Marital status		
Married	76	87.4
Single	3	3.4
Widowed/Divorced	8	9.2
Level of Education		
Elementary school	6	6.9
Junior high school	15	17.2
Senior high school	28	32.2
College or university	38	43.7
Occupation		
Housewife	52	59.8
Employee	34	39.1
Retired	1	1.1
Family monthly income (IDR) ^a		
<i>Mdn (IQR) = 3,000,000 (3,000,000)</i>		
<i>Min = 500,000</i>		
<i>Max = 50,000,000</i>		
Insurance status		
No insurance	24	27.6
Government insurance	51	58.6
Private insurance	12	13.8
Place of residence		
Urban	65	74.7
Rural	22	25.3

^aUSD 1 ≈ IDR 13,197.50

Table 3 (Continued)

Variable	<i>n</i>	%
History of breast problem		
Yes	11	12.6
Fibroadenoma	1	1.1
Cyst	3	3.4
Pain under armpit	1	1.1
Lump	6	6.9
No	76	87.4
Time of breast problem (years ago)		
≤ 1	2	18.2
> 1-2	0	0.0
> 2	9	81.8
<i>M</i> (<i>SD</i>) = 10.67 (8.18)		
<i>Min</i> = 0.08		
<i>Max</i> = 29		
Seeking help for breast problem		
Yes	11	100.0
Regular contact with health care provider		
Yes	31	35.6
No	56	64.4
Breast cancer information		
Breast cancer symptoms	51	58.6
Breast cancer risks	40	46.0
Breast self-exam (BSE)	56	64.4
Clinical breast-exam (CBE)	31	35.6
Mammography	30	34.5
Sources of information ^b		
Health care provider	35	41.2
Village health volunteer	3	3.5
Friend	4	4.7
Family member	15	17.7
Internet and media	28	32.9
Had been invited for breast cancer screening program		
Yes	13	14.9
No	74	85.1

^bThe respondent could select more than one source. The percentages are based on total responses.

As shown in Table 3, the mean age of the respondents was 48.74 years (*SD* = 5.87). Most of the respondents were married (87.4%), Islam (85.1%), lived in an urban area (74.7%), housewives (59.8%), and came from diverse ethnic groups, but with a relatively high number of Javanese (34.5%). Nearly half of the respondents had completed college or university study (43.7%). Most of the respondents (72.4%)

had health insurance with a median family income of IDR 3,000,000 (USD 227.14) per month.

The majority of the respondents reported no history of breast problems (87.4%), whereas 12.6 percent of the respondents had a history of breast problems which were lump (6.9%), cyst (3.4%), fibroadenoma (1.1%), and pain under the armpit (1.1%). Among those who had a breast problem, the majority (81.8%) had a breast problem more than two years ago (Table 3).

More than half of the respondents received information regarding breast cancer which included information on breast self-examination (BSE) (64.4%) and breast cancer symptoms (58.6%). However, less than half of the respondents received information regarding breast cancer risks (46%), clinical breast-examination (CBE) (35.6%), and mammography (34.5%). In this study, the health care provider was the major source of information (41.2%), followed by the internet and media (32.9%), and family members (17.7%). Most of the respondents were never invited to a breast cancer screening program (85.1%). The majority of Indonesian women respondents in this study did not have regular contact with a health care provider (64.4%) (Table 3).

Risks of breast cancer in the Indonesian women respondents

In this study, the risk of the respondents in developing breast cancer was calculated using the computerized program of the IBIS Breast Cancer Risk Evaluation Tool to identify the eligible respondents who were at moderate to high risk (Chapter 3 page 63). The number and percentage of the risk status of the respondents are presented in Table 4.

Table 4

Number and Percentage of the Risk Statuses of the Respondents (N = 87)

Variable	<i>n</i>	%
Lifetime risk of breast cancer based on the IBIS model (%) ^a		
Mean (SD) = 22.14 (6.18)		
Risk classification		
High risk	46	52.9
Moderate risk	41	47.1

^aComparison of individual risk to the general population.

As shown in Table 4, the mean lifetime risk of breast cancer based on the IBIS model of the respondents was 22.14 percent ($SD = 6.18$). Based on risk classification, more than half of the respondents were at high risk (52.9%) while 47.1 percent were at moderate risk of developing breast cancer (Table 4).

Family history risk factors of breast cancer

In this study, as mentioned in Chapter 3 (page 63), the family history risk factors of breast cancer consist of the details of the family history in first-degree relatives and other relatives and the age at diagnosis of breast cancer in the relative. Data analysis was done to identify the family history risk factors of breast cancer of the respondents. The number and percentage of the family history risk factors of breast cancer of the respondents are presented in Table 5.

Table 5

Number and Percentage of the Family History Risk Factors of the Respondents (N = 87)

Variable	<i>n</i>	%
Number of family history of breast cancer		
1	76	87.4
2 – 3	11	12.6
Number of first-degree relatives with breast cancer		
1	84	96.6
2	3	3.4

Table 5 (Continued)

Variable	<i>n</i>	%
First-degree relatives with breast cancer ^a		
Mother	19	21.6
Sister	67	76.1
Daughter	2	2.3
Age at diagnosis of first-degree relatives (years)		
<i>M(SD) = 50.72 (10.33)</i>		
First-degree relatives with bilateral breast cancer		
Yes	8	9.2
No	79	90.8
Age of second breast cancer affected (years)		
<i>M(SD) = 49.75 (6.88)</i>		
Other relatives with breast cancer		
Yes	11	12.6
No	76	87.4
Age at diagnosis of other relatives with breast cancer (years)		
<i>M(SD) = 46.45 (9.23)</i>		

^aEither bilateral or unilateral breast cancer. The respondent could have more than one first-degree relative with breast cancer. The percentages are based on total responses.

As shown in Table 5, the majority of the respondents had a family member with a history of breast cancer (87.4%) that complied with a first-degree relative with breast cancer (96.6%). Having a sister with breast cancer was reported as the highest number of first-degree relatives (76.1%). The mean age at diagnosis of first-degree relatives with breast cancer, and a first-degree relative with bilateral breast cancer was 50.72 (*SD* = 10.33) and 49.75 (*SD* = 6.88), respectively. In addition, 9.2 percent of the respondents had a first-degree relative with bilateral breast cancer. Also, 12.6 percent of the respondents reported the existence of breast cancer in other family members. The mean age at diagnosis of other relatives with breast cancer was 46.45 (*SD* = 9.23).

Personal risk factors of breast cancer

In this study, as mentioned in Chapter 3 (page 63), the personal risk factors of breast cancer consisted of age at menarche, parity and age of the first child, history of benign breast disease, menopausal status and age at menopause, use of

hormone replacement therapy (HRT), and height and weight. Data analysis was done to identify the personal risk factors of breast cancer of the Indonesian women respondents. The number and percentage of the personal risk factors of breast cancer of the respondents are presented in Table 6.

Table 6

Number and Percentage of the Personal Risk Factors of the Respondents (N = 87)

Variable	<i>n</i>	%
Age at menarche (years)		
≤ 12	35	40.2
> 12	52	59.8
<i>M (SD) = 12.87 (1.43)</i>		
Parity		
Nulliparous	13	14.9
Parous	74	85.1
Age at first child (years) ^a		
≤ 30	61	82.4
> 30	13	17.6
<i>M (SD) = 25.81 (5.72)</i>		
Benign breast disease		
Fibro adenoma	1	1.1
No benign breast disease ^b	86	98.9
History of ovarian cancer		
Yes	0	0.0
No	87	100.0
Menopausal		
Postmenopausal	30	34.5
Premenopausal	55	63.2
Perimenopausal	2	2.3
Age at menopause (years) ^c		
≤ 55	29	96.7
> 55	1	3.3
<i>M (SD) = 50.61 (3.57)</i>		
Body mass index ^c		
> 25	20	67.7
≤ 25	10	33.3
HRT used ^d		
Current used	0	0.0
Never used	87	100.0

^aThe values are based on the respondents who had given birth. ^bIncludes no proliferative disease, unknown lump and pain. ^cThe values are based on the respondents who were post-menopause. ^dHRT used due to menopausal symptoms, ovarian resection and/or hysterectomy.

As shown in Table 6, the mean age of menarche of the respondents was 12.87 years ($SD = 1.43$). The majority of respondents (85.1%) had given birth and had their first child at or under the age of 30 years (82.4%). Most of the respondents (63.2%) were in pre-menopause. For the respondents in post-menopause (34.5%), the majority of them (96.7%) were menopausal before the age of 55 years, and more than half of them (67.7%) had a higher body mass index of over 25. No respondents currently used HRT and had never used HRT (100%). Almost all respondents (98.9%) had no history of benign breast disease.

Breast Cancer Awareness among Indonesian Women at Moderate to High Risk of Developing Breast Cancer

This part aims to describe breast cancer awareness among Indonesian women at moderate to high risk of developing breast cancer. In this study, as mentioned in Chapter 1 (page 10), breast cancer awareness consists of knowledge regarding breast cancer; the confidence, skills to detect a breast change; and the perception of a heightened risk of developing breast cancer. Breast cancer awareness in this study comprised of eight domains which included knowledge of breast cancer symptoms, frequency of breast checking, confidence to detect a breast change, knowledge of age-related risk, knowledge of lifetime risk, perceived heightened risk, as well as the knowledge of risk factors, and screening program. As mentioned in Chapter 3 (page 65), each domain had different types of questions as well as specific data analysis and interpretation. From this, the results of each domain were interpreted, described and presented specifically. The number and percentage of breast cancer awareness of the Indonesian women respondents are presented in Table 7.

Table 7

Number and Percentage of Breast Cancer Awareness of Indonesian Women at Moderate to High Risk (N = 87)

Variable	Breast cancer awareness			
	Aware		Not aware	
	<i>n</i>	%	<i>n</i>	%
Knowledge of symptoms ^a	46	52.9	41	47.1
Frequency of breast checking ^b	49	56.3	38	43.7
Confidence to detect a breast change ^c	53	60.9	34	39.1
Knowledge of age-related risk ^d	0	0.0	87	100.0
Knowledge of lifetime risk ^e	27	31.0	60	69.0
Perceived of heightened risk ^f	48	55.2	39	44.8
Knowledge of risk factors ^g				
Knowledge of screening program ^g				

^aRecognizing five or more of non-lump symptoms. ^bReporting breast checking at least once a week or once a month. ^cFairly to very confident to detect a breast change. ^dIdentifying a 70-year-old woman as most likely to get breast cancer. ^eKnowing 1 in 8 women will develop breast cancer in their lifetime. ^fPerceived risk as little higher or much higher. ^gThe number and percentage of knowledge of each breast cancer risk factor and screening program are provided (see Table 9 and Table 10).

Knowledge of breast cancer symptoms

Knowledge of breast cancer symptoms, as mentioned in Chapter 3 (page 65), consists of 11 symptoms. As seen from Table 7, more than half of the respondents (52.9%) correctly identified at least five symptoms of non-lump symptoms. An additional data analysis of each symptom was done to identify the proportion of respondents in recognizing each potential breast cancer symptom (Table 8).

Knowledge of each potential breast cancer symptom

As seen in Table 8, the majority of respondents recognized a lump in the breast (74.7%) or a discharge from the nipple (62.1%) as a potential symptom of breast cancer. More than half of the respondents recognized a change in size (56.3%), change in shape (52.9%), and pain in one of the breasts (52.9%) as potential symptoms of breast cancer. Less than half of the respondents recognized a lump under

the armpit (43.7%), change in nipple position (43.7%), nipple rash (42.5%), and redness of breast skin (41.4%) as potential symptoms of breast cancer. However, one-third of the respondents recognized puckering of breast skin as a potential symptom of breast cancer (39.1%).

Table 8

Number and Percentage of Knowledge of Each Potential Breast Cancer Symptom of Indonesian Women at Moderate to High Risk (N = 87)

Variable	Breast cancer awareness			
	Aware		Not aware	
	<i>n</i>	%	<i>n</i>	%
Change in nipple position	38	43.7	49	56.3
Pulling in of nipple	44	50.6	43	49.4
Pain in one of breasts or armpit	46	52.9	41	47.1
Puckering or dimpling of breast skin	34	39.1	53	60.9
Discharge or bleeding from nipple	54	62.1	33	37.9
A lump or thickening in the breast	65	74.7	22	25.3
Nipple rash	37	42.5	50	57.5
Redness of breast skin	36	41.4	51	58.6
A lump or thickening under an armpit	38	43.7	49	56.3
Change in the shape of the breast or nipple	46	52.9	41	47.1
Change in the size of the breast or nipple	49	56.3	38	43.7

Frequency of breast checking

More than half of respondents checked their breast at least once a week or once a month (56.3%) (Table 7), but almost half of the respondents rarely or never checked their breasts (40.2%) (Appendix J, Table 18).

Confidence to detect a breast change

Nearly two-thirds of respondents reported fairly to very confident in their ability to detect a breast change (60.9%) (Table 7), whereas 35.6 percent were slightly to not at all confident to detect a breast change (Appendix J, Table 18).

Knowledge of age-related risk

Awareness of knowledge of age-related risk, as mentioned in Chapter 3 (page 66), was interpreted if the respondents correctly identified that “a 70-year-old woman” as most likely to get breast cancer. However, none of the respondents in this study correctly identified this item as an age-related risk or most likely to get breast cancer (0%) (Table 7). Almost half of the respondents identified “a woman at any age” as most likely to get breast cancer (49.4%) (Appendix J, Table 18).

Knowledge of lifetime risk

Awareness of knowledge regarding lifetime risk, as mentioned in Chapter 3 (page 66), was interpreted if the respondent correctly identified that “1 in 8 women” will develop breast cancer in the lifetime. As seen from Table 7, only 31 percent of respondents correctly identified this item as a lifetime risk to get breast cancer.

Perceived heightened risk

As mentioned in Chapter 3 (page 66), awareness regarding a perceived heightened risk was interpreted if the respondent correctly identified that they have a little higher or much higher chance of getting breast cancer as compared with other women who do not have a close relative with breast cancer. As shown in Table 7, more than half of the respondents correctly identified their risk as “a little higher or much higher” (55.2%), but almost half of the respondents perceived that their risk as “lower to about the same” chance of getting breast cancer (43.7%).

Knowledge of risk factors

Knowledge of risk factors in developing breast cancer, as mentioned in Chapter 3 (page 67), consisted of 10 items which included doing less moderate physical activity, having a late menopause, starting the period at an early age, having

children later on in life or not at all, having a close relative with breast cancer, being overweight, drinking alcohol, using an exogenous hormone, having certain benign breast disease, and having a past history of breast cancer. The awareness of risk factors was interpreted if the respondent identified their agreement as “strongly agree” or “agree.” The data analysis was done specifically for each item as displayed in Table 9.

Table 9

Number and Percentage of Knowledge of Breast Cancer Risk Factors of Each Item of Indonesian Women at Moderate to High Risk (N = 87)

Variable	Breast cancer awareness			
	Aware		Not aware	
	<i>n</i>	%	<i>n</i>	%
Having a past history of breast cancer	56	64.4	31	35.6
Having certain benign breast disease	57	65.5	30	34.5
Using exogenous hormone	35	40.2	52	59.8
Drinking alcohol	41	47.1	46	52.9
Being overweight	22	25.3	65	74.7
Having a close relative with breast cancer	45	51.7	42	48.3
Having children later on in life or not at all	32	36.8	55	63.2
Starting the periods at an early age	11	12.6	76	87.4
Having a late menopause	16	18.4	71	81.6
Doing less moderate physical activity	30	34.5	57	65.5

As seen from Table 9, around two-thirds of the respondents answered strongly agree or agree for items about having certain benign breast disease (65.5%) and having a past history of breast cancer (64.4%) as risk factors to develop breast cancer. More than half of the respondents were aware of having a close relative with breast cancer as an increased risk factor for breast cancer (51.7%). Almost half of the respondents identified drinking alcohol (47.1%), using exogenous hormone (40.2%), and having children after the age of 30 or having no children at all (36.8%) as risk factors to develop breast cancer. A quarter of respondents (25.3%) strongly

agreed/agreed that being overweight was a risk factor of breast cancer. Only 18.4 percent and 12.6 percent of respondents strongly agreed or agreed that having a late menopause and starting the period at an early age were risk factors of breast cancer, respectively.

Knowledge of screening program

The knowledge of breast cancer screening program, as mentioned in Chapter 3 (page 67), consisted of eight items. The number and percentage of knowledge of breast cancer screening program among Indonesian women at moderate to high risk of developing breast cancer are presented in Table 10.

Table 10

Number and Percentage of Knowledge of Breast Cancer Screening Program of Indonesian Women at Moderate to High Risk (N = 87)

Variable	Breast cancer awareness			
	Aware		Not aware	
	<i>n</i>	%	<i>n</i>	%
Knowing the existence of screening program	62	71.3	25	28.7
Knowing the age of first invitation is 30 years old ^a	24	38.7	38	61.3
Knowing the age of first CBE ^a	21	33.9	41	66.1
Knowing the age of first mammography ^a	12	19.4	50	80.6
Knowing the age of first BSE ^a	43	69.4	19	30.6
Knowing the frequency of CBE ^a	39	62.9	23	37.1
Knowing the frequency of mammography ^a	8	12.9	54	87.1
Knowing the frequency of BSE ^a	47	75.8	15	24.2

^a*n* = 62

As shown in Table 10, around two-thirds of respondents were aware of the existence of breast cancer screening program in Indonesia (71.3%), but only 38.7 percent knew the age of the first invitation for breast cancer screening.

With regard to the age of starting breast cancer screening modalities and the recommended frequency, two-thirds of the respondents knew the

recommended frequency of BSE (75.8%), age of the first BSE (69.4%), and the recommended frequency of a CBE (62.9%), but only 33.9 percent knew the age of the first CBE. However, the majority of respondents were not aware of the age of when mammography screening starts and the recommended frequency. As shown in Table 10, only 19.4 percent knew the age of the first mammography and only 12.9 percent knew the recommended frequency of mammography (Table 10).

Adherence to Screening Program among Indonesian Women at Moderate to High Risk of Developing Breast Cancer

This part aims to describe the adherence to the screening program among Indonesian women at moderate to high risk of developing breast cancer. In this study, the adherence to breast cancer screening program consisted of adherence to the clinical breast examination (CBE) and mammography screening. A data analysis was done to identify the overall adherence to CBE and mammography screening, as well as the additional analysis of time since the last CBE and mammography based on each age group, and the reason for having and not having a CBE and/or mammography.

As mentioned in Chapter 3 (page 70) in this study, adherence to a CBE was interpreted if the respondent had a CBE for screening purposes in the past year (\leq 12 months ago). While adherence to mammography was interpreted if the respondent was older than 50 years or between 40 and 50 years old and had a mammography for screening purposes in the past year (\leq 12 months ago) or in the past two years (\leq 24 months ago), respectively. The number and percentage of adherence to a CBE and mammography screening of Indonesian women at moderate to high risk are presented in Table 11.

Table 11

Number and Percentage of Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87)

Variable	<i>n</i>	%
Adherence to CBE screening		
Adherence	4	4.6
Non-adherence	83	95.4
Adherence to mammography screening		
Adherence	3	3.4
Non-adherence	84	96.6

As seen from Table 11, only 4.6 percent of all respondents had undergone CBE screening and almost all respondents never had a CBE screening in the past year (95.4%). Only 3.4 percent of respondents had undergone a mammogram according to the Indonesian age-related guideline. Almost all respondents never had a regular mammogram screening (96.6%).

As mentioned earlier, the time since last CBE and mammography combined with the reason of undergoing last CBE and/or mammogram for screening purposes was used to identify adherence to the breast cancer screening program for both CBE and mammography in this study according to the Indonesian age-related guideline (Ministry of Health Republic of Indonesia, 2015b). An additional data analysis of time since the last CBE and mammography based on the age group was also done to identify the proportion of respondents who adhered to the Indonesian age-related guideline based on the age groups.

Time since last CBE and mammography screening based on age groups

The number and percentage of time since the last CBE and mammography screening of the study respondents based on age groups are presented in Table 12.

Table 12

Number and Percentage of Time since Last CBE and Mammography Screening of Indonesian Women at Moderate to High Risk Based on Age Groups (N = 87)

Variable	<i>n</i>	%
Time since last clinical breast exam		
<i>All women</i>		
Never had or had a non-screening CBE	74	85.1
Screening CBE, ≤ 12 months ago*	4	4.6
Screening CBE, > 12 – 24 months ago	3	3.4
Screening CBE, > 24 months ago	6	6.9
<i>Women age 40 – 50 years^a</i>		
Never had or had a non-screening CBE	50	87.7
Screening CBE, ≤ 12 months ago*	3	5.3
Screening CBE, > 12 – 24 months ago	1	1.7
Screening CBE, > 24 months ago	3	5.3
<i>Women age > 50 years^b</i>		
Never had or had a non-screening CBE	24	80.0
Screening CBE, ≤ 12 months ago*	1	3.3
Screening CBE, > 12 – 24 months ago	2	6.7
Screening CBE, > 24 months ago	3	10.0
Time since last mammography		
<i>All women</i>		
Never had or had a non-screening mammography	79	90.8
Screening mammography, ≤ 12 months ago	3	3.4
Screening mammography, > 12 – 24 months ago	2	2.3
Screening mammography, > 24 months ago	3	3.4
<i>Women age 40 – 50 years^a</i>		
Never had or had a non-screening mammography	53	93.0
Screening mammography, ≤ 12 months ago*	2	3.5
Screening mammography, > 12 – 24 months ago*	0	0.0
Screening mammography, > 24 months ago	2	3.5
<i>Women age > 50 years^b</i>		
Never had or had a non-screening mammography	26	86.7
Screening mammography, ≤ 12 months ago*	1	3.3
Screening mammography, > 12 – 24 months ago	2	6.7
Screening mammography, > 24 months ago	1	3.3

^a*n* = 57. ^b*n* = 30.

*Adherence to Ministry of Health Republic of Indonesia breast cancer screening program

As seen in Table 12, the majority of the respondents in both age groups never had or had a non-screening CBE (85.1%) and mammography (90.8%). Among

women aged 40 to 50 years, only 3.5 percent had undergone mammography screening within the past two years. Among women older than 50 years, only 3.3 percent had undergone mammography screening within the past year (Table 12).

An additional data analysis regarding the main reason for Indonesian women respondents having or not having a recent CBE and/or mammogram were also collected and analyzed as follows to provide room for improvement.

Reason of having CBE and/or mammogram of Indonesian women at moderate to high risk of developing breast cancer

In this study, the Indonesian women respondents were asked to identify and prioritize the main reasons to receive a CBE and/or mammography. As mentioned earlier, the reasons to receive a CBE or mammography were categorized into screening purpose and non-screening purpose as displayed in Table 13. The number and percentage of the main reasons to have CBE and/or mammogram are presented in Table 13.

Table 13

Number and Percentage of the Main Reasons for Having CBE and/or Mammogram

Reasons	CBE (<i>n</i> = 22)		Mammogram (<i>n</i> = 10)	
	<i>n</i>	%	<i>n</i>	%
Screening purpose				
Part of a regular check-up or routine screening	5	22.7	3	30.0
Part of Indonesian breast cancer screening program	1	4.5	0	0.0
Family history of breast cancer	7	31.8	5	50.0
Non-screening purpose				
Referred from health care provider due to breast problem or symptom	8	36.4	1	10.0
Cannot solve the problem of breast symptoms after waiting, doing self-care, or looking the other way	1	4.5	1	10.0

Overall, as shown in Table 13, among women who either had a CBE and/or mammogram, the reasons for screening purpose became the main reasons for the majority of the respondents to have a CBE (59%) and mammogram (80%). Among those, the “family history of breast cancer” was the most common reason for Indonesian women respondents to have a CBE (31.8%) and mammogram (50%), followed by “part of a regular check-up or routine screening.”

Reasons not to have a CBE and/or mammogram screening of Indonesian women at moderate to high risk of developing breast cancer

In this study, the Indonesian women respondents were asked to identify and prioritize the main reasons of not follow a CBE and/or mammogram screening according to the Indonesian age-related guideline. The number and percentage of the reasons not to have a CBE and/or mammogram are presented in Table 14.

Table 14

Number and Percentage of Reasons for Not Having CBE and/or Mammogram (N = 84)

Reasons	<i>n</i>	%
Detecting a small lump in breast is not serious and need not to hurry to seek help	2	1.5
Cannot expose the breast and be examined by male doctor	2	1.5
Being not able to get free time to visit a medical doctor due to the role as mother and wife to take care of children or family	26	19.0
Fear (painful, may find something wrong)	24	17.5
Transportation problems	4	2.9
Being not able to pay and insurance problem	9	6.5
Not needed or no problems or appearance of symptoms	50	36.5
Not knowing the screening information and where it is conducted	13	9.5
Feel enough by doing breast self-examination	4	2.9
Negligence	3	2.2

Note. The proportion of reasons for not having CBE screening in the past year, and mammography screening in the past two years (women aged 40-50) and in the past year (women aged older than 50). The respondent could select more than one reason.

As displayed in Table 14, the most common reason of not having a CBE and/or mammography screening of the Indonesian women respondents was not needed or no problems or appearance of symptoms (36.5%), followed by not having enough time to visit a medical doctor due to the roles as mother and wife (19%), and fear of pain or may find something wrong (17.5%) (Table 14).

The descriptions of both breast cancer awareness and adherence to the breast cancer screening program among Indonesian women at moderate to high risk of developing breast cancer leads the following section to determine the association between these two variables.

Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk of Developing Breast Cancer

The relationship between breast cancer awareness and adherence to Indonesian breast cancer screening program was analyzed to determine a relationship between these two variables as the research hypothesis of this study. Fisher's exact test was used to determine the relationship between breast cancer awareness and adherence to the breast cancer screening program in each domain. Specifically, as mentioned in Chapter 3 (page 77), breast cancer awareness in this study consisted of eight domains; the awareness regarding age-related risk was not included in the data analysis due to no variability of its response (i.e., constant).

Both CBE and mammography screening were analyzed to determine the relationship with breast cancer awareness in each domain. The relationship between breast cancer awareness and adherence to the screening program in each

domain, except for the knowledge of risk factors and knowledge of the screening program is presented in Table 15.

Table 15

Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87)

Breast cancer awareness	Adherence to screening program									
	CBE					Mammography				
	Adherence (n = 4)		Non-adherence (n = 83)		p value	Adherence (n = 3)		Non-adherence (n = 84)		p value
n	%	n	%	n		%	n	%		
Knowledge of symptoms										
Aware	2	50.0	44	53.0	1.00	2	66.7	44	52.4	1.00
Not aware	2	50.0	39	47.0		1	33.3	40	47.6	
Frequency of breast checking										
Aware	4	100.0	45	54.2	.13	3	100.0	46	54.8	.25
Not aware	0	0.0	38	45.8		0	0.0	38	45.2	
Confidence to detect a breast change										
Aware	4	100.0	49	59.0	.15	3	100.0	50	59.5	.28
Not aware	0	0.0	34	41.0		0	0.0	34	40.5	
Knowledge of lifetime risk										
Aware	1	25.0	26	31.3	1.00	1	33.3	26	31.0	1.00
Not aware	3	75.0	57	68.7		2	66.7	58	69.0	
Perceived of heightened risk										
Aware	3	75.0	45	54.2	.62	3	100.0	45	53.6	.25
Not aware	1	25.0	38	45.8		0	0.0	39	46.4	

As shown in Table 15, there was no significant relationship between breast cancer awareness and adherence to the screening program. The relationship between breast cancer awareness with regard to knowledge of risk factors, knowledge of screening program and adherence to screening program is presented in Tables 16 and 17.

Table 16

Relationship between Knowledge of Breast Cancer Risk Factors and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87)

Knowledge of breast cancer risk factor	Adherence to screening program										
	CBE					<i>p</i> value	Mammography				
	Adherence (<i>n</i> = 4)		Non-adherence (<i>n</i> = 83)		Adherence (<i>n</i> = 3)		Non-adherence (<i>n</i> = 84)		<i>p</i> value		
<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%				
Having a past history of breast cancer											
Aware	4	100.0	34	41.0	.29	3	100.0	53	63.1	.55	
Not aware	0	0.0	49	59.0		0	0.0	31	36.9		
Having certain benign breast disease											
Aware	3	75.0	39	47.0	1.00	3	100.0	54	64.3	.59	
Not aware	1	25.0	44	53.0		0	0.0	30	35.7		
Using exogenous hormone											
Aware	1	25.0	22	26.5	.65	1	33.3	34	40.5	1.00	
Not aware	3	75.0	61	73.5		2	66.7	50	59.5		
Drinking alcohol											
Aware	2	50.0	42	50.6	1.00	1	33.3	40	47.6	1.00	
Not aware	2	50.0	41	49.4		2	66.7	44	52.4		
Being overweight											
Aware	0	0.0	28	33.7	.57	0	0.0	22	26.2	.57	
Not aware	4	100.0	55	66.3		3	100.0	62	73.8		
Having a close relative with breast cancer											
Aware	3	75.0	11	13.3	.62	3	100.0	42	50.0	.24	
Not aware	1	25.0	72	86.7		0	0.0	42	50.0		
Having children later in life or not at all											
Aware	4	100.0	16	19.3	.02*	3	100.0	29	34.5	.05	
Not aware	0	0.0	67	80.7		0	0.0	55	65.5		
Starting menarche earlier											
Aware	0	0.0	28	33.7	1.00	0	0.0	11	13.1	1.00	
Not aware	4	100.0	55	66.3		3	100.0	73	86.9		
Having late menopause											
Aware	0	0.0	52	62.7	1.00	0	0.0	16	19.0	1.00	
Not aware	4	100.0	31	37.3		3	100.0	68	81.0		
Doing less physical activity											
Aware	2	50.0	54	65.1	.61	1	33.3	29	34.5	1.00	
Not aware	2	50.0	29	34.9		2	66.7	55	65.5		

**p* < .05

Overall, as shown in Table 16, no relationship was found between almost all items of knowledge of breast cancer risk factors and adherence to a screening program. However, a significant relationship was found between the knowledge of having children later on in life or not at all and the adherence to clinical breast examination screening ($p = .02$) (Table 16).

Table 17

Relationship between Knowledge of Screening Program and Adherence to Screening Program of Indonesian Women at Moderate to High Risk (N = 87)

Knowledge of screening program	Adherence to screening program									
	CBE					Mammography				
	Adherence (n = 4)		Non-adherence (n = 83)			p value	Adherence (n = 3)		Non-adherence (n = 84)	
n	%	n	%	n	%		n	%		
The existence of screening program										
Aware	4	100.0	58	69.9	.32	3	100.0	59	70.2	.55
Not aware	0	0.0	25	30.1		0	0.0	25	29.8	
Age of first invitation ^a										
Aware	2	50.0	22	37.9	.64	2	66.7	22	37.3	.55
Not aware	2	50.0	36	62.1		1	33.3	37	62.7	
Age of first CBE ^a										
Aware	3	75.0	18	31.0	.11	2	66.7	19	32.2	.26
Not aware	1	25.0	40	69.0		1	33.3	40	67.8	
Frequency of CBE ^a										
Aware	4	100.0	35	60.3	.29	3	100.0	36	61.0	.29
Not aware	0	0.0	23	39.7		0	0.0	23	39.0	
Age of first mammogram ^a										
Aware	1	25.0	11	19.0	1.00	1	33.3	11	18.6	.48
Not aware	3	75.0	47	81.0		2	66.7	48	81.4	
Frequency of mammogram ^a										
Aware	0	0.0	8	13.8	1.00	0	0.0	8	13.6	1.00
Not aware	4	100.0	50	86.2		3	100.0	51	86.4	

^aFor CBE, n = 58 for non-adherence, n = 4 for adherence; for mammography, n = 59 for non-adherence, n = 3 for adherence.

* $p < .05$

Table 17 (Continued)

Knowledge of screening program	Adherence to screening program									
	CBE					Mammography				
	Adherence (n = 4)		Non-adherence (n = 83)		p value	Adherence (n = 3)		Non-adherence (n = 84)		p value
n	%	n	%	n		%	n	%		
Age of first BSE ^a										
Aware	0	0.0	43	74.1	.01*	0	0.0	43	72.9	.03*
Not aware	4	100.0	15	25.9		3	100.0	16	27.1	
Frequency of BSE ^a										
Aware	4	100.0	43	74.1	.56	3	100.0	44	74.6	1.00
Not aware	0	0.0	15	25.9		0	0.0	15	25.4	

^aFor CBE, n = 58 for non-adherence, n = 4 for adherence; for mammography, n = 59 for non-adherence, n = 3 for adherence.

* $p < .05$

Overall, as shown in Table 17, there was no relationship between the awareness of each item of knowledge of a screening program and adherence to a screening program. However, relationships were found between the knowledge regarding the age of first BSE and adherence to the clinical breast examination ($p = .01$) and mammography screening ($p = .03$).

Discussions

This section presents the discussions of the findings according to the objectives of this study and aligned with the research questions and the research hypothesis. Here, the study results of the breast cancer awareness, the adherence to breast cancer screening program, and the relationship between breast cancer awareness and adherence to the screening program among Indonesian women at moderate to high risk of developing breast cancer are sequentially discussed.

Demographic Characteristics of the Study Population and Risks of Breast Cancer

The study population was first-degree relatives of breast cancer patients who had higher and moderate risk of developing breast cancer according to the IBIS or Cuzick-Tyrer model. In this study, the average lifetime risk of developing breast cancer based on the IBIS model of the respondents was 22.14 percent or in higher risk of developing breast cancer. Currently, there is no published study found in Indonesia regarding lifetime risk of developing breast cancer. Similarly, previous studies revealed a higher risk of developing breast cancer among women in Turkey (Açıkgöz & Ergör, 2013) and in the UK (Evans et al., 2012).

According to the IBIS model, a family history of breast cancer as well as ovarian cancer are used to predict the risk of developing breast cancer, in particular, in a high risk of familial breast cancer (Amir et al., 2003; Evans & Howell, 2007). In this study, as mentioned previously, the majority of the Indonesian women respondents had a family history of breast cancer (87.4%). Nowadays, breast cancer has been ranked as the topmost female cancer in Indonesia (Ferlay et al., 2013; Ministry of Health Republic of Indonesia, 2015c).

Most of the Indonesian women respondents in this study had one first-degree relative with breast cancer. In accordance with the American Cancer Society (ACS, 2014a), women with a positive family history of breast cancer in their mother, sister, or daughter will have twice the risk of developing breast cancer. Twice the risk was also estimated for first-degree relatives diagnosed between the ages of 40 to 50 years and an approximate 1.5 times the risk for first-degree relatives diagnosed in the age range of 50 to 65 years (Amir et al., 2010). In this study, the average age at

diagnosis in the first-degree relative was 50.72 years. However, they reported no personal history of breast cancer.

Beyond the family history of breast cancer, age was used as one of the personal risk factors to determine the risk in developing breast cancer. In this study, the majority of the Indonesian women respondents were aged between 40 and 50 years, with the average age of 48.74 years which was within the age group of women at increased risk of developing breast cancer (Kmietowicz, 2004; Nelson et al., 2012; Tirona, Sehgal, & Ballester, 2010). In addition, the average age of the respondents' first-degree relatives as well as other relatives with breast cancer in this study was 50.72 years and 46.45 years, respectively.

Accordingly, the peaks of the age ranges at diagnosis of breast cancer in Asian countries were between 45 and 50 (Youlden, Cramb, Yip, & Baade, 2014). Similarly, the average age of Indonesian women diagnosed with breast cancer was between 40 and 50 (Dharmais National Cancer Center, 2012). According to McPherson and colleagues (2000), the risk of getting breast cancer increases with age and approximately doubles every 10 years until menopause. Theoretically, the body cells have a greater chance to make mistakes in the cell division as the age increases which results in developing cancer (Cancer Research UK, 2014).

In addition, the majority of Indonesian women respondents in this study were premenopausal, which was a greater risk of developing breast cancer than post-menopausal women in the age range of 45 to 54 years (Collaborative Group on Hormonal Factors in Breast Cancer, 2012).

Among those personal risk factors, the majority of Indonesian women respondents in this study presented with a low risk regarding age at menarche, parity, and age at the first child. According to McPherson and colleagues (2000) and the

American Cancer Society (ACS, 2014a), the risk of developing breast cancer increased with prolonged exposure to endogenous estrogen in women who were menarche at the age of 12 years or younger, being nulliparous and having the first child at or after 30 years of age. In this study, the average age of menarche was 12.87 years and more than half of the respondents were menarche at the age of 12 years or older. In addition, most of the women in this study were married and had given birth of their first child at younger than 30 years old.

The low risk of developing breast cancer with regard to age at menarche, parity, and age at the first child of the respondents in this study possibly resulted from the fruitful Indonesian context and culture. Under Indonesian, as well as Javanese religio-cultural and sociocultural circumstances, marriage is viewed as one of the most important roles in achieving and fulfilling social status of an individual or family (Cunningham, n.d.). In addition, being a mother as well as giving birth and raising the children is an essential role of Javanese women and it determines a woman's identity. To be childless is, therefore, viewed as a social stigma and indicates failure in achieving the maternal role (Bennett, Wiweko, Hinting, Adnyana, & Pangestu, 2012). Moreover, a high value is placed on having more than one child to take care of them and the family when they get older (Bennett, 2012). From this, the majority of Indonesian women respondents, as well other Islamic Indonesian women, preferred getting married and having more than one child which resulted in a decreased risk of developing breast cancer.

In this study, a history of HRT use could also be identified as a low risk factor of developing breast cancer. As mentioned earlier, all of the Indonesian women respondents in this study reported they never used HRT. Generally, HRT is a treatment for menopausal symptoms as well as for women who have undergone ovarian

resection and hysterectomy (Brett & Chong, 2001). In Indonesia, the use of HRT is still limited among postmenopausal Indonesian women (Baziad, 2001, 2008).

Additionally, the Indonesian women respondents in this study did not have a history of gynecological surgery. Moreover, only 34.5 percent of the respondents in this study were postmenopausal. In this regard, the menopausal symptoms among women in Indonesia as well as other Asian countries were least reported by women (Baziad, 2001). This may be due to the traditional perception of menopause as a natural process as well as the stronger belief in traditional or herbal remedies for elevating menopausal symptoms (Huang, 2010). Although, HRT use is included in the national health insurance program in Indonesia, it is available only in tertiary care settings (Ministry of Health Republic of Indonesia, 2013).

As discussed above, although the Indonesian women respondents in this study had higher and moderate risks of developing breast cancer, they reported no personal history of breast cancer. Accordingly, a report from the American Cancer Society revealed that less than 15 percent of women with a positive family history developed breast cancer (ACS, 2014a). Here, since not all women who had a higher risk of developing breast cancer developed this disease, an underestimation of developing cancer could have happened. As seen, the major reason of the Indonesian women respondents in this study for not attending a screening program was “not needed or no problems or appearance of symptoms.” Moreover, since the average time of breast problems of the Indonesian women respondents in this study was 10.67 years with no evidence in the medical records, this raises the question regarding the validity of the history of breast problem. Therefore, raising the awareness regarding this issue is highly needed.

With regard to breast cancer information, as mentioned previously, information regarding a BSE was most frequently received by the respondents in this study, whereas information regarding mammography was the least frequently received in this study. In addition, the health care providers were the major sources of information in this study, followed by the internet and media, and family members.

Information regarding the BSE is a major part of health education from health care providers in Indonesia, in particular in primary care (Ministry of Health Republic of Indonesia, 2015a). Since the BSE is a highly accessible method recommended for all women, it is necessary for health care professionals to suggest to all women to perform the BSE, which can be performed independently by women (Sunjorn, 2002). On the contrary, information regarding mammography was provided in a hospital setting as well as in cancer center organizations and through electronic sources (e.g., websites) (Indonesian Breast Cancer Foundation, 2013). Due to a lack of dissemination and a lack of internet access particularly in rural areas, information regarding mammography did not achieve optimal impact (Bustan, 2007; Iskandarsyah, 2013).

Importantly, even though the Ministry of Health Republic of Indonesia (2015b) requires women to attend a CBE every year and mammography every two years for women aged 40-50 and every year after the age of 50 with a reason for screening, most Indonesian women respondents in this study were never invited to a breast cancer screening program. This raises questions regarding the awareness and adherence of Indonesian women as well as utilization of the national breast cancer screening program which is discussed in the following sections.

Breast Cancer Awareness among Indonesian Women at Moderate to High Risk of Developing Breast Cancer

The study results regarding breast cancer awareness among Indonesian women at moderate to high risk of developing breast cancer revealed that the highest awareness was regarding knowledge of screening program for the item about frequency of BSE. Other domains that indicated high awareness were knowledge of risk factors for the item about having certain benign breast disease, followed by confidence to detect a breast change, frequency of breast checking, perceived heightened risk, and knowledge of symptoms.

On the other hand, the lowest awareness was regarding the knowledge of age-related risk. Other domains that indicated low awareness were knowledge of lifetime risk, followed by knowledge of screening program for the item about frequency of mammography, and knowledge of risk factors for the item about starting the periods at an early age. The discussions of each domain of breast cancer awareness are sequentially addressed as follows.

Knowledge of breast cancer symptoms

The majority of Indonesian women respondents in this study were aware of five or more of non-lump symptoms of breast cancer (52.9%), whereas only 18 and 8.7 percent of the respondents in previous UK and Indonesian studies were aware of this knowledge, respectively (Forbes et al., 2010; Nurleli, 2013). Similarly, previous studies conducted among Iranian adult women and Chinese women revealed that women with a family history of breast cancer were more likely to have higher awareness regarding breast cancer warning signs and symptoms (Tazhibi & Feizi, 2014) as well as general awareness of breast cancer (Liu et al., 2014).

Since the Indonesian women respondents in this study were the first-degree relatives of breast cancer patients, raising the awareness regarding the knowledge of breast cancer symptoms was probably derived from their first-hand experience in encountering or taking care of family members with breast cancer. As mentioned previously, health care providers and family members were reported by the respondents in this study as two major sources of information. As seen, the majority of the respondents in this study received information regarding breast cancer symptoms.

In the Indonesian hospital context, family members are generally involved and they participate in the process of health education or information given to the patients (Effendy et al., 2015; Hasan Sadikin Hospital of Indonesia, n.d.). Also, the traditional roles in taking care of family members who get sick and being the main care providers are often the responsibilities of Indonesian women (Do-Le & Raharjo, 2002). In addition, the majority of the Indonesian respondents in this study had senior high school and college or university levels of education (75.9%). According to Linsell and colleagues (2008) and Liu and colleagues (2014), women with a higher level of education were more likely to be aware of breast cancer symptoms.

Getting a chance to participate with health care providers or encounter breast cancer care situations of a first-degree relative diagnosed with breast cancer, could increase the awareness regarding the knowledge of breast cancer symptoms in the majority the Indonesian respondents in this study who also had a high level of education.

Frequency of breast checking

More than half of Indonesian women respondents in this study were aware to check their breasts at least once a week or once a month as the frequency of

breast checking (56.3%). Similarly, a previous study conducted among Indonesian women at risk of developing breast cancer reported that 52.3 percent of women had a BSE every month (Desanti et al., 2010). Whereas a study conducted among Indonesian breast cancer patients revealed only 27.4 percent had a BSE (Nurleli, 2013). The higher proportion regarding frequency of breast checking found among women in this study could have resulted from having had a first-degree relative diagnosed with breast cancer and having a high level of education as discussed in the former part.

On the other hand, with regard to this argument, nearly half of the respondents in this study were not aware of the frequency of breast checking. The scope of this study, however, did not specifically explore each group. As mentioned previously, the most common reason not to have a breast cancer screening was that it was not needed or the respondents perceived to have no problems or appearance of symptoms, followed by fear and lack of free time to visit a medical doctor.

According to Mikhail and Petro-Nustas (2001), women who perceived more benefits and fewer barriers in performing a BSE were more likely to practice it. Similarly in a study conducted by Yadollahie and colleagues (2011), negative beliefs or perceptions regarding the benefits of breast checking as a preventive health measure for asymptomatic women, as well as the barriers of fear and having a lack of time of the respondents in this present study, led to a lack of awareness and the women did not practice BSE.

Confidence to detect a breast change

Having a fairly to very confident in detecting a breast change in the majority of Indonesian women respondents in this study was consistent with previous studies (Forbes et al., 2011; Linsell et al., 2008). A fairly to a very confident in

detecting a breast change possibly resulted from the majority of the women who were aware of the knowledge of the breast cancer symptoms as well as checking their breasts and being aware of the frequency of BSE. Increased knowledge enhanced the positive perception on the benefits of breast checking which in turn improved the performance of breast checking and strengthened the confidence to detect a breast change (Karayurt, Dicle, & Malak, 2008).

Moreover, as discussed previously, direct experience in encountering breast cancer care of their first-degree relatives diagnosed with breast cancer might be another reason that enhanced their confidence to detect a breast change. From this, a fairly to a very confident to detect a breast change could be observed from the majority of Indonesian women respondents in this study.

Knowledge of age-related risk, knowledge of lifetime risk, and perceived heightened risk

The results of this study revealed that all Indonesian women respondents lacked of awareness regarding the age-related risk of developing breast cancer. Likewise, previous studies revealed that most of the women respondents were not aware that women at an older age have the greatest risk of developing breast cancer (Moser et al., 2007; Nurleli, 2013). Similar to a study conducted by McMenamin and colleagues (2005), one third of the respondents in this study were aware of the knowledge of the lifetime risk. In consistence with previous studies, the majority of women were overly optimistic concerning the risks of developing breast cancer (Grundfeld et al., 2002; Linsell et al., 2008; Webster & Austoker, 2006).

Interestingly, even though the respondents in this study were the first-degree relatives of patients diagnosed with breast cancer, almost half of them

perceived their risk as lower to about the same chance of getting breast cancer as compared to other women with no family history of breast cancer.

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

Knowledge of risk factors

In this study, the Indonesian women respondents were mostly aware of having certain benign breast disease, having a past history of breast cancer, and having a close relative with breast cancer as risks of developing breast cancer. Similarly, previous studies revealed that the majority of women respondents with a family history of breast cancer reported family history as a risk factor of developing breast cancer (Al-Dubai et al., 2011; McMenamin et al., 2005; Subramanian et al., 2013; Tazhibi & Feizi, 2014). Direct experience in encountering breast cancer care of their first-degree relative diagnosed with breast cancer, as discussed previously, might be the vital factor raising their awareness of the risk factors. However, the awareness regarding the other risk factors, in particular starting the periods at an early age and

having a late menopause were still low in this study. As discussed previously, the information regarding the overall risk factors to develop breast cancer is not included in the general breast cancer prevention education programs provided by healthcare providers in the Indonesian primary health care context (Bustan, 2007; Ministry of Health Republic of Indonesia, 2015a).

Knowledge of screening program

The results of this study revealed that the majority of Indonesian women respondents were aware of the existing Indonesian breast cancer screening program, in particular the BSE. Also, the respondents had a higher awareness of the frequency of BSE and the age of the first BSE than the CBE and mammography. However, only one-third of the respondents in this study were aware of the age of the first invitation to a breast cancer screening program. In contrast, the results from a previous study conducted among first-degree relatives of Malaysian breast cancer patients revealed that the respondents were aware of mammography (Subramanian et al., 2013).

While mammography is a well-established screening method for the early detection of breast cancer in developed countries, it can be cost-prohibitive and may not be feasible in developing countries (Corbex, Burton, & Sancho-Garnier, 2012). Currently, mammography screening services in Indonesia are allocated and available in tertiary care settings, or private hospitals in large cities, including Jakarta Province, which was the place of residence of the majority of respondents in this study. Also, the number of mobile mammography services as well as education programs, materials, and websites regarding mammography allocated by Dharmais Hospital National Cancer Center and Indonesian Cancer Foundation has been increasing (Iskandarsyah, 2013). However, according to Iskandarsyah (2013) the lack

of an adequate dissemination of information as well as a lack of internet access led to a lack of sources of knowledge regarding mammogram screening.

According to General Electric Healthcare (GEHC, 2014), the awareness of the benefits of a mammogram in Indonesia in comparison with other nations was still low. A previous study conducted among Acehnese women with breast cancer revealed that none of the women ever had a mammogram (Nurleli, 2013). Mammography screening was more likely for individuals that had access to the service based on her own initiative or awareness (Ministry of Health Republic of Indonesia, 2015b). From this, even the majority of the Indonesian women respondents were aware of the screening program in general, but still lacked of an awareness regarding mammography screening.

Adherence to Screening Program among Indonesian Women at Moderate to High Risk of Developing Breast Cancer

Overall, the study results revealed a significant lack of adherence or poor practice for mammography and CBE screening among the Indonesian women respondents in this study, which was consistent with previous studies conducted in Indonesia, Asia, and Middle Eastern countries (Charkazi et al., 2013; Elobaid et al., 2014; Islam, Bell, Billah, Hossain, & Davis, 2015; Sobani et al., 2012; Subramanian et al., 2013). In contrast, previous studies conducted among women at moderate to high risk of developing breast cancer in Western countries revealed high numbers of adherence to CBE and mammography screening (Antill et al., 2006; Campitelli et al., 2011).

Adherence or compliance to the national breast cancer screening program with a reason for screening is a key to the success of early detection of breast

cancer which results in reducing morbidity, mortality, and down staging of breast cancer, in general (Charkazi et al., 2013). Even though the Indonesian women respondents in this study were at moderate to higher risk of developing breast cancer, they still lacked of adherence to breast screening which might put them at higher or the highest risk of developing breast cancer.

In this study, as mentioned previously, the most common reason of not having the CBE and mammogram screening was their perception that it was not needed or there were no problems or appearance of any symptoms. Here, it can be inferred that the respondents in this study were not aware of the significance or benefits of breast cancer screening or they perceived that the screening was not important. In accordance with Ahmadian and Samah (2012), Charkazi and colleagues (2013), and Nurleli (2013), a lack of adherence to breast cancer screening possibly resulted from sociocultural factors as well as individual awareness and beliefs.

In this study, more than one-third of the respondents perceived that breast cancer screening was needed when there was an appearance of symptoms (36.5%). As mentioned previously, although the Indonesian screening program and services have improved in recent years and the service cost is included under national health insurance (JKN), poor cancer screening practice among Indonesian women with a family history of breast cancer was still evident in this study.

Comparably, breast cancer screening was not viewed as important for promoting breast health and preventing breast cancer among Korean, Chinese, and Hong Kong women (Chua et al., 2005; Im, Park, Lee, & Yun, 2004). Here, underutilization of screening services and the perception of women that screening is mainly used for diagnostic purposes were reported as factors for worst adherence to

the breast cancer screening program (Al-Dubai et al., 2011; Elobaid et al., 2014; Islam et al., 2015; Nurleli, 2013; Subramanian et al., 2013).

In congruence with previous studies, not being able to get free time to visit a medical doctor or have breast cancer screening was also reported by the respondents in this study as a barrier for not having breast cancer screening. As discussed previously, the role of Indonesian women as mother and wife caused them to give a higher priority to their family and devote most of their time to their children and husband, rather than their personal health (Chua et al., 2005; Nurleli, 2013; Subramanian et al., 2013).

Similar to previous studies (Ahmadian & Samah, 2012; Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Murabito et al., 2001; Walker, 2014), the fear of pain from a mammography and the medical establishment and the fear that something wrong may be found were the other reasons for not having breast cancer screening of the respondents in this study.

Under modern Indonesian society, the religious and cultural values of not exposing the breast and being examined by a male medical doctor were still reported by the Indonesian women respondents in this study as reasons to not have a CBE and mammogram. Accordingly, the results from a previous study revealed that embarrassment and absence of a female oncologist were significant barriers in accessing breast cancer screening for Acehese women (Nurleli, 2013). The cultural values regarding the body of a woman as invisible and inaudible by others (Im et al., 2004) still influences Indonesian women to avoid presenting their body, in particular their breast, to others including healthcare providers. Consequently, the value of not exposing the breast and being examined by a male medical doctor became one of the major barriers of not having breast cancer screening in this study. From this, the lack

of adherence or noncompliance to the national breast cancer screening program with a reason for screening was evident in this study.

Similar to previous studies (Açıkgöz & Ergör, 2013; Subramanian et al., 2013), hospital care costs as well as transportation problems were not the major barriers for breast cancer screening of the respondents in this study. As mentioned previously, the respondents in this study had a median income slightly higher than the national average monthly income in Indonesia (International Labour Organization [ILO], 2015). Also, the majority of the respondents had health insurance and resided in urban areas near health care services and hospitals.

Although the family history of breast cancer placed the Indonesian women respondents in this study at a higher risk to develop breast cancer, this factor was accompanied with receiving knowledge and recommendations from health care professionals which raised the awareness and facilitated the respondents to have breast cancer screening (see Appendix J, Table 24). Accordingly, the results from a previous study revealed the significance of social support from family members and healthcare providers in increasing women's adherence to breast cancer screening (Nurleli, 2013). This provides recommendations in the following chapter.

Relationship between Breast Cancer Awareness and Adherence to Screening Program of Indonesian Women at Moderate to High Risk of Developing Breast Cancer

Overall, there were no significant relationships between breast cancer awareness and adherence to breast cancer screening program in this study. Accordingly, a previous study revealed that the perceived risk of developing breast cancer was not correlated with a woman's adherence to mammography (Walker,

2014). Likewise, previous studies found a considerable contrast between awareness and the practice of breast cancer screening (Nurleli, 2013; Wong-Kim & Wang, 2006).

In contrast with previous studies, relationships were found between the knowledge of breast cancer risk factors and mammography used (Subramanian et al., 2013), and adherence to screening guidelines (Sadler et al., 2007), as well as between knowledge of breast cancer screening and practice (Elobaid et al, 2014). Besides, a significant correlation was found between CBE practice and BSE knowledge ($p < .001$) among Pakistani women (Sobani et al., 2012).

Specifically, significant relationships were found in this study between the knowledge of risk factors for the item about having children later on in life or not at all and the adherence to a CBE; as well as between knowledge of screening program for the item about age of first BSE and adherence to a CBE and mammography. Here, adherence to the screening program of the Indonesian women respondents in this study did not rely on breast cancer awareness with the exception of awareness on items about having children later on in life or not at all and age of first BSE. From this, having an awareness of breast cancer did not increase the number of the Indonesian women respondents in this study to practice or comply with the Indonesian breast cancer screening program.

The perceived benefits of breast cancer screening program might be one of the vital reasons of the non-relationship between breast cancer awareness and adherence to a screening program. According to Graham (2002), women who believed that a breast cancer screening was beneficial, were more likely to undergo screening than those who did not see the screening as having a benefit. As discussed previously, beliefs that were developed for breast cancer screening which were

viewed as important for diagnostic purposes influenced the poor breast cancer screening practice among the Indonesian women respondents in this study.

Accordingly, the health beliefs could influence health behavior, including adherence to breast cancer screening and treatment among Indonesian women (Juanita et al., 2012).

Beyond less perceived benefits of breast cancer screening, more perceived barriers could also be another vital reason of the non-relationship between breast cancer awareness and adherence to screening program among Indonesian women respondents in this study. As discussed previously, the lack of time, pain, fear of finding something wrong, and embarrassment due to the value of not exposing their breast and the absence of a female oncologist inhibited Indonesian women respondents in this study to adhere or comply with breast cancer screening.

In congruence with previous studies, fear and excess anxiety of finding a lump, as well as the belief that nothing can prevent breast cancer were the major barriers among Indonesian women at increased risk who did not practice breast self-exam (Desanti et al., 2010; Nurleli, 2013).

The strong influence of culture on breast cancer screening might be another argument for the perceived negative benefits and more barriers regarding breast cancer screening that resulted in the non-relationship found in this study. According to Helman (2007), culture has its own beliefs, perceptions, and ideas about health and illness which can affect people's beliefs and further influence the behavior towards their health. Previous studies revealed the role and influence of culture on breast cancer screening (Juanita et al., 2012; Nurleli, 2013). Therefore, cultural factors seem to have a greater influence on the perceptions, attitudes, and behaviors among the Indonesian respondents (Iskandarsyah, 2013).

The results and discussion in this chapter, including all previous chapters lead to the conclusions and recommendations in the following chapter to intricately tie and link the whole picture of this thesis.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

This chapter brings together the conclusions and recommendations from all chapters in this thesis. The summary is drawn precisely to interconnect all of the major findings. The recommendations include the implications of the study findings relating to clinical practices, nursing education, and future studies regarding breast cancer awareness and adherence to breast cancer screening program.

Conclusions

This descriptive correlational study was conducted to describe breast cancer awareness, adherence to breast cancer screening, and the relationship between these two variables among Indonesian women at moderate to high risk of developing breast cancer. This study was undertaken based on three vital concepts of breast cancer awareness, adherence to the breast cancer screening program, and the relationship between these two variables derived from a structured literature review.

Data were obtained from eighty-seven first-degree relatives of breast cancer patients aged 40 years or older, who met the inclusion criteria. The data collection was conducted from February to March, 2016 at Dharmais Hospital National Cancer Center, Jakarta, Indonesia. The IBIS Breast Cancer Risk Evaluation Tool was used to identify women at moderate to high risk of developing breast cancer.

A structured questionnaire was used for data collection by interviewing each respondent. The validity of the questionnaires was approved by three experts.

The reliabilities of the Modified Breast Cancer Awareness Measure and the Modified Personal History and Screening Questionnaire were .78 and .86, respectively. The data was analysed using SPSS for Windows version 20.0 both descriptive and inferential statistics. The Fisher exact test was used for hypothesis testing.

The mean age of the respondents was 48.74 years old. Most of the respondents were married, Islam, lived in an urban area, housewife, and had health insurance. None of the respondents had a history of breast cancer, and the majority of them had no history of breast problems. More than half of respondents were at high risk of developing breast cancer since the majority of them had one first-degree relative with breast cancer with a mean age of diagnosis of 50.72 years old. Most of respondents had a sister with breast cancer. The majority of the respondents were pre-menopausal women, menarche at age above 12 years old, and had given birth at or under 30 years of age.

The highest awareness was knowledge of screening program for the item about frequency of BSE. Other domains that indicated high awareness were knowledge of risk factors for the item about having certain benign breast disease, followed by confidence to detect a breast change, frequency of breast checking, perceived heightened risk, and knowledge of symptoms.

The lowest awareness was knowledge of age-related risk. Other domains that indicated low awareness were knowledge of lifetime risk, followed by knowledge of a screening program for the item about frequency of mammography, and knowledge of risk factors for the item about starting the periods at an early age.

A significant lack of adherence for CBE and mammography screening among the Indonesian women respondents was concluded. Having no appearance of any symptoms, not having enough time, and having fear were the most common

reasons for women at moderate to high risk of developing breast cancer not to undergo CBE and mammography screening.

Overall, there were no relationships between breast cancer awareness and the adherence to CBE or mammography screening. However, an association was found between the knowledge of risk factors for the item about having children later on in life or not at all and the adherence to CBE screening. Other associations were found between the knowledge of screening program for the item about age of first BSE and adherence to CBE and mammography screening.

Strengths and Limitations of the Study

Strengths of the Study

This was the first study conducted among Indonesian women at moderate to high risk of developing breast cancer, and provided evidence of breast cancer awareness, adherence to a screening program, and the relationship between these two variables among Indonesian women at moderate to high risk of developing breast cancer. This study was conducted at Dharmas Hospital National Cancer Center in Jakarta, which serves as the national cancer referral center in Indonesia. The study population could represent Indonesian women at moderate to high risk of developing breast cancer.

Limitations of the Study

While this study constructs evidence on breast cancer awareness, adherence to breast cancer screening, and the relationship between these two variables

among Indonesian women at moderate to high risk of developing breast cancer, there were some limitations.

First, since the data relied on the reports and recall of the respondents, as such breast problems and specific times of screening adherence without other sources of data to confirm the data, this possibly led to errors in reporting specific data.

Second, the IBIS Breast Cancer Risk Evaluation Tool which was developed in a Western context has no published data of its use in the Indonesian context, and some items were not feasible or did not fit with Indonesian women, including items of genetic testing and the country rate – as the age standardized incidence of breast cancer in Indonesia was lower than Western countries. This raises the question regarding 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. Based on current expert opinion, genetic testing is not commonly used in countries other than Western countries and Indonesia is no exception.

Implications and Recommendations

The highest goal in conducting this study was to disseminate and utilize the study findings to raise the awareness of breast cancer as well as increase the number of Indonesian women to adhere to breast cancer screening. In order to achieve this goal, the following implications and recommendations are drawn for nursing education, nursing practices, and future nursing research in the field of breast

cancer care that is focused on breast cancer awareness and adherence to a breast cancer screening program.

1. Nursing education

The Indonesian nursing curriculum as well as nursing curricula in other regions should add the knowledge, attitude, and practices regarding breast cancer awareness and adherence to the breast cancer screening program, in particular among women at moderate to high risk of developing breast cancer. Raising the awareness and appropriate attitudes regarding these issues should also be cultivated and embedded in nursing students.

2. Nursing practice

The following recommendations are offered for nursing practice;

2.1 The IBIS Breast Cancer Risk Evaluation Tool should be employed for all Indonesian women, in particular women with familial risk, as a part of an early detection program to screen women who are at higher risk of developing breast cancer for early detection and diagnosis, as well as an increased effectiveness of treatments.

2.2 Education regarding knowledge of lifetime risk as well as heightened risk of developing breast cancer, including the benefits of a screening program should be added into a national routine early detection program.

Furthermore, family members should be involved in the education sessions.

Increasing the number of sources and media of breast cancer education and screening programs is needed to cover all aspects of breast cancer awareness to ease the access for all Indonesian women.

2.3 Develop a breast cancer screening campaign, in particular for women with a family history of breast cancer to raise their awareness and adherence for national breast cancer early detection. Moreover, the care of breast cancer patients

should include screening of their first relatives. Individual counselling by health care providers, in particular primary health care providers, is also beneficial for women at increased risk of developing breast cancer. The breast cancer screening services, including mammography, should also be allocated for availability at least in every regional level.

2.4 The cultural barriers raise the ideal recommendation to increase the number of female medical doctors and staff to serve women with cancer.

3. Nursing research

The following recommendations are offered for future research;

3.1 Reliability testing of the IBIS Breast Cancer Risk Evaluation Tool for application in the Asian population should be examined further.

3.2 The interval or ratio scale of measurement for breast cancer awareness and adherence to screening program should be considered for application in future studies to examine the correlation between these two variables.

3.3 An intervention study should be conducted to increase women's beliefs on the benefits of screening and alleviate the socio-cultural barriers to adherence to a screening program.

3.4 A study to develop a culturally sensitive breast cancer screening program should also be conducted to increase the adherence to a breast cancer screening program of Indonesian women as well as women in other context.

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APPENDICES

APPENDIX A

IBIS Breast Cancer Risk Evaluation Tool

No. : Method: Face-to-face
 Date and time : Telephone

I. Personal Information

1. Woman's age : years old
2. Age at menarche : years old
3. Parity
 - Parous;
 - Age at first child : years old
 - Nulliparous
 - Unknown
4. Benign breast disease
 - Hyperplasia (not atypia)
 - Atypical hyperplasia
 - LCIS
 - Others
 - Unknown benign breast disease
 - No benign breast disease
5. Ovarian cancer
 - Yes No
6. Menopausal information
 - Premenopausal
 - Perimenopausal
 - Postmenopausal;
 - Age at menopause :years old
 - No information
7. Height : (m)
 Weight : (kg)
8. Hormone replacement therapy (HRT) information
 - Never
 - 5 or more years ago
 - Less than 5 years ago;
 - Length of use (years) :
 - How long ago HRT used :
 - Type of HRT : Estrogen only
 Combination of estrogen and progesterone
 - Current user;
 - Length of use (years) :
 - Intended length of use :
 - Type of hormone : Estrogen only
 Combination of estrogen and progesterone

II. Family History

Family history		Age at diagnosis	Genetic testing
Mother		<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Bilateral breast cancer	
		<input type="checkbox"/> Breast cancer	
		<input type="checkbox"/> No history	
Sister	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Bilateral breast cancer	
		<input type="checkbox"/> Breast cancer	
Daughter	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Bilateral breast cancer	
		<input type="checkbox"/> Breast cancer	
Paternal grand	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Maternal grand	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Paternal aunt	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Maternal aunt	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Father		<input type="checkbox"/> Breast cancer	
Brother		<input type="checkbox"/> Breast cancer	
Paternal half sister	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Maternal half sister	Numbers:	<input type="checkbox"/> Ovarian cancer	
		<input type="checkbox"/> Breast cancer	
Affected cousin	Numbers:	<input type="checkbox"/> Breast cancer	
Affected niece	Numbers:	<input type="checkbox"/> Breast cancer	
Respondent			

III. IBIS Breast Cancer Evaluation Tool Version 7.02

The screenshot displays the IBIS Breast Cancer Risk Evaluation Tool version 7.02. The interface is organized into several functional areas:

- Personal factors:** Includes fields for Woman's age (20), Menarche (?), Height (ft), Weight (kg), and Measurements (Metric: Imperial:).
- Patient information:** Patient id: no.: 1, with a 'Calculate Risk' button.
- Competing mortality:** A checkbox option.
- Risk Options:** A button to access additional settings.
- HRT use:** Radio buttons for 'Never' (selected), '5 or more years ago' (0), 'Less than 5 years ago', and 'Current user'.
- Family History:** A pedigree chart showing a patient at age 20.
- Relatives:** Sections for Mother, Sisters, Paternal Gran, Maternal Gran, Paternal aunts, Maternal aunts, and Daughters, each with checkboxes for Ovarian and Breast cancer, and an 'Age' field.
- Other features:** 'Ashkenazi inheritance' checkbox, 'Show start up screen' button, and buttons for 'Male relatives', 'Half Sisters', 'Affected cousins', 'Affected Nieces', and 'Genetic Testing'.

Figure 3. IBIS Breast Cancer Risk Evaluation Tool version 7.02. Adapted from “IBIS Breast Cancer Risk Evaluation Tool version 7.02” by J. Cuzick, J. Tyrer, and A. R. Brentnall, 2013.

APPENDIX B

Personal Characteristic and Health-Related Questionnaire

No. : Method: Face-to-face
 Date and time : Telephone

Please fill out the form or check (✓) the box that relevant

1. Ethnicity

- | | |
|---------------------------------|--------------------------------------|
| <input type="checkbox"/> Betawi | <input type="checkbox"/> Sunda |
| <input type="checkbox"/> Jawa | <input type="checkbox"/> Others..... |

2. Religion

- | | | |
|-----------------------------------|---------------------------------------|--------------------------------|
| <input type="checkbox"/> Islam | <input type="checkbox"/> Christian | <input type="checkbox"/> Hindu |
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Others | |

3. Marital status

- | | |
|----------------------------------|-----------------------------------|
| <input type="checkbox"/> Married | <input type="checkbox"/> Single |
| <input type="checkbox"/> Widowed | <input type="checkbox"/> Divorced |

4. Level of education

- | | |
|---|---|
| <input type="checkbox"/> No schooling | <input type="checkbox"/> Elementary school |
| <input type="checkbox"/> Junior high school | <input type="checkbox"/> Senior high school |
| <input type="checkbox"/> University | |

5. Occupation

- | | |
|---|--|
| <input type="checkbox"/> Student | <input type="checkbox"/> Housewife |
| <input type="checkbox"/> Private employee | <input type="checkbox"/> Government employee |
| <input type="checkbox"/> Retired | |

6. Family monthly income: IDR (USD 1 ≈ 13,197.50 IDR)

7. Health insurance status

- | | |
|--|--|
| <input type="checkbox"/> Government | <input type="checkbox"/> Charity |
| <input type="checkbox"/> Private insurance | <input type="checkbox"/> No health insurance |

8. Place of residence
 Rural area; specify..... Urban area; specify.....
9. Have you ever had any breast problems (such as breast lump, swollen, tender, or cyst etc.)?
 Yes, please identify;
 When about did you have the problem/s..... month.....year
 No
10. Have you ever seen a doctor about a change you have noticed in one of your breasts or any problems in question no. 9?
 Never noticed a change in one of my breasts
 Yes
 No
11. Have you ever been diagnosed with breast cancer?
 Yes, please identify;
 When about did you have breast cancer?month.....year
 No
12. Do you have any regular contact with health care provider (e.g., family physician or primary health care)?
 Yes No
13. Have you ever received any information regarding breast cancer and its screening as listed below? *Please check (✓) the box either 'received' or 'not received' that best corresponds to your answer*

Information	Received	Not received
- Breast cancer symptoms	<input type="checkbox"/>	<input type="checkbox"/>
- Breast cancer risks	<input type="checkbox"/>	<input type="checkbox"/>
- Breast self-exam	<input type="checkbox"/>	<input type="checkbox"/>
- Clinical breast exam	<input type="checkbox"/>	<input type="checkbox"/>
- Mammography	<input type="checkbox"/>	<input type="checkbox"/>

14. From question No. 13, have you received the information from one or any of the following information sources? *Please check all that apply.*

- Health care provider, such as doctor, nurse, midwife, and others
- Village health volunteer or community health teams
- Friend
- Family member
- Internet, television, radio, books, newspaper, leaflet

15. Have you ever been invited to the breast cancer screening program?

- Yes
- No

APPENDIX C

Modified Breast Cancer Awareness Measure

No. : Method: Face-to-face
 Date and time : Telephone

We are asking these questions to find out more about breast cancer awareness. It is not a test to assess your knowledge or skills. There are no right or wrong answers. We are interested in your thoughts and beliefs so please answer the questions as honest as you can. All your answers will be kept confidentially. This questionnaire will take around 20 minutes to complete.

1. Do you know the warning signs of breast cancer?

Yes No

If yes, please indicate whether each of these following items is the warning sign of breast cancer or not, please check (✓) the box either 'yes' or 'no' that best corresponds to your answer for each item below

Items	Yes	No
Change in nipple position	<input type="checkbox"/>	<input type="checkbox"/>
Pulling in of nipple	<input type="checkbox"/>	<input type="checkbox"/>
Pain in one of breasts or armpit	<input type="checkbox"/>	<input type="checkbox"/>
Puckering or dimpling of breast skin	<input type="checkbox"/>	<input type="checkbox"/>
Discharge or bleeding from nipple	<input type="checkbox"/>	<input type="checkbox"/>
A lump or thickening in breast	<input type="checkbox"/>	<input type="checkbox"/>
Nipple rash	<input type="checkbox"/>	<input type="checkbox"/>
Redness of breast skin	<input type="checkbox"/>	<input type="checkbox"/>
A lump or thickening under armpit	<input type="checkbox"/>	<input type="checkbox"/>
Change in the shape of breast or nipple	<input type="checkbox"/>	<input type="checkbox"/>
Change in the size of breast or nipple	<input type="checkbox"/>	<input type="checkbox"/>

The next four questions are about finding changes in your breasts.

2. How often do you self-check your breasts?
Please tick (✓) one box only.
 - Rarely or never
 - At least once every 6 months
 - At least once a month
 - At least once a week
 - Do not know
3. How confident do you feel regarding notice a change in your breasts?
Please tick (✓) one box only.
 - Not confident at all
 - Slightly confident
 - Fairly confident
 - Very confident
 - Do not know
4. In the next year, who is most likely to get breast cancer?
Please tick (✓) one box only.
 - A 30-year-old woman
 - A 50-year-old woman
 - A 70-year-old woman
 - A woman of any age
 - Do not know
5. How many women will develop breast cancer in their lifetime?
Please tick (✓) one box only.
 - 1 in 3 women
 - 1 in 8 women
 - 1 in 100 women
 - 1 in 1,000 women
6. In your opinion, in comparison with other women who do not have a close relative with breast cancer, what are your chances of getting breast cancer someday?
Please tick (✓) one box only.
 - Lower
 - About the same
 - A little higher
 - Much higher

7. How much do you agree that each of these following items can increase the chance of getting breast cancer? *Please tick (✓) one box only of each of these following items.*

Items	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a past history of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having certain benign breast disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using exogenous hormone, such as HRT (Hormone Replacement Therapy), oral contraceptives, or diethylstilbestrol during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking more than a small single glass (25 ml) of alcohol a day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being overweight (Body Mass Index over 25)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a close relative with breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having children later on in life or not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Starting the periods at an early age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a late menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing less than 30 minutes of moderate physical activity 5 times a week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next set of questions is about breast cancer screening.

8. Is there an Indonesian breast cancer screening program?
- Yes
- No
- Do not know
9. At what age are women first invited to the breast cancer screening program?
- 20 years old
- 30 years old
- 40 years old
- Do not know
10. At what age do women should start undergoing a clinical breast exam?
- 20 years old
- 30 years old
- 40 years old
- Do not know

11. How often do you should undergo a clinical breast exam?

Please tick (✓) one box only.

- At least every year
- At least every two years
- At least every three years
- Do not know

12. At what age do women should start undergoing mammography?

- 20 years old
- 30 years old
- 40 years old
- Do not know

13. How often do you should undergo mammography?

Please tick (✓) one box only.

- At least every year
- At least every two years
- At least every three years
- Do not know

14. At what age do women should start performing a breast self-exam?

- 20 years old
- 30 years old
- 40 years old
- Do not know

15. How often do you should perform a breast self-exam?

Please tick (✓) one box only.

- At least every year
- At least every six months
- At least every month
- Do not know

APPENDIX D

Modified Personal History and Screening Questionnaire

No. : Method: Face-to-face

Date and time : Telephone

Please fill out the form or check (✓) the box in the answer column that relevant

PART I. ADHERENCE-RELATED QUESTIONS

No.	Question	Answer
1.	Have you ever had your breasts examined (clinical breast exam) by a doctor, nurse, midwife, or other health professional?	<i>Please tick (✓) one box only</i> <input type="checkbox"/> Yes <input type="checkbox"/> No → go to Part I, question no. 4 <input type="checkbox"/> Do not know → go to Part I, question no. 4
2.	When have you had your recent clinical breast exam ?	<i>Please tick (✓) one box only</i> <i>Please indicate your age and/or date of your recent clinical breast exam</i> Age : years old Month : Year :
3.	What was the main reason for having your recent clinical breast exam ?	<i>Please tick (✓) one box only</i> <input type="checkbox"/> Part of a regular check-up or routine screening <input type="checkbox"/> Part of Indonesian breast cancer screening program <input type="checkbox"/> Family history of breast cancer <input type="checkbox"/> Age or old enough <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Life style <input type="checkbox"/> Referred from health care provider due to breast problem or symptom <input type="checkbox"/> Cannot solve the problem of breast symptoms after waiting, doing self-care, or looking the other way <input type="checkbox"/> Other, <i>please specify</i> :.....
4.	Have you ever had a mammogram ?	<i>Please tick (✓) one box only.</i> <input type="checkbox"/> Yes <input type="checkbox"/> No → go to Part II, question no. 7 <input type="checkbox"/> Do not know → go to Part II, question no. 7

5.	When have you had your recent mammogram done?	<p><i>Please indicate your age and/or date of your recent mammogram</i></p> <p>Age : years old</p> <p>Month :</p> <p>Year :</p>
6.	What was the main reason you underwent your recent mammogram ?	<p><i>Please tick (✓) one box only</i></p> <p><input type="checkbox"/> Part of a regular check-up or routine screening</p> <p><input type="checkbox"/> Part of Indonesian breast cancer screening program</p> <p><input type="checkbox"/> Family history of breast cancer</p> <p><input type="checkbox"/> Age or old enough</p> <p><input type="checkbox"/> Hormone therapy</p> <p><input type="checkbox"/> Life style</p> <p><input type="checkbox"/> Referred from health care provider due to breast problem or symptom</p> <p><input type="checkbox"/> Cannot solve the problem of breast symptoms after waiting, doing self-care, or looking the other way</p> <p><input type="checkbox"/> Other, <i>please specify</i>:.....</p> <p>→ GO TO PART II QUESTION NO. 8</p>

PART II. ADDITIONAL QUESTIONS RELATED TO SCREENING

7.	What are your reasons for not having a clinical breast exam within past year or a mammogram within past two years?	<p><i>Please check all that apply and then rate in the bracket which indicate the importance of your reasons starting from 1 – the most importance, to 5 – the lowest importance</i></p> <p><input checked="" type="checkbox"/> (1)</p> <p><input type="checkbox"/> () Nothing can be done to prevent or stop getting breast cancer, because it is fate and God's will</p> <p><input type="checkbox"/> () Detecting a small lump in breast is not serious and need not to hurry to seek help</p> <p><input type="checkbox"/> () Female cannot expose their breast and cannot be examined by male doctor</p> <p><input type="checkbox"/> () Being not able to get free time to visit a medical doctor due to the role as mother and wife to take care of children or family</p> <p><input type="checkbox"/> () Fear (painful, may find something wrong)</p> <p><input type="checkbox"/> () Transportation problems</p> <p><input type="checkbox"/> () Being not able to pay</p> <p><input type="checkbox"/> () Not old enough</p>
----	--	--

		<input type="checkbox"/> () Not needed or no problems <input type="checkbox"/> () Doctor has not recommended it <input type="checkbox"/> () Language problems <input type="checkbox"/> () Hate or dislike having one done <input type="checkbox"/> () Other, <i>please specify</i> :
8.	Have you ever had any other tests to check for breast cancer?	<input type="checkbox"/> Yes, <i>please specify (✓) all that apply.</i> <input type="checkbox"/> Breast magnetic resonance imaging (MRI) <input type="checkbox"/> Ultrasound <input type="checkbox"/> Other test, <i>please specify</i> : <input type="checkbox"/> No
9.	What was the main reason for taking the test on question no.8?	<i>Please tick (✓) one box only</i> <input type="checkbox"/> Part of a regular check-up or routine screening <input type="checkbox"/> Family history of breast cancer <input type="checkbox"/> Referred from health care provider due to breast problem or symptom <input type="checkbox"/> Other, <i>please specify</i> :
10.	Who or what did encourage you to have a clinical breast exam or mammogram?	<i>Please check all that apply.</i> <input type="checkbox"/> Physician <input type="checkbox"/> Nurse or midwife <input type="checkbox"/> Village health volunteer <input type="checkbox"/> Familial cancer genetic clinic (genetic counselor, geneticist) <input type="checkbox"/> Family member <input type="checkbox"/> Friend <input type="checkbox"/> Family member with breast cancer <input type="checkbox"/> Someone with breast cancer <input type="checkbox"/> Media (internet, television, radio, magazine) <input type="checkbox"/> Community presentation <input type="checkbox"/> Other, <i>please specify</i> :

APPENDIX E

List of Translators

Three experts translated the instruments; Modified Breast Cancer Awareness Measure (Modified Breast-CAM) and Modified Personal History and Screening Questionnaire (Modified PHSQ), as follows:

1. In Ruminda, S.S., M. Hum

English lecturer, Islamic State University of Sunan Gunung Jati, Bandung, Indonesia

2. Gartika, S.S., M. Hum

English lecturer, University of Padjadjaran, Bandung, Indonesia

3. Heri Heryono, S.S., M. Hum

English lecturer, University of Padjadjaran, Bandung, Indonesia

APPENDIX F

List of Experts

Three experts validated the content validity of the instruments;
Modified Breast Cancer Awareness Measure (Modified Breast-CAM) and Modified
Personal History and Screening Questionnaire (Modified PHSQ), as follows:

1. Asst. Prof. Dr. Wipa Sae-sia

Nursing lecturer, Department of Surgical Nursing, Faculty of Nursing, Prince of
Songkla University

2. Dr. Charuwan Kritpracha

Nursing lecturer, Department of Medical Nursing, Faculty of Nursing, Prince of
Songkla University

3. Dr. Srila Samphao, M.D

Oncologist surgeon, Department of Surgery, Faculty of Medicine, Prince of
Songkla University

APPENDIX G

Patient's and First-degree Relative(s)' Information Form

No. :

Ward/Bed no. :

Date and time :

1. Age : years old

2. Age at diagnosis

Unilateral : years old

Bilateral : years old

3. Family history of breast cancer

Yes

No

4. Contact information of the first-degree relative(s) (mother, sister, or daughter)
aged 40 or older

Name of first-degree relative	Relationship with patients	Address	Telephone number
.....
.....
.....
.....
.....

APPENDIX H

Informed Consent Form

Dear Participants,

My name is Aira Putri Mardela. I am a master degree student from the Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a study entitled “Breast Cancer Awareness and Adherence to Screening Program among Indonesian Women at Moderate to High Risk”. This study will evaluate the breast cancer awareness and the adherence to screening program. Also, this study will evaluate the relationship between breast cancer awareness and adherence to screening program of Indonesian women at moderate to high risk of developing breast cancer. This study has been approved from Prince of Songkla University Thailand and also obtained permission from research committee of Dharmais Hospital National Cancer Center.

The results from this study will benefit to increase awareness regarding early detection of breast cancer which in turn will be contributed to decrease mortality and increase survival rates of breast cancer patients.

The participants for this study are selected based on criteria including first-degree relatives (mother, sisters, or daughters) of breast cancer patients, aged 40 years or older, having moderate to high risk of developing breast cancer based on IBIS Breast Cancer Risk Evaluation Tool, and not being diagnosed with breast cancer.

You are asked to participate in this study. If you are a breast cancer patient, you are asked for permission to contact your first-degree relatives (mother, sisters, or daughters) to participate in this study and provide your personal information. If you are the first-degree relative of breast cancer patient, your personal information was obtained from your relative, and you are asked to participate in this study. If you are willing to participate in this study, you agree to follow and accept these following procedures:

- 1) You will be asked some questions to assess your personal risk of breast cancer by using IBIS Breast Cancer Risk Evaluation Tool. It takes around 10 minutes. If you are not categorized as moderate to high risk, your information will be deleted from the study records. However, if you are categorized as moderate to high risk, you will be asked other questionnaires in the following.

- 2) You will be asked some questions related to your personal information. It will take around 10 minutes.

3) You will be asked some questions from the Modified Breast-CAM questionnaire. It will take around 20 minutes.

4) You will be asked some questions from the Modified PHSQ questionnaire. It will take around 10 minutes.

There is no evidence shown risk of responding to the questionnaires. However, there is a possibility that some questions may make you feel discomforts. Please do not hesitate to let me know, if you feel so or need further help. If you decided not to continue your involvement in this study at any time, for any reason, you may discontinue without getting penalty and any of your contribution can be withdrawn too.

All data will be kept confidentially and anonymously. Your name and identity will not be used in the report. However, the results of this study may be used in publications or presentations. To preserve confidentiality and anonymity, you can choose pseudonyms. Throughout the research process, I will use pseudonyms and codes. I will use these pseudonyms for the final report, publications, and presentations.

Your participation in this study is entirely voluntary. You have right to withdraw from this study at any time. There is no penalty for you to withdraw from this study. There will be no influences on the service you received from hospital if you decided to withdraw from this study. If you are willing to participate in this study, you can kindly sign your name on the consent form.

Thank you for your kindly cooperation. If you have any questions you can kindly contact the researcher or the advisor listed below.

Advisor

Assist. Prof. Dr. Khomapak Maneewat
Surgical Nursing Department, Faculty of Nursing
Prince of Songkla University, Thailand
Email: khomapak.m@psu.ac.th

Researcher

Miss Aira Putri Mardela
Master of Nursing Science (International Program)
Prince of Songkla University, Thailand
Phone: +6281210026753
Email: airamardela@yahoo.com

Informed Consent Form (Continued)

Patient's Consent

I am, I understand that I am asked to participate in this study to provide information and permission to contact my first-degree relatives (mother, sisters, or daughters) to participate in the study entitled "Breast Cancer Awareness and Adherence to Screening Program among Indonesian Women at Moderate to High Risk". The detail of the study has been well explained to me. I have read and understand this consent, and all of my questions have been answered. I was guaranteed that my identity will not be exposed and the results may be used in publications and presentations. I also realize that my participation in this study is entirely voluntary and I may withdraw from the study at any time. If I need to, I can contact the researcher, Miss Aira Putri Mardela, or the advisor, at any time during the study.

With all of these considerations, I would like to say that I am willing to participate in this study and provide information and permission to contact my first-degree relatives to participate in this study without any force. I understand that I will be given a copy of this signed consent form.

(.....)	(.....)	(.....)
Patients	Signature	Date

Researcher




I had given the detailed information of the study entitled "Breast Cancer Awareness and Adherence to Screening Program among Indonesian Women at Moderate to High Risk" to the patient, and the patient has consented.

(Miss Aira Putri Mardela)	(.....)	(.....)
Researcher	Signature	Date

APPENDIX I

Approval Letters

1. Ethics committee approval from the Faculty of Nursing, Prince of Songkla University, Thailand

		<p>PRINCE OF SONGKLA UNIVERSITY</p> <p>P.O. BOX 9, KHOR HONG, HATYAI SONGKHLA, THAILAND, 90112 FAX NO. 66-74-286421 TEL. NO. 66-74-286456, 66-74-286459</p>
<p>MOE 0521.1.05/ ๒๒1๒</p> <p>Ethics Committee Approval</p> <p>November 27, 2015</p> <p>To whom it may concern:</p> <p>This letter is to confirm that the Nursing Faculty Ethics Committee approved the research study of Miss Aira Putri Mardela ID. 5710420002 entitled "Breast Cancer Awareness and Adherence to Screening Program Among Indonesian Women at High Risk" on October 29, 2015. The study is a major part of Miss Aira Putri Mardela' s Master Degree at the Faculty of Nursing, Prince of Songkla University, Thailand. The study ensures the rights, safety, confidentiality, and welfare of research participants and it was determined that the study would not be harmful to the participants in the future.</p> <p>Sincerely,</p>  <p>Assistant Professor Umaporn Boonyasopun, PhD., RN Associate Dean Research and Graduate Study Faculty of Nursing, Prince of Songkla University THAILAND</p>		

2. Letter of permission for data collection from the Faculty of Nursing, Prince of Songkla University, Thailand



PRINCE OF SONGKLA UNIVERSITY

P.O. BOX 9, KHOR HONG, HATYAI
SONGKHLA, THAILAND, 90112
FAX NO. 66-74-286421
TEL. NO. 66-74-286456,
66-74-286459

MOE 0521.1.05/ 3264

November 23, 2015

To The Director,
Dharmais Hospital National Cancer Center
Jakarta, Indonesia

This letter is to inform you that Miss Aira Putri Mardela, ID. 5710420002, a master student of the Faculty of Nursing, Prince of Songkla University, Thailand, is taking a thesis in her last semester. As part of the requirement of the course, She has to conduct a research study in Indonesia. Her thesis is entitled: "Breast Cancer Awareness and Adherence to Screening Program Among Indonesian Women at High Risk". The thesis proposal has been approved on 29 October 2015. Therefore, she will try-out research instruments and collect data from the relatives of breast cancer patients in Dharmais Hospital National Cancer Center, Jakarta, Indonesia during December 2015- March 2016.

I will be greatly appreciated if Miss Aira Putri Mardela is permitted to try-out research instruments and collect data in your hospital, as it will provide valuable information for nursing profession in the future.

If you need any further information regarding her study, please do not hesitate to contact us at the above address or e-mail us at: khomapak.m@psu.ac.th.

Sincerely Yours,

Assistant Professor Umaporn Boonyasopun, PhD., RN
Associate Dean Research and Graduate Study
Faculty of Nursing,
Prince of Songkla University
THAILAND

3. Ethical clearance from the committee of Medical Research Ethics of the Dharmais Hospital National Cancer Center, Jakarta, Indonesia



KEMENTERIAN KESEHATAN RI
 DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT KANKER "DHARMAIS"
PUSAT KANKER NASIONAL
 Jl. Let. Jend. S. Parman Kav. 84-86, Slipi, Jakarta Barat 11420
 Telepon : (021) - 5681570 Faksimile : (021) - 5681579



No. : KEPK/005/1/2016

KETERANGAN LOLOS KAJI ETIK
ETHICAL CLEARANCE

Komite Etik Penelitian Kesehatan Rumah Sakit Kanker "Dharmais" dalam upaya melindungi hak asasi dan kesejahteraan subyek penelitian kedokteran, telah mengkaji dengan teliti proposal berjudul :

The committee of the Medical Research Ethics of the "Dharmais" Cancer Hospital, with regards of the protection of human rights and welfare in medical research, has carefully reviewed the proposal entitled :

"Breast Cancer Awareness and Adherence to Screening Program among Indonesian Women at High Risk"

Nama Peneliti Utama : Aira Putri Mardela

Name of the Principal Investigator

Nama Institusi : Prince of Songkla University

Name of Institution

Dan telah menyetujui proposal tersebut di atas.

And approved the above mentioned proposal

Jakarta, 19 Januari 2016

Ketua
 Chairman

Prof. Dr. dr. Rianto Setiabudy, SpFK

*Lolos Kaji Etik (*Ethical approval*) berlaku satu tahun dari tanggal persetujuan ini dikeluarkan

**Peneliti berkewajiban :

1. Menjaga kerahasiaan identitas subyek penelitian
2. Memberitahukan status penelitian apabila:
 - a. Setelah habis masa berlakunya keterangan lolos kaji etik, penelitian masih belum selesai, dan *ethical clearance* harus diperpanjang
 - b. Penelitian berhenti di tengah jalan
3. Melaporkan kejadian serius yang tidak diinginkan (*serious adverse events*)
4. Peneliti tidak boleh melakukan tindakan apapun pada subyek sebelum mendapatkan lolos kaji etik dan *informed consent*
5. Komite Etik Penelitian Kesehatan (KEPK) akan melakukan Pemantauan kegiatan Penelitian dengan Pemberitahuan terlebih dahulu kepada tim Peneliti

Semua prosedur persetujuan dilakukan sesuai dengan standard ICH-GCP

All procedure of Ethical Approval are performed in accordance with ICH-GCP standard procedure

Tampil Lebih Baik, Ramah dan Profesional
 Home page : www.dharmais.co.id Email : dharmais@dharmais.co.id



4. Letter of Permission for Data Collection from Dharmais Hospital National Cancer Center, Jakarta, Indonesia



KEMENTERIAN KESEHATAN RI
DIREKTORAT JENDERAL BINA UPAYA KESEHATAN
RUMAH SAKIT KANKER "DHARMAIS"
PUSAT KANKER NASIONAL

Jl. Let. Jend S. Parman Kav. 84-86, Slipi, Jakarta Barat 11420
Telepon : (021) - 5681570 Faksimile : (021) - 5681579



Nomor : LB.02.01/1 / 378 /2016
Hal : Ijin Penelitian

17 Januari 2016

Kepada Yth:
Faculty of Nursing
Prince of Songkla University
Thailand

Menjawab surat Saudara MOE 0521.1.05/3264. Mengenai Permohonan ijin Penelitian, maka dengan ini kami beritahukan bahwa kami dapat menyetujui dan memberikan ijin untuk melakukan kegiatan tersebut di Rumah Sakit Kanker "Dharmais" kepada Mahasiswa/wi saudara :

N a m a : Aira Putri Mardela
Judul : "Breast Cancer Awareness and Adherence to Screening Program among Indonesia"

Untuk kelancaran pengumpulan data, kami telah menunjuk Pembimbing /Narasumber di Rumah Sakit Kanker "Dharmais" :

Nama : dr. Denni Joko Purwanto, SpB.Onk

Selanjutnya perlu kami informasikan bahwa, sesuai dengan ketentuan yang berlaku di RS Kanker "Dharmais", dan akan dikenakan biaya pada mahasiswa yang bersangkutan sebagai berikut :

1. Biaya Narasumber/Pembimbing	= Rp. 500.000,-
2. Biaya Institusi RS	= Rp. 300.000,-
	= Rp. 800.000,-

(delapan ratus ribu rupiah)

Biaya tersebut agar dibayarkan kepada RS.Kanker Dharmais c.q. Bendahara Penerima Intern RS. Kanker "Dharmais" via Bank Mandiri dengan **N0.Rek. 116.00000.6028.6**
Sebelum melaksanakan kegiatan kami mohon agar yang bersangkutan terlebih dahulu menghubungi Bagian Penelitian dan Pengembangan RS.Kanker "Dharmais".

Demikian atas perhatiannya kami ucapkan terimakasih.-

Direksi RS Kanker "Dharmais"
Direktur Utama.

Prof.dr.Abdul Kadir,PhD.Sp.THT-KL(K),MARS
NIP:196205231989031001

Tembusan Kepada Yth :
- dr. Denni Joko Purwanto, SpB.Onk

Tampil Lebih Baik Ramah dan Profesional
Home page : www.dharmais.co.id Email : dharmais@dharmais.co.id



MS / TW II / 201.

APPENDIX J

Additional Analysis

Table 18

Number and Percentage of Breast Cancer Awareness Based on Each Item's Response of Indonesian Women at Moderate to High Risk (N = 87)

Variable	n	%
Knowledge of symptoms		
Recognizing more than five non-lump symptoms	46	52.9
1-4 symptoms	20	23.0
Do not know	21	24.1
Frequency of breast checking		
Reporting 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 to detect a breast change	53	60.9
Slightly to not at all confident	31	35.6
Do not know	3	3.4
Knowledge of age-related risk		
Identifying a 70-year-old woman as most likely to get breast cancer	0	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		
Knowing 1 in 8 women will develop breast cancer in the lifetime	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
Perceived of heightened risk		
Lower to about the same	38	43.7
A little higher or much higher	48	55.2
Do not know	1	1.1

Table 19

Relationship between Breast Cancer Awareness and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87)

Breast cancer awareness	Adherence to mammography (age 40-50)				<i>p</i> value	Adherence to mammography (age > 50)				<i>p</i> value
	Adherence (<i>n</i> = 2)		Non-adherence (<i>n</i> = 55)			Adherence (<i>n</i> = 1)		Non-adherence (<i>n</i> = 29)		
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	
Knowledge of symptoms										
Aware	1	50.0	30	54.5	1.00	1	100.0	14	48.3	1.00
Not aware	1	50.0	25	45.5		0	0.0	15	51.7	
Frequency of breast checking										
Aware	2	100.0	30	54.5	.50	1	100.0	16	55.2	1.00
Not aware	0	0.0	25	45.5		0	0.0	13	44.8	
Confidence to detect a breast change										
Aware	2	100.0	32	58.2	.51	1	100.0	18	62.1	1.00
Not aware	0	0.0	23	41.8		0	0.0	11	37.9	
Knowledge of lifetime risk										
Aware	1	50.0	19	34.5	1.00	0	0.0	7	24.1	1.00
Not aware	1	50.0	36	65.5		1	100.0	22	75.9	
Perceived of heightened risk										
Aware	2	100.0	33	60.0	.52	1	100.0	12	41.4	.43
Not aware	0	0.0	22	40.0		0	0.0	17	58.6	
Knowledge of risk factors ^a										
Knowledge of screening program ^a										

^aThe relationship between knowledge of risk factors, screening program and adherence to mammography are presented (Table 20 and 21)

Table 20

Relationship between Knowledge of Screening Program and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87)

Knowledge of screening program	Adherence to mammography (age 40-50)				p value	Adherence to mammography (age > 50)				p value
	Adherence (n = 2)		Non-adherence (n = 55)			Adherence (n = 1)		Non-adherence (n = 29)		
	n	%	n	%		n	%	n	%	
Knowing the existence of screening program										
Aware	2	100.0	38	69.1	1.00	1	100.0	21	72.4	1.00
Not aware	0	0.0	17	30.9		0	0.0	8	27.6	
Knowing age of first invited ^a										
Aware	1	50.0	16	42.1	1.00	1	100.0	6	20.7	.32
Not aware	1	50.0	22	57.9		0	0.0	15	51.7	
Knowing age of first mammography ^a										
Aware	0	0.0	7	18.4	1.00	1	100.0	4	13.8	.23
Not aware	2	100.0	31	81.6		0	0.0	17	58.6	
Knowing frequency of mammography ^a										
Aware	0	0.0	3	7.9	1.00	0	0.0	5	17.2	1.00
Not aware	2	100.0	35	92.1		1	100.0	16	55.2	
Knowing age of first CBE ^a										
Aware	1	50.0	14	36.8	1.00	1	100.0	5	23.8	.27
Not aware	1	50.0	24	63.2		0	0.0	16	76.2	
Knowing frequency of CBE ^a										
Aware	2	100.0	26	68.4	1.00	1	100.0	10	47.6	1.00
Not aware	0	0.0	12	31.6		0	0.0	11	52.4	
Knowing age of first BSE ^a										
Aware	0	0.0	28	73.7	.09	0	0.0	15	71.4	.32
Not aware	2	100.0	10	26.3		1	100.0	6	28.6	
Knowing frequency of BSE ^a										
Aware	2	100.0	30	78.9	1.00	1	0.0	14	66.7	1.00
Not aware	0	0.0	8	21.1		0	100.0	7	33.3	

^an = 38 for non-adherence, n = 2 for adherence (age 40 to 50); n = 21 for non-adherence, n = 1 for adherence (age > 50).

Table 21

Relationship between Knowledge of Risk Factors and Adherence to Mammography Screening Based on Age Group of Indonesian Women at Moderate to High Risk (N = 87)

Knowledge of risk factors	Adherence to mammography (age 40-50)				<i>p</i> value	Adherence to mammography (age > 50)				<i>p</i> value
	Adherence (<i>n</i> = 2)		Non-adherence (<i>n</i> = 55)			Adherence (<i>n</i> = 1)		Non-adherence (<i>n</i> = 29)		
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	
Having a past history of breast cancer										
Aware	2	100.0	37	67.3	1.00	1	100.0	16	55.2	1.00
Not aware	0	0.0	18	32.7		0	0.0	13	44.8	
Having certain benign breast disease										
Aware	2	100.0	37	67.3	1.00	1	100.0	17	58.6	1.00
Not aware	0	0.0	18	32.7		0	0.0	12	41.4	
Using exogenous hormone										
Aware	0	0.0	22	40.0	.52	1	100.0	12	41.4	.43
Not aware	2	100.0	33	60.0		0	0.0	17	58.6	
Drinking alcohol										
Aware	1	50.0	31	56.4	1.00	0	0.0	9	31.0	1.00
Not aware	1	50.0	24	43.6		1	100.0	20	69.0	
Being overweight										
Aware	0	0.0	15	27.3	1.00	0	0.0	7	24.1	1.00
Not aware	2	100.0	40	72.7		1	100.0	22	75.9	
Having a close relative with breast cancer										
Aware	2	100.0	31	56.4	.51	1	100.0	11	37.9	.40
Not aware	0	0.0	24	43.6		0	0.0	18	62.1	

Table 21 (Continued)

Knowledge of risk factors	Adherence to mammography (age 40-50)					Adherence to mammography (age > 50)				
	Adherence (<i>n</i> = 2)		Non-adherence (<i>n</i> = 55)		<i>p</i> value	Adherence (<i>n</i> = 1)		Non-adherence (<i>n</i> = 29)		<i>p</i> value
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	
Having children later in life or not at all										
Aware	2	100.0	22	40.0	.17	1	100.0	7	24.1	.27
Not aware	0	0.0	33	60.0		0	0.0	22	75.9	
Starting menarche earlier										
Aware	0	0.0	8	14.5	1.00	0	0.0	3	10.3	1.00
Not aware	2	100.0	47	85.5		1	100.0	26	89.7	
Having late menopause										
Aware	0	0.0	12	21.8	1.00	0	0.0	4	13.8	1.00
Not aware	2	100.0	43	78.2		1	100.0	25	86.2	
Doing less physical activity										
Aware	1	50.0	20	36.4	1.00	0	0.0	9	31.0	1.00
Not aware	1	50.0	35	63.6		1	100.0	20	69.0	

Table 22

Number and Percentage of Other Tests that the Respondents Ever Had (N = 87)

Variable	<i>n</i>	%
Yes		
Breast MRI	0	0.0
USG	5	5.7
No	82	94.3

Table 23

Number and Percentage of Reasons for Having Other Tests (n = 5)

Variable	<i>n</i>	%
Part of regular check-up or routine screening	1	20.0
Family history of breast cancer	3	60.0
Referred from health care provider due to breast problem or symptom	1	20.0

Table 24

Number and Percentage of Who or What Encouraged to Have a CBE and/or Mammogram (n = 22)

Variable	<i>n</i>	%
Physician	2	7.7
Nurse or midwife	1	3.8
Friend	1	3.8
Family member with breast cancer	6	23.1
Family member	4	15.4
Media (internet, television, radio, magazine)	2	7.7
Cancer organization	1	3.8
Other		
Free	1	3.8
Own self	8	30.8

Note. The respondents could be providing more than one answer

Table 25

Number and Percentage of Supplementary of Respondents' Characteristic (N = 87)

Variable	<i>n</i>	%
Place of residence		
Jakarta	39	44.8
Bogor, Depok, Tangerang, Bekasi	23	26.4
Banten	9	10.3
Java (West Java, Central Java, East Java)	12	13.8
Sumatra (Bengkulu, Lampung)	4	4.6

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