



**Personal and Sociocultural Determinants of Patient Delay in Consulting  
a Medical Doctor among Acehnese Women with Breast Cancer**

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**Thesis Title** Personal and Sociocultural Determinants of Patient Delay in Consulting a Medical Doctor among Acehese Women with Breast Cancer

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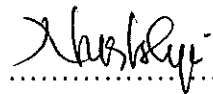
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### ABSTRACT

This descriptive cross-sectional study was designed to examine the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer. Data collection was conducted with one hundred and sixty respondents recruited from surgical and chemotherapy units in and out-patient department of two hospitals in Banda Aceh, Indonesia. The questionnaires consisted of the Personal Characteristic and Disease-related Data Form and the Sociocultural Questionnaire, which comprised 4 sub-questionnaires. The reliability of the Cultural Belief regarding Breast Cancer and Cancer Care Questionnaire and the Social Support Questionnaire was .74 and .84, respectively.

The results found that the respondents' average age was 37 years and more than half were married (57.5%). Most of them had no family history of breast cancer (85.0%). Cancer was mostly presented in stage I (42.5%) and a breast lump was the most commonly recognized initial symptoms of breast cancer (86.9%). The median patient delay was 90 days with the longest duration of delay exceeding 2 years. Statistical analysis revealed a low level of breast cancer awareness and only a

few women who were familiar with breast self or clinical examination; none of them had ever had a mammogram. Essentially, embarrassment accompanied with absence of female oncologist was reported as an enormous barrier for Acehese women to access breast cancer screening.

The majority of the respondents had a high positive score regarding cultural belief regarding breast cancer and social support. However, almost all the respondents had tried traditional therapy. More than half of the respondents (52.5%) had used traditional therapy prior to seeking medical care. The dominant reasons underpinning the respondents' decision to consult a medical doctor were: a) to get a definite diagnosis and get well from their illness; b) alternative therapies had not been successful; and c) the breast lump was enlarging and was associated with pain.

The predictive power of the selected personal and sociocultural variables on the duration of patients delay showed that only two predictors were significantly contributed to patient delay: stage of cancer ( $p = .000$ , Odds Ratio = 3.13) and alternative medicine use ( $p = .001$ , Odds Ratio = 5.07). In other words, the respondents who had more advanced stage and alternative medicine use were approximately 3 and 5 times, respectively, more likely to delay in consulting a medical doctor.

Patient delay in consulting a medical doctor was rooted in a number of personal and sociocultural factors embedded in Aceh. Health care provider should make an effort to shorten the delay time of Acehese women with breast cancer by combining modern cancer care congruent with the needs of Acehese culture.

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## CHAPTER 1

### INTRODUCTION

#### **Background and Significance of the Problem**

Breast cancer is the most commonly diagnosed cancer and the leading cause of death in females worldwide. Globally, the number of new cases and mortality rate of breast cancer patients were 23% (1.38 million) and 14% (458,400), respectively. Out of this figure, about half of the new cases (50%) and deaths (60%) were found in developing countries (Jemal et al., 2011). Indonesia is no exception, among Indonesian females, breast cancer ranked in the top most position (GLOBOCAN, 2008), followed by cervical cancer (Hospital Information Data System [HIDS] of Indonesia, 2007). The report from the Health Research Association in 2007 revealed that 4.3 of every 1000 Indonesian people were afflicted by cancer (Ministry of Health Republic of Indonesia, 2012).

In Indonesia, more than half of new breast cancer patients are diffused and advanced stage of cancer (Ng et al., 2011). A study conducted by Aryandono and colleagues in Yogyakarta with 245 breast cancer patients found that 52% and 44% of patients had already high and intermediate grades of cancer, respectively (Aryandono, Harijadi, & Soeripto, 2006). Accordingly, a study conducted with 197 breast cancer patients in Dharmais Cancer Hospital in Indonesia revealed that about 70% of breast cancer patients came in with already advanced stages (III and IV) and 24.4% of them suffered from bone metastases. Delays in treatment initiation may contribute to poorer breast cancer survival (Irawan, Hukom, & Prayogo, 2008).

Delay is the term used to describe a prolonged time in the diagnostic process, and it is usually divided into patient delay which refers to the period between an individual's first awareness of a sign or symptom of illness and the initial medical consultation while provider delay covers the period of time between the initial medical consultation and definitive treatment of the cancer (Bish, Ramirez, Burgess, & Hunter, 2005; Unger-Saldaña & Infante-Castañeda, 2009). Provider delay has been further divided by some authors into general practitioner (GP) delay and system delay consisting of diagnostic and treatment delay, either encountered in primary health care or secondary health care (Hansen, 2008). However, patient delay is the major factor that contributes mainly to breast cancer morbidity and mortality (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999). The evidence shows that the most frequent delayed presentation in breast cancer was derived from the patient rather than the provider or system delay (Hansen, Vedsted, Sokolowski, Søndergaard, & Olesed, 2011; Lodhi, Ahmad, Shah, Naeem, Dab, & Ali, 2010).

Furthermore, the patient pathways to symptom presentation and initial management are key determinants of cancer patient outcomes. Longer delays in patients who have symptoms are associated with worse outcomes and advanced presentation has been shown to affect low survival (Richards et al., 1999). A longer delay also impacts on the clinical stage, and most studies have found that the longer the delay, the more likely a woman is diagnosed in advanced stages (Unger-Saldaña & Infante-Castañeda, 2009) and with a larger tumor size (Montazeri, Ebrahimi, Mehrdad, Ansari, & Sajadian, 2003). Patients diagnosed with advanced stages of disease have also shown to have significant psychological morbidity in which they may have more trouble with emotional and social functioning such as feelings of

isolation (Turner, Kelly, Swanson, Allison, & Wetzig, 2005). All of these aspects strongly impact a patient's quality of life (Unger-Saldaña & Infante-Castañeda, 2009). Therefore, this study focuses on the patient delay rather than GP delay or system delay.

Studies exploring hospital cancer care and treatment delays or late presentation in receiving cancer treatment initiation from hospital for early breast cancer have been conducted to identify confounding factors among patients in this group worldwide. Delay in receiving cancer treatment initiation from hospital, however, generally happens in developing countries (Agarwal et al., 2009; Jemal et al., 2011). Numerous factors may result in delayed patient presentation which could be categorized into three potentially-overlapping categories: personal, sociocultural, and economic (Sharma, Costas, Shulman, & Meara, 2012). In accordance with Sharma and others, personal factors consist of age, ethnicity, marital status, clinical presentation, personal history, and family history; sociocultural factors consist of breast cancer awareness, alternative therapy use, fear of examination and treatment, stigma of disease, denial and anxiety, and level of social support; and economic factors consist of income status, education level, place of residence, obligations at home, and access to the health system.

Sharma et al. (2012) found strong evidence for personal and economic factors related to patient delay. Age and marital status are included in personal factors. Older women were mostly poor at identifying symptoms of breast cancer and more likely to appraise a symptom as not serious. In addition, they have more negative attitudes about seeking help and are less likely to disclose their symptoms to a close relative or friend. These factors, in turn, lead to a reduced intention to actually



seeking help in the event of a symptom occurrence (Bish et al., 2005). In association between marital status and patient delay, different studies yielded contradictory results. For example, one study found an association between being married and patient delay (Harirchi, Ghaemmaghami, Karbakhsh, Moghimi, & Mazaherie, 2005), while another observed an association between not being married, widowed or divorced and patient delay (Ali, Mathew, & Rajan, 2008; Kumari & Goonewardena, 2011; Montazeri et al., 2003; Thongsuksai, Chongsuvivatwong, & Sriplung, 2000). Thus, these factors need to be interpreted and taken with caution to investigate whether patients will utilize or avoid using available health care services resulting in the late presentation of breast cancer.

In addition, the personal factors, including family history and clinical presentation are associated with a delay. Women with a negative family history of breast cancer are at risk for longer delay and late presentation. Breast cancer patients believe that as long as there is no family history of cancer, they would not be prone to developing breast cancer. Consequently, this leads to a reduced intention to seek help and less likelihood of actually seeking help even when a symptom occurs (Grunfeld, Ramirez, Hunter, & Richards, 2002; Im, Park, Leeb, & Yun, 2004; E. Lee., Reimer, Miller, Sadler, & Lee, 2007). Regarding clinical presentation, it was found that the nature of an initial breast cancer symptom can influence patients in delaying seeking help (Ramirez et al., 1999; Norsa'adah, Rampal, Rahmah, Naing, & Biwal, 2011). Patients with aggressive types of breast cancer usually had progressive symptoms in a short time which can influence them to seek early consultation and diagnosis. Most patients monitored their symptoms and perceived them to be the signs of illness when symptoms did not spontaneously disappear and worsened or when new symptoms

developed that can disrupt their daily life (Smith, Pope, & Botha, 2005). From this, in comparison, a breast lump significantly becomes a sign of illness perceived by breast cancer patients which leads them to earlier consultations than those without the breast lump (Kumari & Goonewardena, 2011; Meechan, Collins, & Petrie, 2003).

In developing countries, socioeconomic factors were noted and a strong association between advanced disease and delay in diagnosis was observed (Aziz, Sana, Akram, & Saeed, 2004). A cohort of 696 women diagnosed with early breast cancer showed that the only socioeconomic variable that was independently associated with a diagnostic delay of more than 5 weeks was low family income (Bairati, Jobin, Fillion, Larochelle, & Vincent, 2007). Socioeconomic barriers include lack of insurance, lack of transportation, and financial concerns, for example inflexible work hours that impede one's ability to seek early care (Ashing, Padilla, Tajero, & Kagawa-Singer, 2003). It was also highlighted in a study by Lodhi and colleagues in 2010, that poverty has a significant influence on late presentation particularly in those patients who had rural backgrounds because they cannot afford the expenditure of education, transport, medical consultation and treatment of breast cancer. Although Acehnese women receive full medical support, they still need to pay for transportation and other intangible costs that may inhibit them to get medical services. From this, economic factors need to be considered not only for health care costs but also for living allowance and transportation in getting medical care.

The sociocultural perceptions would be the main obstacle for women in developing countries to attain any breast-screening program. Asian culture tends to adhere to the patriarchal culture in the hierarchical structure of family system, in which women have always occupied a lower position, and their lower position has

subordinated their own needs, including health care needs to the needs of other family members (Hisham & Yip, 2004; Im et al., 2004). Therefore, women's health problems tend to be regarded as trivial until serious symptoms endanger their health.

In traditional Asian culture, women's bodily exposure is taboo and rarely discussed openly. Generally, women are reluctant and feel embarrassed by clinical breast examinations. Women felt ashamed and humiliated at being examined particularly by a male doctor. Considering the cultural attitudes toward bodily exposure, it becomes the vital reason that many Asian women are unwilling or experience feeling of shame to expose their breasts to healthcare providers (Azaiza & Cohen, 2008; Im et al., 2004). Consequently, Asian women with breast cancer hesitate to get treatment from the hospital at an early stage of the disease (Im et al., 2004).

Most of Asian women avoided getting treatment at the hospital but seek another alternative such as the familiar and trusted traditional or folk healer until they are experiencing severe pain and distress from metastatic cancer symptoms (Hisham & Yip, 2004; Im et al., 2004). Some patients also have less trust in modern medicine because of being left with a bad impression from previous experiences, including the feeling of an unfriendly atmosphere from the healthcare provider in comparison with traditional healers (Norsa'adah et al., 2011). Accordingly, a study conducted by Tiolena (2009) found Indonesian patients with breast cancer came to the hospital in an advanced stage since they firstly made the decision to choose traditional cancer care and to receive modern cancer care from the hospital when experiencing symptom distress, particularly pain.

Here, the cancer care culture as well as meaning and perception of breast cancer ascribed by the patients becomes one of the strongest factors influencing delay in making decisions to receive modern cancer care from a hospital (Hisham & Yip, 2004). Consequently, most breast cancer patients started getting initial cancer treatments from the hospital in advanced stages of breast cancer especially in Asian countries (Parsa, Kandiah, Rahman, & Zulkefli, 2006). Under the era of flourishing evidence-based nursing and medicine, Acehnese women with breast cancer are, however, still making decision to firstly use traditional therapy. From this reason, understanding the personal and sociocultural dimensions underpinning patient's health values, beliefs and behaviors become the most crucial component to achieve successful outcomes in allocating care for breast cancer patients.

In addition, late presentation resulting from sociocultural factors, particularly cultural beliefs, is a major contributor to advanced-stage breast cancer at the first diagnosis (Hisham & Yip, 2004; Parsa et al., 2006) and to the leading cause of poorer survival in developing countries (G. Agarwal, Pradeep, Agarwal., Yip, & Cheung, 2007; Anderson & Jakesz, 2008), including Indonesia. A summary from a systematic review of barriers to breast cancer care in developing countries resulting in delayed patient presentation conducted by Sharma and colleagues (2012) found strong evidence for personal and economic factors relating to patient delay and moderate current evidence for sociocultural ones. The researchers suggested the significance to conduct future research to ascertain the true relationship between sociocultural variables and patient delay in the developing world.

To date, while there have been a number of studies explaining the relationship between patients' personal and sociocultural factors and late presentation

among breast cancer patients, most of the previous studies were conducted in developed countries and other Asian countries with no known published studies found in Indonesia, specifically in the exploration of patient delay and its relating factors. An understanding of these factors is, therefore, crucial to optimize future nursing interventions that pre-empt the late presentation of breast cancer patients in the Indonesian context. This study examined the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer.

### **Objectives of the Study**

The objectives of this study were to:

1. Describe patient delay in consulting a medical doctor among Acehese women with breast cancer.
2. Examine the predictive power of the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer.

### **Research Questions**

The research questions of this study were:

1. What are the characteristics of patient delay in consulting a medical doctor among Acehese women with breast cancer?

2. What is the predictive power of the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer?

### **Conceptual Framework of the Study**

The conceptual framework of this study was developed based on three vital concepts 1) patterns or types of delay in consulting a medical doctor proposed by Hansen (2008), 2) personal and sociocultural factors associated with delays in consulting a medical doctor proposed by Sharma et al. (2012), and 3) traditional culture of Acehese women, cultural attitudes and beliefs toward health and cancer.

Delay in taking or receiving cancer treatments have been acknowledged for several decades. The work of Hansen provides a clear picture of the patterns or types of this concept (Hansen, 2008). They introduced the term “*total delay*” to refer to the total time frame between symptom discovery by the patient and the beginning of cancer treatments. Total delay is further divided into three categories: patient delay, general practitioner (GP)/ doctor delay, and system delay. *Patient delay* in seeking medical help refers to the time from when the patient first perceived their symptom(s) until the first presentation to the general practitioner. Meanwhile, *general practitioner (GP)/ doctor delay* refers to a period from the first presentation to the GP or doctor until the initiation of an investigation of potentially cancer-related symptoms. Hansen use the term ‘doctor delay’ to represent health care practitioner delay in primary care in providing healthcare advice and assessment.

*System delay* is the period of time from the start of the GP- or doctor-initiated investigation until the start of treatment.

Since GP/ doctor delay and system delay are beyond the pure initiation of nursing contribution, they are not a focus of this study. In contrast, patient delay is a major concern because it is the one that nurses, once understood, can identify a means to alleviate this problem. In addition, patient delay has been found to be associated with worse outcomes and advanced presentation has been shown to affect low survival (Richards et al, 1999), more advanced stages at presentation and increased tumor size (Burgess, Ramirez, Richards, & Love, 1998). All of these aspects strongly impact on the patient's quality of life (Unger-Saldaña, & Infante-Castañeda, 2009). Based on this conceptualization, a delay of patients with breast cancer in making the decision to consult a medical doctor when they recognize that they have breast-related symptoms to the time when they decide to visit doctors at the hospital is considered to be "patient delay," which is the main focus of this proposed study.

In successfully identifying a means to reduce patient delay, it was crucial to determine what factors were most important in a breast cancer patient's decision making process. The work of Sharma et al. (2012) was used to guide the researcher's decision in selecting factors most important and relevant to the Indonesian context. Sharma et al. conducted a systematic review of the barriers to breast cancer care in delayed patient presentation. They included 13 studies in the final review and only from developing countries in which nine studies were conducted in Muslim-majority countries: Iran ( $n = 2$ ), Pakistan ( $n = 2$ ), Nigeria ( $n = 2$ ), and one study each from Egypt, Tunisia, and Malaysia. They summarized three sets of barriers

or factors contributing to delayed patient presentation to receive breast cancer care: Personal, economic and sociocultural factors. Further, based on the findings of their review, the researcher modified these factors to fit with the characteristics and cultural beliefs of the Acehnese people. Finally, the researcher decided to select only 11 factors hypothesized to be strong potential predictors in the Acehnese women's decision making delay in seeking treatment. The detail of each factor is addressed in the following.

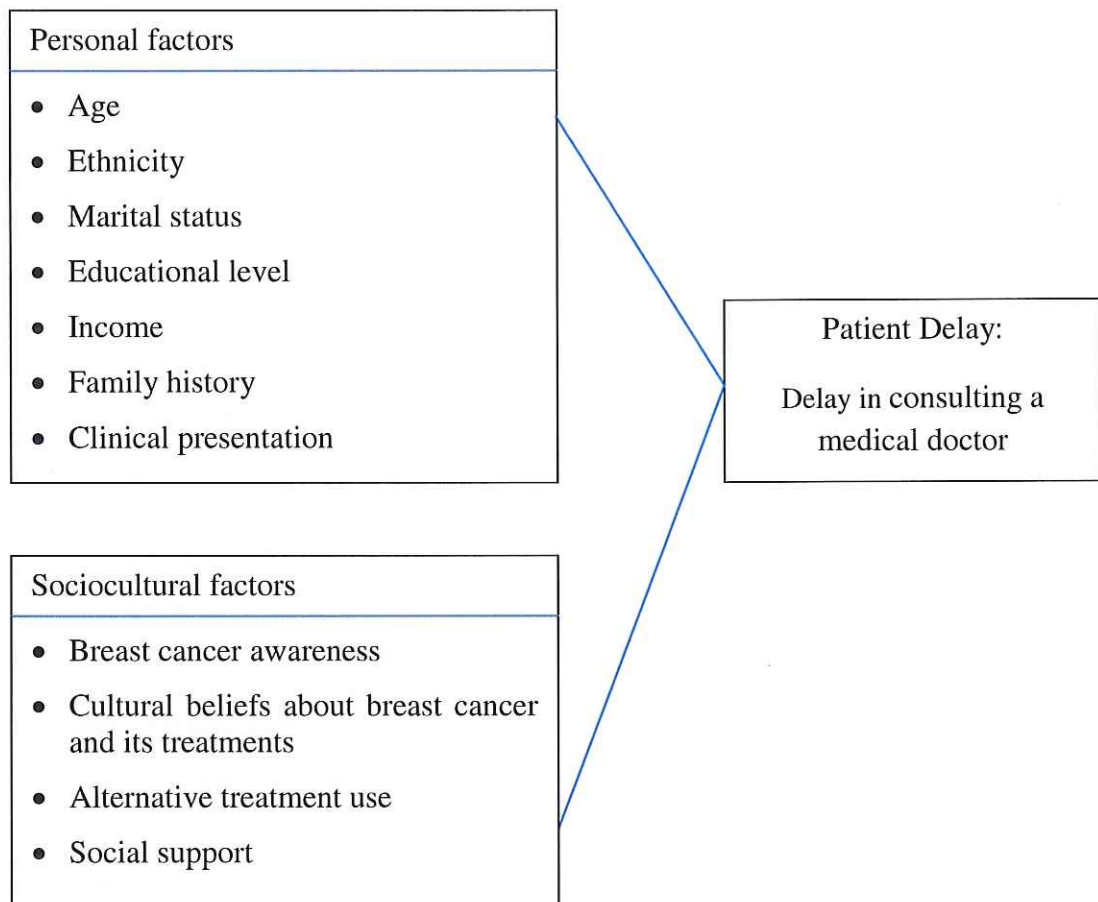
Personal factors included age, ethnicity, marital status, clinical presentation, and family history. In this study, personal history with cancer was excluded since it would change patient's help-seeking pattern. Economic factors included educational level, income level, location of origin, and accessibility. Costs to health care services were excluded in this study since a policy for free care in utilizing health care services allocated for every Acehnese people. Also, the personal factors and economic factors were grouped altogether under "personal factors" because of the overlapping between each other and they have been used interchangeably by many researchers. Sociocultural factors consisted of breast cancer awareness referring to knowledge of symptoms and breast self-examination (BSE) use; alternative treatment use; and overall level of social support. Fear of treatment, stigma of disease, denial/anxiety was included in one factor namely cultural beliefs about breast cancer. Since this study had been conducted in Indonesia, one of the Muslim-majority countries, specifically with Acehnese women, traditional culture, cultural attitudes and beliefs toward health and cancer were also taken into considerations.

In traditional Acehnese culture, women's bodily experiences are taboo and prohibited. Even among women themselves, body experiences are not openly



discussed especially in regard to the breasts because it is a sensitive part of woman. They strongly believe that breast cancer is willed by God and is perceived as an unchangeable fate that cannot be prevented or cured. Acehnese culture has emphasized the importance of the family as an essential unit when women make decisions to choose therapy options and consult a medical doctor. Most of the women did not give their attention to the symptoms they were experiencing and presented themselves as not sick. Rather, they placed a priority on the needs of other family members and did not want to burden their family. Another important cultural attitude and belief in seeking care for various illnesses is the preference for traditional healers. Traditional healers called *dukun* are so embedded in the Acehnese culture that they often became the first and only source of information and treatment even for cancer. Although traditional therapy has not been scientifically proven as either beneficial or detrimental, these therapies are still much chosen and accepted by Acehnese women with breast cancer rather than using modern medical therapy in general.

Based on the previous information outlined, the researcher constructed the conceptual framework to guide this study as delineated in Figure 1.



*Figure 1.* The Conceptual Framework Depicting Personal and Sociocultural Determinants of Patient Delay in Consulting a Medical Doctor among Acehese Women with Breast Cancer

### Hypotheses

1. Personal factors (age, ethnicity, marital status, educational level, economic status, family history, clinical presentation) have a direct effect on patient delay in consulting a medical doctor.

2. Sociocultural factors (breast cancer awareness, cultural beliefs about breast cancer and its treatments, alternative therapy use, social support) have a direct effect on patient delay in consulting a medical doctor.

## Definition of Terms

### Personal Factors

Personal factors are the factors that come from the individual patients that can influence their intention in consulting a medical doctor including age, ethnicity, marital status, educational level, economic status, family history, and clinical presentation.

**Age.** Age is defined as the number of years since the patients were born.

**Ethnicity.** Ethnicity is defined as identity as a member of a cultural group.

**Marital status.** Marital status is defined as being single, married, widowed, divorced, or separated and no longer living as married.

**Educational level.** Educational level is defined as the level of formal schooling acquired by respondents.

**Economic status.** Economic status involves finances encompassing the family income, health insurance, and place of residence.

**Family history.** Family history of breast cancer is defined as having a first-degree relative, i.e. sister, mother or daughter who has had breast cancer.

**Clinical presentations.** Clinical presentations include first/initial symptoms such as a painless breast lump, painful breast lump, axillary mass, breast erythema, nipple inversion, or other symptoms etc., location of the tumor, stage of the disease, tumor size, and lymph node status were obtained from patients' information and patients' medical records.

Personal factors in this study were measured by a personal and disease-related data form developed by the researcher.

## **Sociocultural Factors**

Sociocultural factors is the way how the patient understands the cancer and her attitudes toward the cancer based on her values and beliefs, and practices of a particular group that are learned and shared and can influence the meaning of breast cancer and the patient's decision to consult a medical doctor. These health beliefs, attitudes, values, and knowledge that might influence a patient's need to use health care services.

**Breast cancer awareness.** Breast cancer awareness refers to patients' knowing about the signs and symptoms of breast cancer and the frequency of breast self-examination (BSE) use which may help people recognize possible breast cancer signs and symptoms and therefore influence their attitude toward medical help-seeking behaviors. This was assessed by using the Breast Cancer Awareness Measure (BCAM) developed by Linsell et al. (2010). The respondents were interpreted as getting awareness of breast cancer if they identify five or more non-lump symptoms from the list, identified that a 70 years old woman was most likely to get breast cancer in the next year compared to a young woman or a woman of any age, and reported checking her breasts at least once a week or once a month.

**Cultural beliefs of breast cancer and its treatments.** It refers to the way in which patients perceive and understand breast cancer, cause and symptoms, breast cancer screening and treatments and outcomes of breast cancer which were measured by using the Cultural Belief about Breast Cancer and Cancer Care Questionnaire developed by the researcher concerning the context of Asian countries. This questionnaire uses a 5-point Likert scale: 1 strongly agree, 2 agree, 3 not sure, 4

disagree, and 5 strongly disagree. The possible mean score ranges from 1-5. A high score indicates positive attitudes toward breast cancer and its treatments.

**Alternative treatment use.** Alternative treatment use is defined as any therapies using methods and products not included in conventional modern medicine. The use of alternative treatments was measured by the self-report questionnaire including: First, *types of alternative therapy use* developed by the researcher based on information from the National Center for Complementary and Alternative Medicine, (2011). NCCAM is the Federal Government's lead agency for scientific research on complementary and alternative medicine (CAM) within the U.S. Department of Health and Human Services. Then, the researcher modified the self-reported questionnaire to be appropriate for local alternative therapy used in the context of Aceh. Second, the *main reason* for using alternative therapy for that from a list of possible choices, this question was developed based on a review of literature by Wanchai, Armer, & Stewart (2010).

**Social support.** Social support refers to the perception of the breast cancer patients about help and support from her husband and other family members in the patients' decision making of in seeking breast cancer treatment to present with cancer symptoms. In this study, social support was measured by using the modified Social Support Questionnaire which was initially developed by Hansen (2008). This questionnaire consists of ten items, and each item is scored on a 4-point Likert scale ranging from 0 ('not at all') to 3 ('very much'). Higher scores indicate more social support, and lower scores indicate less social support.

### **Patient Delay in Consulting a Medical Doctor**

Patient delay is a period of time (days) between the date when the patient experienced the first symptom(s) and the date when the patient made decision to take herself to the *first* visit or initial consultation with a health-care professional in order to investigate if she has breast cancer. It was measured by asking patients with breast cancer to “recall” these dates.

### **Scope of the Study**

This study was conducted to examine the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer. The study respondents were Acehese women diagnosed with breast cancer and were recruited from the surgical and chemotherapy units in and out-patient department of dr. Zainoel Abidin General Hospital and Ibu dan Anak Hospital, government-owned hospitals in Aceh Indonesia, from November 2012 to February 2013.

### **Significance of the Study**

The findings of this study can bridge the knowledge gap and improve understanding about how Acehese women with breast cancer perceive the disease and its treatment and what makes or inhibits them in consulting a medical doctor. The findings from this study provide concern for Indonesian nursing staff on the importance of the personal and sociocultural determinants on the late presentation of the patients. The results also provide basis to develop a culturally sensitive care model or strategies for Acehese women with breast cancer to initiate or adhere to cancer treatments with modern medical care in hospital settings at an early stage of cancer which will, in turn, result in less mortality and increasing quality of life.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter presents a review of the literature related to the overview of breast cancer globally, treatments of breast cancer and breast cancer in Indonesia. A critical analysis of the patterns or types of delay in breast cancer treatments, factors influencing patient delay in consulting a medical doctor focusing on personal and sociocultural factors associated with delays in breast cancer patients.

#### **The Overview of Breast Cancer and Its Treatments**

The scope of breast cancer and its treatments overview in this descriptive cross-sectional study to investigate the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer was focused on TNM staging system of breast cancer, treatments of breast cancer and staging systems and treatments of breast cancer in Indonesia.

#### **TNM Staging System of Breast Cancer**

Breast cancer is a malignant tumor that starts in the cells of the breast and can invade surrounding tissues or spread to distant areas of the body (American Cancer Society, 2012). Similarly with other types of cancer, breast cancer uses the most widely the TNM staging systems in determining the prognosis and treatment options. The TNM staging system considers the common elements of the extent of the tumor (T), regional lymph node involvement (N), and the presence or absence of

distant metastasis (M). There are five basic stages, 0 through IV, and a number of sub-stages.

**Stage 0 (Non-invasive breast cancers).** In stage 0, there is no evidence of cancer cells or non-cancerous abnormal cells breaking out of the part of the breast such as ductal carcinoma in situ (DCIS), in which they started, or getting through to or invading neighbouring normal tissue.

**Stage I (Invasive breast cancer).** Stage I describes invasive breast cancer (cancer cells breaking through to or invading normal surrounding breast tissue) which is divided into subcategories IA and IB.

**Stage IA.** This stage describes invasive breast cancer in which the tumor measures up to 2 cm and the cancer has not spread outside the breast; no lymph nodes are involved.

**Stage IB.** This stage describes invasive breast cancer in which there is no tumor in the breast; instead, small groups of cancer cells larger than 0.2 millimeter but not larger than 2 millimeters – are found in the lymph nodes, or there is a tumor in the breast that is no larger than 2 centimeters, and there are small groups of cancer cells larger than 0.2 millimeter but not larger than 2 millimeters – in the lymph nodes.

**Stage II.** Stage II is divided into subcategories known as IIA and IIB.

**Stage IIA.** This stage describes invasive breast cancer in which no tumor can be found in the breast, but cancer cells are found in the lymph nodes under the arm (axillary) or the tumor measures 2 cm or smaller and has spread to the axillary lymph nodes or the tumor is larger than 2 cm but not larger than 5 cm and has not spread to the axillary lymph nodes.



**Stage IIB.** This stage describes invasive breast cancer in which the tumor is larger than 2 cm but no larger than 5 cm and has spread to the axillary lymph nodes or the tumor is larger than 5 cm but has not spread to the axillary lymph nodes.

**Stage III.** Stage III is divided into sub categories IIIA, IIIB, and IIIC.

**Stage IIIA.** This stage describes invasive breast cancer in which either no tumor is found, but cancer is found in axillary lymph nodes, which are clumped together or sticking to other structures, or cancer may have spread to lymph nodes near the breastbone or the cancer is any size and has spread to axillary lymph nodes, which are clumped together or sticking to other structures.

**Stage IIIB.** This stage describes invasive breast cancer in which the cancer may be any size and has spread to the chest wall and/or skin of the breast and may have spread to axillary lymph nodes, which are clumped together or sticking to other structures or the cancer may have spread to lymph nodes near the breastbone. Inflammatory breast cancer is considered at least stage IIIB. Typical features of inflammatory breast cancer include reddening of a large portion of the breast skin, the breast feels warm and may be swollen and cancer cells have spread to the lymph nodes and may be found in the skin.

**Stage IIIC.** This stage describes invasive breast cancer in which there may be no sign of cancer in the breast or, if there is a tumor, it may be any size and may have spread to the chest wall and/or the skin of the breast and the cancer has spread to lymph nodes above or below the collarbone and the cancer may have spread to axillary lymph nodes or to lymph nodes near the breastbone.

**Stage IV.** Stage IV describes invasive breast cancer that has spread beyond the breast and nearby lymph nodes to other organs of the body, such as the

lungs, distant lymph nodes, skin, bones, liver, or brain. The words “advanced” and “metastatic” are commonly used to describe stage IV breast cancer. Cancer may be stage IV at the first diagnosis or it can be a recurrence of a previous breast cancer that has spread to other parts of the body (BREASTCANCER.ORG, 2013).

### **Treatments of Breast Cancer**

The stage of breast cancer is used as one of the important factor in determining treatment strategies. Therapeutic decisions are then formulated according to staging categories at diagnosis, including lymph node status, levels of the estrogens- and progesterone-receptor in the tumor tissue, menopausal and the general health status of the patient. According to the National Cancer Institute (2013) the option of treatments can be selected based on the present stage of breast cancer as follows.

### **Breast Cancer Stages and Treatment Options**

Treatment options for stage 0, non-invasive or ‘ductal carcinoma in situ (DCIS)’ include: breast-conserving surgery and radiation therapy (followed by hormone therapy for women with hormone-sensitive cancer) that many doctors recommend this approach, total mastectomy (followed by hormone therapy for women with hormone-sensitive cancer), and breast-conserving surgery without radiation therapy.

Treatment options for lobular carcinoma in situ (LCIS) include: regular exams and mammograms to monitor any potential changes (observation treatment), hormone therapy to prevent the development of breast cancer (for women with

hormone-sensitive cancer), and mastectomy of both breasts was previously used as treatment, but is now rarely recommended.

Treatment options for stage I and stage II breast cancer may include: breast-conserving surgery (such as lumpectomy) followed by radiation therapy; modified radical mastectomy with or without breast reconstruction; Post-surgical therapy (adjuvant therapy), including radiation of lymph nodes, chemotherapy, or hormone therapy; and Trastuzumab (Herceptin) given along with or following adjuvant chemotherapy for women with Human Epidermal Growth Factor Receptor 2 (HER2) positive cancer.

Treatment options for stage IIIA breast cancer are the same as those for stages I and II. In stage IIIB breast cancer, treatment options may include: chemotherapy, and possibly hormone therapy (sometimes in combination with chemotherapy); chemotherapy followed by surgery (breast-conserving surgery or total mastectomy) with lymph node dissection followed by radiation therapy and possibly more chemotherapy or hormone therapy; and clinical trials.

Treatment options for operable stage III breast cancer are the same as those for stage I and II breast cancers. In inoperable stage III breast cancer, the cancer has spread to the lymph nodes above the collarbone and near the neck on the same side of the body as the affected breast. Treatment options are the same as those for stage IIIB.

Treatment options for advanced cancer stage IV, in which the cancer has spread (metastasized) from the breast to other parts of the body such as to the bone. Because the cancer is considered to be chronic and incurable, the usefulness of treatments is limited. The goals of treatment in this stage are, therefore, to stabilize

the disease and slow its progression, as well as to reduce pain and discomfort.

Treatment options for stage IV cancer include: surgery or radiation for any localized tumors in the breast; chemotherapy, hormone therapy, or both. Targeted therapy with trastuzumab (Herceptin) or lapatinib (Tykerb) should be considered for women with HER2-positive cancer; a cancer that has spread to the brain may require radiation and high-dose steroids; a cancer that has spread to the bone may be helped by radiation or bisphosphonate drugs. Such treatments can relieve pain and help prevent bone fractures; and clinical trials of new drugs or drug combinations, or experimental treatments such as high-dose chemotherapy with stem cell transplant.

Since the increasing level of metastatic breast cancer is inextricably linked to the increasing stage of cancer, being diagnosed and given initial treatments at a very early stage of breast cancer can cure cancer totally. Similarly, the prognosis for stage IV breast cancer patients with a poor response to treatments results in an increasingly high mortality rate. According to the American Cancer Society, most breast cancer is diagnosed just before stage IV because of obvious signs and symptoms of breast cancer such as palpable breast lump reddening of a large portion of the breast skin, a blood-stained or clear fluid discharge from the nipple, a change in feeling or appearance of the skin on the breast or nipple (dimpled, puckered, scaly, or inflamed). However, the incidence of late stage or “advanced” and “metastatic” stage IV breast cancer is still found to be raised among newly diagnosed South East Asian breast cancer patients (Bhikoo, Srinivasa, Yu, Moss, & Hill, 2011; Hisham & Yip, 2004) with no exception to Indonesia.

## **Introduction to Breast Cancer and Its Treatments in Indonesia**

In Indonesia, similar to other South East Asian countries, breast cancer ranks in the top most cancers among Indonesian women (GLOBOCAN, 2008) with an increasing number of late stage cancer patients (Bhikoo et al., 2011; Ng et al., 2011). Statistically, the numbers of new breast cancer cases and breast cancer deaths were 39,831 (25.5%) and 20,052 (19.2%), respectively (GLOBOCAN, 2008). Based on the Health Research Association in 2007, the prevalence of cancer in Indonesia is found in 4.3 persons per 1000 population. The most frequent cancer is breast cancer with the incidence of 26 per 100,000 women (Ministry of Health Republic of Indonesia, 2012).

Nowadays, although the standardized global breast cancer diagnosis and treatments have also been employed in Indonesia with a national policy of free access to all government hospitals, most newly diagnosed breast cancer women present with advanced stages of cancer. The study was conducted among Indonesian breast cancer patients and revealed 52% of high grade breast cancer patients in Yogyakarta (Aryandono et al., 2006) and in West Sumatera yielded 68.6% in advanced stages (IIIa and IIIb) (Azamris, 2006). Accordingly, another report of Indonesian breast cancer patients revealed that about 70% of them were found in advanced stages (III and IV) and 24.4% of them suffered from bone metastases (Irawan et al., 2008).

As seen, more than half of the newly diagnosed breast cancer patients are in the late stage or advanced stage of cancer. Consequently, instead of receiving initial breast cancer treatments at in the early stage of breast cancer to best cure the

cancer, initiating treatments in the metastatic stage might lead to a poor prognosis and decreased breast cancer survival (Irawan et al., 2008). From this, strategies enhancing Indonesian breast cancer women to receive both newly diagnosis and initial treatments at an early stage of breast cancer might decrease the number of late stage patients resulting in decreasing the number of patients with cancer symptom distress and mortality rates.

Generally, early breast cancer detection can be done through breast self-examination followed by getting clinical breast examination and mammography and having initial treatment options (Jemal et al., 2011). Differing duration period in getting this diagnostic testing and initial treatment is also different among different nations, regions and within specific populations which is further linked to mortality and survival rates. Therefore, the interest in studying specific factors underlying the patterns of cancer patients among the group of late presentation to consult a medical doctor either to be diagnosed or to receive initial cancer treatments can improve understanding the patient delay as well as to uncover confounding factors and develop a strategy to overcome barriers.

### **A Critical Analysis of Patterns or Types of Delay in Breast Cancer Patients**

Delay is the term used for describing the prolonged time in the diagnostic investigation process (Bish et al., 2005; Unger-Saldaña & Infante-Castañeda, 2009). Delay in the diagnosis of cancer has become an issue of scientific concern throughout the last century. The first study on cancer delay was introduced in 1938 by Pack and Gallo (as cited in Unger-Saldaña & Infante-Castañeda, 2009). They

defined undue patient delay as an interval between the onset of symptoms and the first visit to a physician of more than three months. Although the time threshold was arbitrarily developed, it has been used for 70 years in most studies of patient delay. In 1999, Richards and colleagues in their meta-analysis of observational 87 studies published between 1907 and 1996 demonstrated that women with delays of more than three months have shorter survival times than women who start treatment within three months of symptom discovery. In addition to lower survival, patients with delay of three months or longer had a significantly higher probability of local cancer spread or distant metastases compares to those with shorter delays (Richard et al., 1999). According to the Montazeri et al.'s study in 2003, they found that the delay of more than three months was significantly associated with advanced disease and larger tumor. Based on the above evidences, this study therefore used the time more than three month as the cut-off point of patient delay.

Previous research regarding delay has tended to focus on delays attributable to patients as seen from the existing published evidence (Lodhi et al., 2010), especially in developing Asian countries. Thongsuksai et al., 2000 has reported that 25% of breast cancer patients from Thailand had waited 12 weeks or more from the recognition of their symptoms before seeking medical advice. Similar patterns of delay behavior have also been observed amongst women from Iran (42.5%) (Hirachi et al., 2005), Malaysia (72.6%) (Norsa'adah et al., 2011), and Sri Lanka (38%) (Kumari & Goonewardena, 2011). A longer delay was found among women in Pakistan (95%) who first visited healthcare providers after 24 weeks of the initiation of their symptoms (Talpur, Surahio, Ansari, & Ghumro, 2011).

Possible consequences of the late presentation are higher morbidity, decrease treatment options, higher cost of therapy, low chances of treatment success due to advanced nature of the disease and ultimately higher mortality (Richard et al., 1999; Unger-Saldaña & Infante-Castañeda, 2009). Therefore, better understanding of the reasons behind late presentation and finding appropriate remedial measures can be expected to eventually improve the outcome of patients with breast cancer.

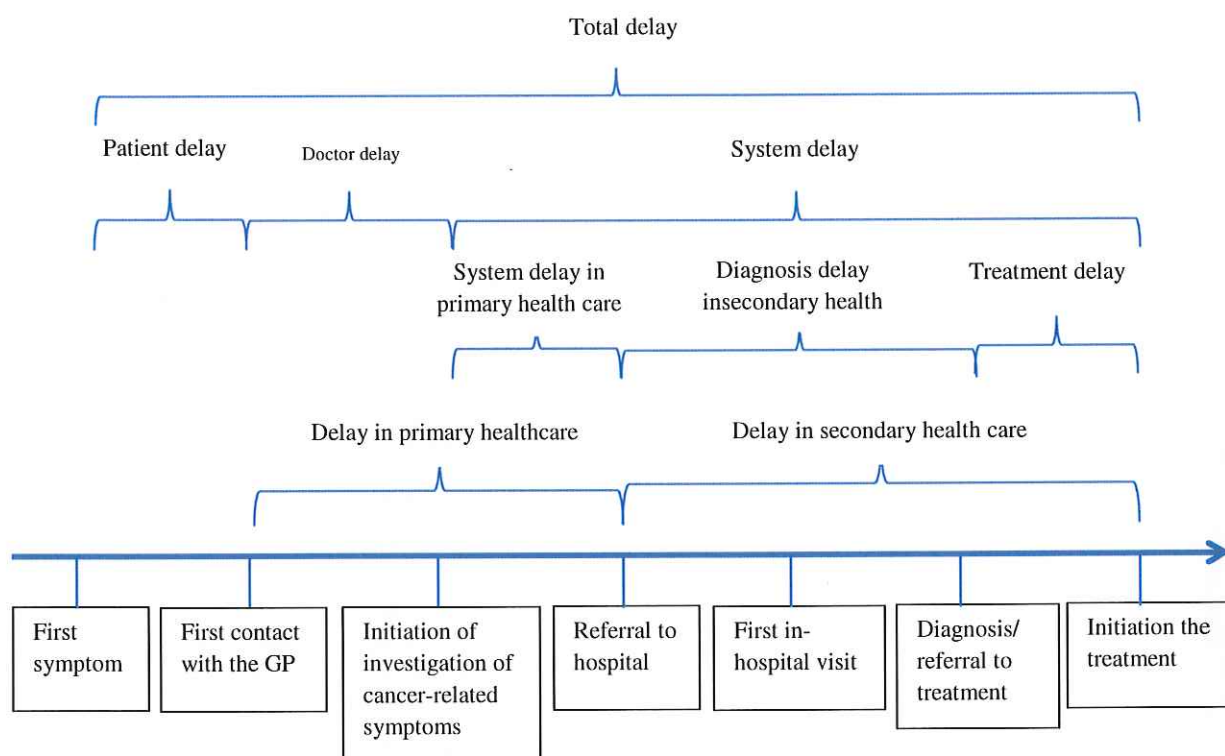
Since late presentation can root from many factors, delay has been categorized to focus specifically either on the patient, health care provider, or health care systems. Further exploration of this concept, delay, would help the researcher to appropriately select the specific type of delay for this investigation.

### **Categorization of Diagnosis Delay**

Hansen describes three categories of delay which are also used to identify the types of delay (Figure 2). First, patient delay defines the duration of time from when the patient firstly perceived her symptoms until the initial presentation to the general practitioner. Second, the general practitioner/ doctor delay is a period from the first symptom presentation until the initiation of an investigation of potentially cancer-related symptoms. Hansen uses the term 'doctor delay' to represent healthcare practitioner delays in primary care. The term healthcare practitioner will be used to represent all practitioners involved in giving healthcare advice and assessment. Third, system delay infers to the time from the start of the general practitioner-initiated investigation until the start of the treatment. System delay has also been divided into delay encountered in primary healthcare and in secondary health care. Individuals with cancer will present to primary care practitioners and directly to secondary care.



Finally, total delay is defined as the interval from the first perceived patient symptom until the treatment starts (Hansen, 2008; Hansen, Vedsted, Sokolowski, Søndergaard, & Olesen, 2011).



*Figure 2. Categorization of diagnosis delay. Adapted from “Time Intervals from First Symptom to Treatment of Cancer: A Cohort Study of 2,212 Newly Diagnosed Cancer Patients,” by R.P. Hansen, P. Vedsted, I. Sokolowski, J. Søndergaard, and F. Olesen, 2011, *Journal of BMC Health Services Research*, 11, p. 286.*

In conclusion, from the description above, any delay between first symptom discovery and the first medical consultation has implicitly been considered to be the patient’s responsibility. In the same way, delays occurring after the first medical consultation have been assumed to be the health providers’ responsibility. Andersen et al presented a general model of total patient delay (‘the Andersen Model’) which distinguishes between the various stages of patient delay.

## Stages of Patient Delay

The Andersen's Model provides the basis for clarifying the interval of delay for cancer patients at each stage of the cancer continuum from the period between an individual's first awareness of a marker of the illness and a medical consultation and receiving appropriate treatment. This model of 'total patient delay' (Figure 3) describes five stages which comprise of (1) *appraisal delay*: focuses on the delay processes of symptom interpretation, this first interval accounts for most of the delay in seeking a cancer diagnosis; (2) *Illness delay*: the number of days elapsing from the time an individual is ill to the day seeking medical help; (3) *Behavioural delay*: the time elapsed between the decision to seek medical help and the person acting on this decision by making an appointment; (4) *Scheduling delay*: the time that elapses between the patients making an appointment and first receiving medical help; (5) *Treatment delay*: the time between the first appointment with a healthcare provider and the onset of treatment (Anderson, Cacioppo, & Roberts, 1995).

The review of the Andersen's model of total patient delay in cancer diagnosis confirms that appraisal delay, illness delay, and behavioural delay are attributable to the patient. While, scheduling delay may be contributed to by both the patients (it takes a while, when the time is convenience for the patient to have an appointment) and the health service (when it is impossible to make an appointment within a certain time). The treatment delay is due to the healthcare provider and not to the potential from patients themselves (Walter, Webster, Scott, & Emery, 2011). However, this study considered total patient delay and did not distinguish between the various stages of the Andersen's model.

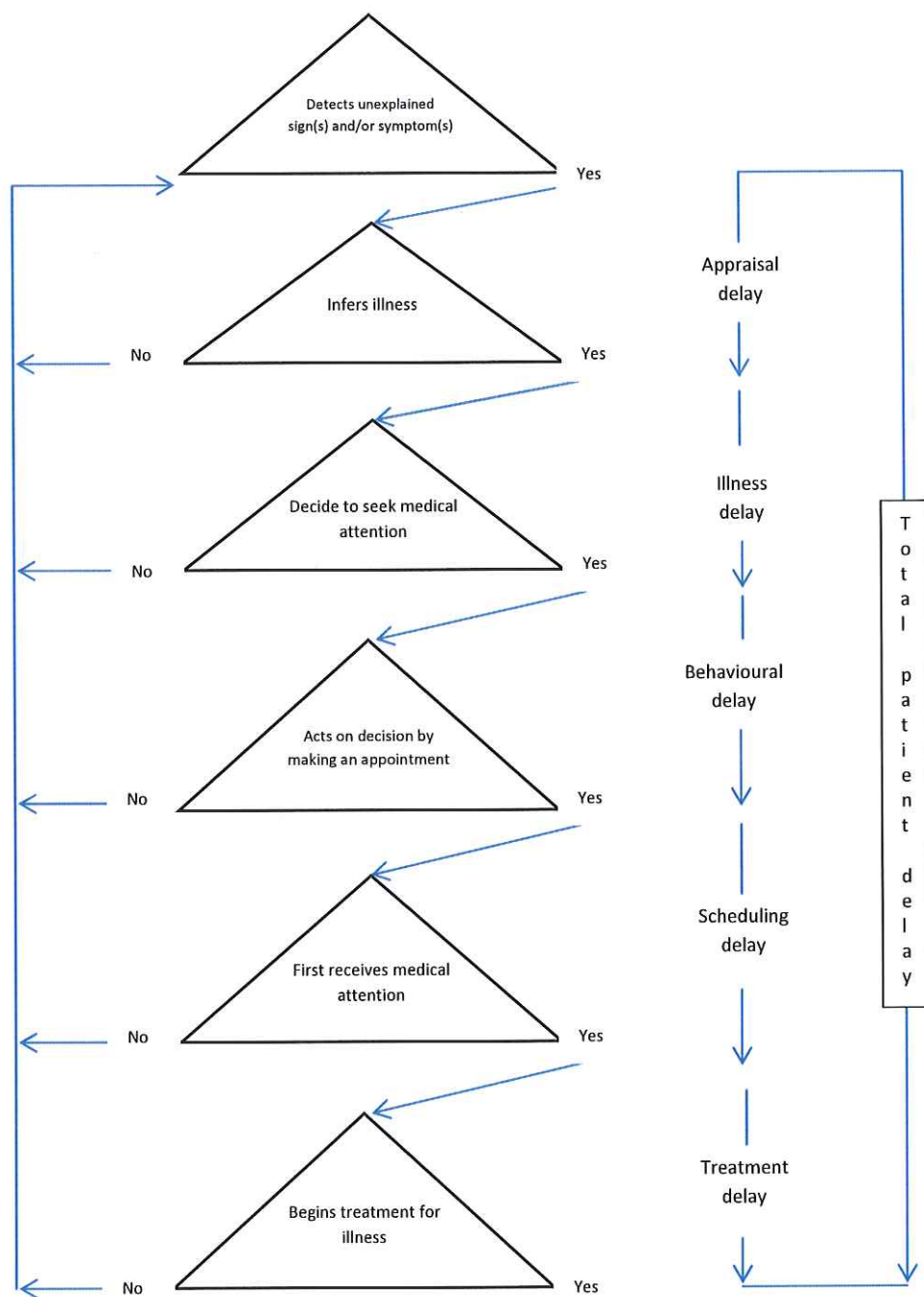


Figure 3. A general model of total patient delay. Adapted from "Delay in Seeking a Cancer Diagnosis: Delay Stages and Psychophysiological Comparison Processes," by B. L. Anderson and J. T. Cacioppo, 1995, *British Journal of Social Psychology*, 34, p. 35.

According to the Andersen's model, the emphasis is on 'patient delay' rather than delays which later occur in the pathway. In cancer especially for breast cancer, delay in consulting a medical doctor often increases morbidity and mortality. Specifically, if one day of delay less and the disease is less advanced at diagnosis,

then the likelihood of cure may be increased. The survival rates, as well as the quality of life following treatments are typically related to the extent of the disease at diagnosis. In short, patient delay in consulting a medical doctor is an important problem that requires great attention to improve the quality of care for patient with breast cancer. Therefore, the patient delay is considered to be the main focus in this study.

Andersen et al. stated that delay period has been identified in identical ways. Suggestions have been made to include both the way people interpret symptoms with high consideration to identify socio-demographic and psychological differences when people interpret a symptom. Additionally, the sociocultural context was suggested to use to establish the relation between bodily sensation, symptom and diagnosis when estimating patient delay (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009).

### **Factors Influencing Patient Delay in Consulting a Medical Doctor**

The advanced stage of breast cancer in the developing world has largely been attributed to the delays in seeking medical attention (Hisham & Yip, 2004). Reluctance to initially consult a medical doctor is related to specific populations of breast cancer patients with several factors. Studies examined factors regarding the mortality and survival rates of cancer among specific populations revealed population structure (i.e. age, race, and ethnicity), lifestyle, environment, socioeconomic status, risk factors, prevalent behaviors, mammography used, the stage of cancer at the time of being diagnosed, and experience in accessing high-quality

care (Yip, Taib, & Mohamed, 2006). Additionally, confounding mortality and survival rates factors included previous medical help-seeking behaviors (Ramirez et al., 1999). Importantly, lack of awareness, unavailability of breast cancer screening methods and sociocultural barriers of hesitation on the part of women to have their breasts examined and seek treatment seem to result in a late stage diagnosis in most Asian women (Agarwal et al., 2007).

Dubayova and colleagues reviewed 15 articles then identified other factors associated with a patient's delay which was fear. Fear appears to be an important psychological factor in delay, and its intensity may have an influencing on early arrival to a health care professional as well as influences the decision-making process in patients on help-seeking behavior. However, the decision process in patients experiencing fear was also influenced by other factors, such as embarrassment (the feeling that the symptoms were trivial or that the symptoms affected a sensitive body area), pressure from a patient's relatives or the fear of financial consequences, fear of discovering the cause of their symptoms, fear about the consequences of a diagnosis (Dubayova et al., 2010; Smith, Pope, & Botha, 2005).

Sharma et al. (2012) conducted a systematic review of the barriers to breast cancer care in delayed patient presentation with the final review from studies conducted in developing countries in which nine out of thirteen studies were conducted in Muslim-majority countries. The study results revealed three sets of factors contributing to delayed patient presentation in receiving breast cancer care: Personal, economic and sociocultural factors. The work of Sharma et al. is, therefore, has provided a basis in selecting the two most important and relevant factors to fit the Indonesian context as discussed next.

## **Personal Factors**

Specific personal characteristics and disease related factors have been identified as being predictive of other self-care behaviours and reflect health care access issues and the increased use of health care services (Balneaves, Weeks, & Seely, 2008). As mentioned above, Sharma et al. categorized the personal factors including age, ethnicity, marital status, clinical presentation, and family history. While education level, income status, employment status, place of residence, access to the health system are included in socioeconomic status (Sharma et al., 2012).

Another review also raises several possible factors for patient delay that contribute to three main classifications as follows: socio-demographics, including age, socioeconomic status, and ethnic origin; clinical factors, including the nature of the first symptom apparent to the patient or the health professional; and psychosocial factors, including emotional, cognitive, behavioural responses, social influences, psychiatric history, and previous medicals help-seeking. A review by Ramirez et al. (1999) formulated the factor predicting delayed presentation of symptomatic breast cancer associated with older age.

Strong evidence was found in the association between older ages and late presentation. Older women (aged more than 65 years) were particularly poor at identifying symptoms of breast cancer and risk factors associated with breast cancer. Many older women have less knowledge of breast cancer symptoms and believe that breast cancer more likely strikes younger women. They held negative beliefs that breast cancer and its treatment could be disabling, disfiguring or having economical implications. These beliefs make them less likely to seek help for breast symptoms (Bish et al., 2005; Grunfeld et al., 2002).

Surprisingly, a controversial relation between age and cancer was found in a study conducted in Asian countries. The result from this study revealed that nowadays, breast cancer occurs at a relatively young age with aggressive biological characteristics. The proportions of young patients (< 35 years) were up to 25% in developing Asian countries, which carries a poorer prognosis (Bhikoo et al., 2011; Agarwal et al., 2007).

Beside age, lower educational levels also had the strong influences on the delayed presentation of breast cancer patients (Alhurishi, Lim, Potrata, & West, 2011). In India and Iran, for instances, illiterate women with a primary school education level had elevated risks for late stages among breast cancer patients (Ali, Mathew, & Rajan, 2008), as well as less education Iranian women were more likely to delay seeking medical care. A lack of knowledge regarding the necessity of such visits, fear, negligence, lack of access to physicians, and poverty were also found as the main reasons for delayed presentation (Harirchi et al., 2005). Here, the knowledge of the early symptoms of cancer would be associated with a greater likelihood of having perceived a symptom as possibly due to cancer (Simon, Waller, Robb, & Wardle, 2010).

The marital status is one of the personal factors associated with delayed presentation and inconsistent results were found among different countries. The traditional central role of married women influences the association between marital status and delayed presentation. For instance, since married Iranian women devoted most of their time to their children and husband, being married was found associated with late presentation among Iranian women (Harirchi et al., 2005). In contrast, being single, widowed or divorced was associated with delayed presentation

among breast cancer women in India, Sri Lanka, and Thailand (Ali et al., 2008; Kumari & Goonewardena, 2011; Thongsuksai et al., 2000). They argued that motivation and good support from husbands of married women among these countries might make this different (Kumari & Goonewardena, 2011).

The nature of the initial breast cancer symptom, in particular a breast lump, can influence delayed presentation. Specifically, women with no lump symptoms have been found to be less likely to attribute their symptoms to a definite cause and are less likely to consider the possibility of breast cancer. From this, women with delayed presentation are more likely to experience the absence of a breast lump (Bish et al., 2005). Patients who had a breast lump therefore had earlier consultations than those without a breast lump. This difference however, may not have any influence on the presence of an advanced stage of cancer at the time of diagnosis due to the degree of malignancy (Kumari & Goonewardena, 2011; Meechan et al., 2003).

In developing countries, socioeconomic factors have had a strong association with diagnostic delay and advanced disease (Aziz, Sana, Akram, & Saeed, 2004). Most cases of breast cancer delayed presentation and those that presented in advanced stages were due to poor economic status and illiteracy (Lodhi et al., 2010; Talpur et al., 2011). This can be viewed as a lack of ability to pay for a doctor's visit, treatment, and transportation among breast cancer women with low-income and was found as a major barrier for a much longer delay since they had experienced the first symptom until the initial seeking of medical treatments (Ali et al., 2008). In Indonesia poverty remains widespread, over 100 million people live on less than \$ 2 US per day which can impact on health care seeking ability and education services (Factbase, 2011).



Advanced stages of breast cancer were mostly found in remote areas where proper facilities of health care and health education are not available, in general (Talpur et al., 2010). It was also highlighted in a study by Agarwal and Ramakant (2008) that poverty has a significant influence on late presentation particularly in those patients who had rural backgrounds because of the poor access to high-quality treatment facilities, few treatment facilities for the population, and poor financial resources of the patient. As a result, the breast cancer patients presented in an advanced disease stage and had numerous poor prognostic factors.

To conclude, the personal factors associated with the delayed presentation of breast cancer patients in Indonesian women and the Indonesian context, in particular Acehese culture were examined in this study and included age, ethnicity, marital status, educational level, economic status, family history, and clinical presentation.

### **Sociocultural Factors**

The influence and strong relationship between sociocultural factors health beliefs, and health seeking behaviours, including cancer beliefs and treatments options have been acknowledged. Sociocultural values are linked to cancer outcomes through beliefs, attitudes, and behavior in terms of prevention and screening, provider-patient relationships and interactions, and adherence to medical treatment (Meyerowitz et al. as cited in Kagawa-Singer, Dadia, Yu, & Surbone, 2010). Hence, understanding the sociocultural dimensions underlying a patient's health values, beliefs and behaviors is critical to a successful outcome of a clinical goal (Meneses & Yarbro, 2007). In addition, cultural variation can be seen in beliefs about disease

etiology, appropriate treatments, proper self-care and preventive treatment, human physiology, and appropriate doctor and patient conduct. Cultural differences even influence the perceptions of symptoms and emotional states (Shaw, Huebner, Armin, Orzech, & Vivian, 2009).

Reciprocally, the impact of cultural beliefs and practices on cancer outcomes is cumulative, occurring at every stage of the cancer continuum from prevention, screening, early detection to access and response to treatment, enrollment in clinical trials, rehabilitation and survivorship/ palliative care, and end-of-life care (Kagawa-Singer et al., 2010). Culture also affects both the risk factors for cancer as well as the meaning of the disease by establishing norms of behavior and providing guidance for its members to respond emotionally, cognitively, and socially to this disease (Kagawa-Singer, 1995).

Assessment of the appropriateness of response to the cancer experience must be made within the correct cultural context. Body image, issues, concepts of disability and impairment, the meaning of death and family reactions are also framed in a cultural context. Additionally, pain response, use of traditional medicines, drug metabolism, visiting patterns, communication patterns, concepts of dependency, and decision making patterns whether the patient is told about her diagnosis are also influenced by cultural values and beliefs (Kagawa-Singer, 1995).

Culture also frames attitudes toward gender roles, concept of health and suffering, meaning of body parts, and decisions about life, illness, death, religion, and world view (Kagawa-Singer et al., 2010). For breast cancer, gender role is of special importance, because it dictates the kinds of support a woman may have available to her, and the kinds of support deemed appropriate to expect and to seek.

Kagawa-Singer (1995) stated that a woman's culture influences how she will respond to the fact and meaning of cancer either for screening, early detection, or diagnosis, how side effects will be understood and experienced, and how emotions will be expressed.

**Cultural belief about breast cancer within the context of Asian countries.** Dein (2004) stated that “culture determines the different ways that patients understand cancer, the ways they explain it and their attitudes towards it” (p. 119). Leininger defines culture as the values, beliefs, norms, and practices of a particular group that are learned and shared and that guide thinking, decisions and actions in a patterned way (Leininger, 1988). It has been well recognized that culture plays an important role in forming human perceptions, values, world views, behaviors and health beliefs and influences human experiences (Kemp, 2005).

Cultural health beliefs refer to the ways in which people perceive illness, how they explain their present health status and problems, how they define quality care, and how they select their caregiver (Wong-Kim, Sun, & DeMattos, 2003). With this regard, cultural cancer care was developed within a specific local context which in turn influences the way people view and give the meaning of cancer, including the way they appraise the cancer treatments. Hence, the cultural meaning and perceptions of breast cancer is the most important contributor of the advanced stage presentation among women in Asian countries (Agarwal et al., 2007; Azaiza & Cohen, 2008; Harirchi et al., 2005; Hisham & Yip, 2004; Im et al., 2004; Taib, Yip, Ibrahim, Ng, & Farizah, 2007; Wong-Kim et al., 2003; Wu, West, Chen, & Hergert, 2006).

The cultural values regarding a woman's body becomes one of cultural impeding factors for Asian women with breast cancer in consulting a medical doctor. Asian culture tends to make women's bodily experience invisible and inaudible. They are reluctant to show their breasts to others, including to a healthcare provider (Im et al., 2004). In traditional Asian culture, women's bodily experiences are taboo and rarely discussed openly even among women themselves especially the breast because it is a sensitive part for women (Azaiza & Cohen, 2008). For example, a shameful and cultural prohibition made them use special indirect words when referring the word, "breast", and have symbolic meaning in labeling this body part in a modest way (Lee et al., 2007). Some Asian breast cancer women avoid discussing breast cancer and the use of the term cancer because of fear and cancer terminology provides a sense of a dramatic story and worst connotations (Wu & Bancroft, 2006).

A common issue about cancer among Asian and Indonesian women is the feeling of stigma. They fear creating stigma for their daughters, fear of being ostracized from society, fear of being contagion, language barriers, and a preference for using traditional healers (Parsa et al., 2006). While Chinese women with breast cancer believe in the law of karma in that breast cancer is a kind of punishment for previous life deeds and might result in self-blame. The stigma associated with the diagnosis would bring shame to the entire family. Thus, many Chinese families chose to keep cancer as a private family affair (Wong-Kim, Sun, Merighi, & Chow, 2005; Tsai, Morisky, Kagawa-Singer, & Ashing-Giwa, 2011).

Similarly, Iranian and Malaysian women perceived that breast cancer is willed by God and the outcome of the illness is God's control (Ashing et al., 2003; Azaiza & Cohen, 2008; Farooqui et al., 2011). Islam, the religious faith of Muslims,

as set forth in the Qur'an, teaches that God, whose Arabic name is Allah, is the only God. A Muslim is often characterized as one who strives to submit to the total will of God. They believe everything is in God's hands and their destiny is to return to God. Even this religion also encourages people to take responsibility for their body and must take the best possible care of it, they still believe that cancer is a fate, determined by God, and nothing can be done. Therefore, once they get a disease they will rarely try to consult a medical doctor (Azaiza & Cohen, 2006; Underwood, Shaikha, & Bakr, 1999).

Misconceptions about breast cancer are also naturally developed among Asian women within their local contexts. Among three ethnics group of women in Penang, Malaysia as well as in Arabia and China, breast cancer was viewed as "equal death" an incurable disease (Azaiza & Cohen, 2008; Hadi, Hassali, Shafie, & Awaisu, 2010; Wong-Kim et al., 2005). Consequently, they might not seek any treatments and cares because this is the way they have to be and they can do nothing to avoid or stop getting cancer and dying.

In Aceh of Indonesia, since the majority of Acehnese women are Muslim, the Islamic culture is integrated in their daily life. Purity, modesty, and decency in behaviour, appearance, dress, and speech are expected of all Muslim women. According to Islamic principles, exposing the body in public, other than hands, feet or face, is not allowed. Muslim women are encouraged to "veil and cover" their bodies from the attention of men and have been familiar with this practice since they were young. They address restrictions in dress and beliefs concerning the privacy of the body, particularly the breasts which are generally not openly discussed.

Consequently, cultural and religious beliefs and traditional practices regarding female gender influence Muslim women to avoid or be hesitant to consult a male medical doctor, receive diagnostic methods in hospital, in particular a clinical breast examination or mammography (Banning & Hafeez, 2009; Rashidi & Rajaram, 2001; Taha, Al-Qutob, Nyström, Wahlström, & Berggren, 2012; Underwood et al., 1999). Importantly, since medical doctors or healthcare staff providing breast cancer consultation, diagnostic processes, and treatments are of both genders, a major cultural barrier can be identified. Here, the spiritual gap between breast cancer services and cultural beliefs and practices can be diagnosed as well as there is no question about the vital relationship between sociocultural factors and delayed presentation among Acehnese women with breast cancer.

#### **Cultural beliefs about risk factors and signs of breast cancer.**

Culture also has an influence on the perception of people about risk factors for breast cancer. Major proportions of women in Asian countries perceived the risk factors associated with breast cancer from different views which consist of a combination of modern biomedical views and traditional concepts (Azaiza & Cohen, 2008). Women pointed to tradition-based views that the evil eye or contagion may cause cancer, while others attributed it to the heredity factors in the onset of breast cancer. They believe that as long as there is no family history of cancer, they would not be prone to develop breast cancer (Azaiza & Cohen, 2008; Grunfeld et al., 2002; Im et al., 2004; Lee et al., 2007).

Additional factors that influenced people's beliefs about the risk factors of breast cancer were related to the environment and the modern way of life, such as cellular phones and antennas, smoking, air pollution, chemicals in food, high

fat diets, hormones in meat (Azaiza & Cohen, 2008), obesity, stress, older age, not breast feeding, and a negative mental attitude (Lee et al., 2007; Lin, Menon, Pett, Nail, Lee, & Mooney, 2007). Another perspective also found among Chinese women with breast cancer was that they had a distinct meaning for predisposing them to breast cancer that are based on Taoism beliefs due to an unbalanced energy flow in the human body or surrounding environment and suffering in Buddhism to accept their illness and possible death as an inevitable part of nature plus not maintaining attachments as well (Tsai et al., 2011; Wong-Kim et al., 2005).

The perception of the seriousness of symptoms also influenced the seeking behavior and this depended on the first symptom and how fast the symptom is damaging (Norsa'adah et al., 2011). Most women with cancer assumed that symptoms would disappear without intervention. They did not perceive the importance of early detection, as influenced by the culture in which they have been raised as in a patriarchal culture where women have always had the lower position. Most of the women did not pay attention to the symptoms they were experiencing and behaved as not sick. They did not want to burden their family because they could not perform their usual role (Im et al., 2004).

**Cultural beliefs about screening test and treatment of breast cancer.** As discussed above, most Asian women with breast cancer perceive the outcome of their illness as being in God's hands and everything comes from God. They held a strong belief in the power of prayer, and some may place more importance on spirituality than on healthcare providers. These women may be less inclined to actively participate in the treatment and believe that screening is not necessary and is not of benefit to them (Ashing et al., 2003).

Some community members were not familiar with cancer screening as a preventive measure. They do not perceive a significant need for breast examination without presenting any signs and symptoms, including lack of experience of breast cancer from a family history with a healthy lifestyle (Im et al., 2004; Kwok & White, 2011; Wu et al., 2006). This would tend to make them decide to delay receiving medical diagnosis and treatment in hospital until experiencing recognizable symptoms and feeling sick. Consequently, the late stage of breast cancer might be presented at the initial presentation when the treatment would no longer be effective or of less benefit.

Delay in making a decision to receive modern therapy was also attributed to a strong belief in traditional therapy (Hisham & Yip, 2004; Malik & Gopalan, 2003). There are numerous reasons why patients prefer using traditional medicine than receiving modern care treatments in hospital. The lists of reasons include fear of surgery and negative results after a mastectomy, recommendation by family and friends, perception on better benefits and credibility of alternative therapy, a previously bad experience in the hospital service, financial problems, lack of time, role expectations in the family, less appraisal of the harmful symptoms, including feeling uncomfortable and ashamed with the diagnostic process (Taib et al., 2007; Muhammad, Meriam, & Suhami, 2011). Some patients also have less trust in modern medicine because of having bad memories from previous experiences, including the feeling of an unfriendly atmosphere from healthcare provider in comparison with traditional healers. From this, breast cancer patients decide firstly to choose alternative treatment (Hisham & Yip, 2004; Norsa'adah et al., 2011).



In Aceh, the preference for traditional healers is one of cultural attitudes and beliefs in seeking care for various illnesses. Traditional healers or *dukun* (Indonesian term) are still the first choice in terms of information and treatment seeking when people get sick, even with cancer (Cunningham, 2012). Previous experiences in accessing hospital services, beliefs, perceptions, misconceptions about modern cancer treatments, in particular fear of surgery and negative results influence cancer patients to seek help from traditional healers. Acehese women viewed a mastectomy as creating a disability, loss of womanhood and motherhood.

Salient barriers are fears of the side effects from treatments (Farooqui et al., 2011) and not needing mammograms if there is an absence of symptoms, the view that modern cancer treatment as a long process will worsen their illness (Grunfeld et al., 2002; Hadi et al., 2010) even worse than breast cancer itself and these barrier have become significance factors relating to delay in seeking treatment (Kwok & White, 2011; Norsa'adah et al., 2011). Regarding hospital services, the fear of being touched and examined by a male practitioner or stranger, the waiting time is too long, and not knowing where to get a mammogram influence delayed presentation (Wu et al., 2006).

Traditional healers, on the other hand, in the way they treat cancer patients provides a sense of trust as in they are someone who can be cured. Importantly, the relationships between traditional healers and cancer patients/their families develop under a friendly and home-like-atmosphere or people on the same rung. Under the era of advanced modern cancer care and treatments and the flourish of evidence-based medicine and nursing as well as no evidence to support traditional therapy, *dukun* is still playing a major role in spiritually influencing Acehese breast

cancer patients (Cunningham, 2012). From this, local culture and cancer care culture has an influence on women with breast cancer in delaying making decisions to receive modern cancer care in hospital.

**Social support.** Social support from spouse and family members (spouses, mothers, siblings, children), including the disclosure of symptoms to a close relative or friend associated with shorter patients delay among female patients (Pedersen, Olesen, Hansen, Zachariae, & Vedsted, 2011). Family members usually accompanied them to most of their medical care visits regarding breast cancer diagnosis and treatments (Ashing et al., 2003; Taha et al., 2012). Lack of social support was therefore postulated as a negative influence in seeking medical care (Im et al., 2004).

In traditional Acehnese culture, the influence of family members is critical; women's decisions and actions are controlled by men. From this, any efforts will not be blessed without getting sanction from the family, in particular parents and spouse. In the hierarchical structure of the Acehnese family system, women have always occupied a lower position (Cunningham, 2012). Most of the women perceived feelings of femininity via the completeness in taking the women's role as a wife and mother which would be threatened by the presence of the disease. They place a priority on the needs of other family members and tend to be ignored and trivialized in their health care needs until they are experiencing distress from cancer symptoms. They hide the disease from their relatives, parents, or their spouses and act as if they are not sick.

Acehnese women give value to family and friends as sources of information, sounding boards, and supporting systems. Pressure and influence from

relatives, family and friends was reported as one of the most powerful reasons underpinning when women make a decision to choose therapy options and consult a medical doctor (Pederson et al., 2011).

In short, the sociocultural factors associated with a delayed presentation of breast cancer patients, in particular Acehese women were examined in this study and this includes breast cancer awareness, cultural beliefs about breast cancer, alternative treatment use, and social support.

### **Summary**

The evidence from the literature review enacts and highlights the significance of personal and sociocultural factors within a specific local context of Asian countries which in turn influences patient delay to consult a medical doctor. From this, most Asians as well as Asian-related groups of breast cancer patients were diagnosed and received cancer treatments in hospital in advanced stages of breast cancer. Here, patient delay has long been recognized as an important factor which leads to negative consequences, metastases of breast cancer as a result in increasing distress from cancer symptoms, decreasing survival rate and quality of life. Along with this, the strong influence of personal and sociocultural factors on patient delay has been acknowledged.

Being a multicultural province within a multicultural state of Aceh under the richness of cultural and religious beliefs and traditional practices of Acehese women make this more significant than real. Several studies have shown the influence of personal and sociocultural factors on patient delay among women in

Asian countries with breast cancer. To date, there is however still no known report or clear knowledge related to the determinants of personal and sociocultural factors, in particular the predictive power of the personal and sociocultural determinants on patient delay from the time elapsed from the first symptoms to the initial consultation with a medical doctor among Acehese women with breast cancer. The gap in the literature demonstrates a need for further study of the predictive power of the personal and sociocultural determinants on patient delay among women with breast cancer in Acehese cultural context.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

This chapter presents research design, variables, setting, population and sample, sampling procedure, research instruments, validity and reliability of the instruments, translation of the instruments, ethical consideration, data collection methods, and data analysis.

#### **Research Design**

The descriptive cross-sectional study using questionnaires and an open-ended question were employed to examine the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehnese women with breast cancer.

#### **Variables**

The independent variables were personal factors including age, ethnicity, marital status, educational level, economic status, family history of breast cancer, clinical presentation; and sociocultural factors including breast cancer awareness; cultural beliefs about breast cancer; alternative treatment used; and social support. The main outcome variable was patient delay in consulting a medical doctor.

## Setting

This study was undertaken at two government hospitals. The first hospital setting was in the surgical unit and chemotherapy units, in either the outpatient department (OPD) or inpatient department of dr. Zainoel Abidin General Hospital, the tertiary hospital in Banda Aceh, Indonesia. This hospital is the biggest government-owned hospital which serves as the top referral centre for Aceh. It is a major research and educational facility for undergraduate and postgraduate education of medical doctors and nurses. The surgical outpatient department, especially for the oncology department provides for newly diagnosed breast cancer patients and is available for 2 days in the week (Tuesday and Thursday). The second hospital setting was in the Ibu dan Anak Hospital in Banda Aceh, Indonesia. This secondary hospital which also provides for newly diagnosed breast cancer patients every day. Both hospitals are free from all medical expenses because the medical cost is covered by the government. Routinely, the basic diagnostic process which is clinical breast examination (CBE) and other investigations such as mammogram, ultrasound, and fine-needle aspiration biopsy (FNAB) are used as standardized procedures for the differential diagnosis of breast cancer in these hospitals.

Similarly with standardized CBE in other regions, the procedure of CBE in these hospitals is allocated by a medical doctor. Patients need to take off their clothes above the waist without being given a gown to wear during the examination. First, the doctor asks the patients' questions about any problems they may have, their medical history, and factors for breast cancer. The doctor examines each breast, underarm, and collarbone area for changes in breast size, skin changes, or signs of

to be quicker than the specified schedule. Usually the schedule could be accelerated if there are other patients who cancel their operation. Whereas, the general first regimen for a late stage breast cancer patient is considered palliative and the intent is to keep metastases in control and provide individuals with more time and better quality of life. This may consist of hormone therapy, chemotherapy, or some combination of these treatments. Treatment can shrink tumors, improve symptoms, and help patients live longer, but it is unable to cure these late stage cancers.

## **Population and Sample**

### **Population**

The population of this study was patients with breast cancer admitted to the surgical and chemotherapy units or those who attended the breast clinic in the outpatient department (OPD) of dr. Zainoel Abidin General Hospital and Ibu dan Anak Hospital, Banda Aceh, Indonesia for diagnosing and treating breast cancer.

### **Sample Size**

All consecutive eligible breast cancer patients either in scheduled consultation with a physician at outpatients or those who were admitted to the surgical and chemotherapy units were included to obtain approximately 160 respondents. To produce close estimates of the correlation in a population or respondent size needed for this study, Thorndike's formula was employed and revealed 160 respondents (Thorndike, 1978 p. 184 as cited in Prescott, 1987).

$n \geq (10 k) + 50$ , where  $n$  is sample size,  $k$  is the number of independent variables (11 variables).

A rule of thumb for planning multiple logistic regression and proportional hazard analysis is that for every independent variable in the model needs at least ten cases if the outcome occurs in equivalent number for each group (Katz, 2011). Therefore the sample size in this study was sufficient for to be dichotomous independent variable with the number of the respondents' ratio in delay group: in not delay group (78:82).

### **Sampling Procedures**

Convenient sampling technique was used to select the respondents in this study. From this, the respondents were selected because of their convenient accessibility and proximity to the researcher. To control the homogeneity of the study, respondents were selected if they had the following criteria: 1) diagnosed with breast cancer; 2) firstly recognized a breast-related symptoms by herself; 3) newly diagnosed with breast cancer or just starting the breast cancer treatment; 4) able to read and communicate; 5) willing to participate voluntarily and give informed consent. Respondents with regular check-up recognition, psychiatric and general medical co-morbidities (e.g., depression, severe stress, anxiety disorders, personality disorders, cognitive impairment) were excluded from this study.



## **Instrumentation**

In this study, data were collected using a structured questionnaire consisting of 2 parts, Part I is the Personal Characteristics and Disease-related Data Form. The Sociocultural Questionnaire in the second part comprising of 4 sub-questionnaires: (1) the Breast Cancer Awareness Measure (BCAM); (2) the Cultural Belief about Breast Cancer and Cancer Care Questionnaire; (3) the Alternative Therapy Used Questionnaire; and (4) the Social Support Questionnaire. Details of each part of the instruments and the questionnaires are described as follows:

Part I. The Personal Characteristics and Disease-related Data Form (Appendix B). This questionnaire was developed by the researcher based on a systematic review which was conducted by Sharma et al. (2012) about the barriers to breast cancer care in developing countries resulting in delayed patient presentation. It comprises of 11 questions related to personal and disease related information of the respondent including age, ethnicity, marital status, level of education, economic status (family income, health insurance, place of residence), family history of breast cancer and clinical presentation (first symptoms, stage of breast cancer, and tumour size). Respondents were asked to place a tick (✓) in a given box of each question that most closely matched to their opinion accordingly. Relevant documentation, in particular patients' medical records was used as another source for clinical presentation data. Patient Delay in Consulting Medical Doctor items was also included in this part. The respondents were asked about the period from the first onset of symptoms to the first medical consultation to indicate patient delay. The duration from 0-3 months was categorized into not delay, and the duration > 3 months was categorized into delay.

Part II. The Sociocultural Questionnaire consists of a set of 4 questionnaires. First, the Breast Cancer Awareness Measure (BCAM) (Appendix C). This questionnaire was developed by Linsell et al. (2010) and tested in 1035 women attending the National Health Service (NHS) Breast Screening Program in South East London. The BCAM had high readability, and test-retest reliability was moderate to good (.42-.70), it had good construct validity, with cancer experts achieving higher scores than non-medical academics (50% versus 6%,  $p = .001$ ). This questionnaire consists of questions regarding knowledge of breast cancer symptoms, knowledge of age-related risk, and reported frequency of breast checking.

Knowledge of breast cancer symptoms includes change in the nipple position, pulling in of the nipple, pain in one 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, change in the size of the breast or nipple, and change in the shape of the breast or nipple. The respondents were asked to circle the items and were able to choose more than one item that matched their opinion for each potential symptom of breast cancer. The number of symptoms endorsed by each respondent was summed to produce a total knowledge score (range 0 to 11). In this study, the respondents were interpreted as having awareness of breast cancer if they identified five or more non-lump symptoms from the list, could identify that 70 year old women were most likely to get breast cancer in the next year compared to a young woman or a woman of any age, and reported checking her breasts at least once a week or once a month.

Second, the Cultural Belief regarding Breast Cancer and Cancer Care Questionnaire (Appendix D). This questionnaire was developed by the researcher

based on a literatures review about culture beliefs of breast cancer within the context of Asian countries. Furthermore, the researcher made it more appropriate and best fit with the local cultural context, including cultural and cultural health beliefs and practices of Acehnese. This questionnaire has positive and negative statements which consist of beliefs about breast cancer, belief about risks and symptoms of breast cancer, beliefs about screening, and beliefs about the treatment of breast cancer. It uses a 5-point Likert scale, ranging from 1 strongly agree, 2 agree, 3 not sure, 4 disagree, to 5 strongly disagree for negative statements and was reversed for positive statements. The possible scores range from 1-5. A high score indicated positive attitudes toward breast cancer and its treatments.

In addition to the above questionnaires, one open-ended question was added to further explore the other vital reasons or events underpinning the respondents' decision-making to initially consult a medical doctor.

Third, the Alternative Therapy Use Questionnaire (Appendix E). This questionnaire comprises of *types of alternative therapy use* modified by the researcher based on information from the National Center for Complementary and Alternative Medicine (NCCAM, 2011). The NCCAM is the Federal Government's lead agency for scientific research on complementary and alternative medicine (CAM) within the U.S. Department of Health and Human Services. In the utilization of the original version of the questionnaire in this study, the researcher was highly concerned on the difference between Western culture and Acehnese culture. Because of this, unusual, uncommon and unfamiliar types of Western alternative therapy for Acehnese people were excluded and local alternative therapy as used in the context of Aceh was included. The current questionnaire for this study comprises of 5 types of traditional

therapy. The dichotomous scale 'yes' or 'no' was used. The respondents should be able to select either 'yes' or 'no' which indicates that each item was used or never been used by the respondents, respectively.

The second part consists of questions regarding the *main reason* for using selected alternative therapy, the current questions in this study were developed based on a literature review by Wanchai et al. (2010). This questionnaire also used dichotomous scale 'yes' or 'no'. The respondents rated the items that matched their opinion or experience of using traditional therapy. Where, 'yes' indicated that the respondents agreed or had experience of each item whereas 'no' indicated that the respondents disagree or have no experience of each item.

Finally, the Social Support Questionnaire (Appendix F) was primarily developed by Hansen (2008). This questionnaire assessed the patient's perceptions of how her partner and others in her social life reacted to her worries associated with experiencing a symptom. Since this questionnaire was firstly developed and used under the context of European countries, some kinship or relationship terms used are different in Acehnese culture. In this study, the term 'partner' was replaced with husband and the term 'others' was detailed specifically according to each respondent at the heading of the questionnaire. Originally this questionnaire asked repeatedly 10 items for husband and 10 items for others, but the researcher modified by firstly identifying the main persons who provided support then asked simultaneously. 5 items consisted of positive support and 5 items were negative support (avoidance). For positive support, each item was scored on a 4-point Likert scale ranging from 1 ('not at all') to 4 ('very much') and the score was reversed for negative support (avoidance). The minimum and maximum scores of each items was 10 - 40,

respectively. Higher scores indicated more social support whereas lower scores indicated the less social support.

### **Translation of the Instruments**

In this study, the questionnaires were initially developed in the English language. In order to ensure the equivalence of these instruments in Indonesian language, the researcher used the back translation technique performed by three independent translators (Hilton & Skrutkowski, 2002). The instruments were translated from the original English version to an Indonesian version by an Indonesian bilingual translator. Subsequently, the Indonesian version questionnaires were translated back into an English version. Finally, the two English versions were examined for comparability of language and similarity of interpretation. A third translator finally assessed any discrepancies and evaluated the differences between the original version and the back-translated version. There were no discrepancies found between the two English versions.

### **Validity and Reliability of the Instruments**

The instruments were evaluated for content validity, language suitability, and criteria scoring of the entire questionnaire by three experts from the Faculty of Nursing, Prince of Songkla University (PSU). Each item was evaluated for appropriateness with its related construct. Modification and revision of the content of the instruments was organized by the researcher based on the suggestions and recommendations of the experts. The content validity confirms the degree to which

the instruments have appropriate items to measure the personal and sociocultural determinants of patient delay.

The reliability of the translated instruments for the Cultural Belief about Breast Cancer and Cancer Care Questionnaire and the Social Support Questionnaire was assessed for internal consistency using the Cronbach's alpha coefficient. The researcher used 20 respondents who met the inclusion criteria of the study. The result showed that the reliability of the Breast Cancer and Cancer Care Questionnaire was .74, which is considered as reliable for a newly developed instrument. For the Social Support Questionnaire, the Cronbach's alpha coefficient was .84.

### **Data Collection Procedure**

The emergent design has resulted in two distinct study phases of data collection outlined as follows:

#### **Preparation Phase**

In the preparation phase, the vital processes were done readily prior to collecting the data. A permission letter issued by the Dean of the Faculty of Nursing, Prince of Songkla University was obtained as well as getting approval and permission from the director of dr. Zainoel Abidin General Hospital and director of Ibu dan Anak Hospital in Banda Aceh, Indonesia. The approved revised version of the questionnaires according to the experts' comments and suggestions included an informed consent form as well as the process of testing validity and reliability of the

instruments which was done under complete supervision. In this study, the researcher recruited two research assistants (RAs) who have completed a Bachelor in Nursing and worked at the target hospitals. The RAs were responsible for finding the appropriate respondents and collecting the data using the questionnaire and interview. Before collecting the data, the RAs received a detailed explanation from the researcher about the objectives of the study, the inclusion criteria of the respondents, and the instruments used in this study. The researcher explained her role and responsibility for discovering the appropriate respondents and collecting the data. Lastly, the researcher and RAs reviewed each item in the instruments. During this process, the researcher and RAs discussed and clarified any confusion to ensure the RAs would be able to answer any possible questions asked by the respondents.

### **Data Collection Phase**

Initially, the researcher explained and provided information about the objectives, design, and purpose of the study to the head nurses in the surgical OPD, IPD, and chemotherapy unit. Then the researcher and RAs identified the respondents who meet the criteria to be included in this study. A potential patient was firstly approached by the RAs and the researcher and ascertained for their interest in and willingness to participate. In the recruitment process, the researcher made an appointment with each respondent, introduced herself and informed the respondents regarding the purpose of this study, the study procedures or the way the respondents are involved in this study, risk, benefits, rights and responsibilities, and the process in keeping respondents' confidentiality. When eligible respondents agreed to participate in this study, they were asked to sign the informed consent form.

After the researcher and RAs had explained the study, they distributed a complete set of questionnaires to the respondents and also the way informed them of the way to return the questionnaires directly to the researcher. The researcher and RAs stayed with the respondent until they had completely filled in every questionnaire. Respondents were given time to read the question and choose the item based on their opinion freely. For the items patient delay in consulting a medical doctor and the nature of the initial breast cancer symptom, the researcher interviewed the respondents. Particularly for clinical presentations, the researcher filled in the data based on the information from the medical records. Every respondent was asked to complete every part of the questionnaire at the same time. Finally, the researcher collected the answered questionnaires and inspected each set of the entire questionnaires to ensure their completeness and correctness. The questionnaires and interview were completed in approximately 20 minutes. During data collection, the researcher did not find the respondents feeling upset nor have any cancer symptoms. The researcher also used an empty room while interviewing the respondents in order to maintain their privacy. All the respondents who have been approached were willing to complete all of the questionnaires and cooperated well.

### **Ethical Consideration**

Concerning the rights of the human respondents in this study, the researcher asked for and received approval from the Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand, and permission to access the respondents was granted from the director of dr. Zainoel Abidin General Hospital and



the director of Ibu dan Anak Hospital in Banda Aceh, Indonesia. In this study, a verbal and written explanation about the purpose and benefits of the study, confidentiality and identity protection was given to every respondent. Privacy was maintained throughout the study because the researcher is well aware of the issue surrounding respondents' stigmatization. Regarding this issue, the respondents were approached without attracting attention from others and everything was adjusted to the patient's condition and situation at the time of data collection. In addition, the respondents were assured that they have the right to refuse or withdraw from the study at any time for any reasons without suffering negatives consequences. Codes and pseudonyms were used with no personal identification of the respondents through the process of data collection and data analysis.

### **Data Analysis**

All data were entered, cross-checked, and analyzed using computer software. Data were analyzed using descriptive statistic for answering the first research question as mentioned below.

1. Personal factors of the respondents were analyzed using frequencies, means, standard deviations, and percentages. Age and monthly income was summarized as mean (standard deviation, *SD*).

2. Sociocultural factors were analyzed using frequencies, means, standard deviations, and percentages. Cultural beliefs of breast cancer and the social support score were summarized as mean (standard deviation, *SD*), whereas breast

cancer awareness and alternative therapy used data was presented as a frequency (percentage).

3. Patient delay in consulting a medical doctor was not normally distributed. So, frequencies, percentages, median, and interquartile range (IQR) were used to describe this variable.

For testing the hypotheses, the following analytical procedures were employed:

4. The independent variables that were in categorical level including ethnicity, marital status, educational level, family history, clinical presentation, and alternative therapy use were dummy coded.

5. The economic status consists of three subsets: family income, health insurance, place of residence. Only family income was used in the regression analysis, and the clinical presentation which consisted of three subsets: first symptoms, stage of breast cancer, and tumour size. Only first symptom and stage of breast cancer were used in the regression analysis.

6. The variable “income” contained 15 missing values (9.4%) due to the reluctance of the respondents to provide this information. The pattern of these missing values were assessed by testing whether missing (0) or not missing (1) would have an influence on a dependent variable using the Mann-Whitney U test. The result revealed no significant difference, indicating the pattern of “Missing Completely at Random”. As the amount of missing values were less than 10%, no further imputation was needed. However, to get more power in this study, the decision was made to do imputation using the Expectation Maximization (EM) method (Schlomer, Bauman, & Card, 2010).

7. It was revealed that the dependent variable, patient delay was not normally distributed. The binary logistic regression was therefore considerably used based on a number of its principles. Firstly, the binary logistic regression does not need a linear relationship between the dependent and independent variables. Secondly, the independent variables do not need to be multivariate normal. Also the predictors do not have to be multivariate normally distributed. Thirdly, homoscedasticity is not needed. Binary logistic regression does not need variances to be heteroscedastic for each level of the independent variables. Lastly, the independent variables do not need to be interval or ratio level and the dependent variable could be in categorical level. From this, the researcher categorized the dependent variable into not delayed (0) representing with a delay time of less than 3 months and delayed (1) representing with a delay time of more than 3 months.

8. Hierarchical binary logistic regression was performed. The predictors were sequentially entered into the model by the researcher based on the theoretical considerations. The personal factors including age, marital status, education level, income, family history, first symptoms, and stage of breast cancer as unmodifiable factors were entered as the independent variables, followed by the sociocultural factors as modifiable factors including cultural beliefs about breast cancer, alternative therapy used, and social support. Ethnicity and breast cancer awareness included in the initial framework were excluded in this analysis due to none variability of the responses. Each independent variable's predictive ability was presented as an odds ratio (OR) with a 95% confidence interval (95% CI). A significant level of all analyses was set at .05.

In addition, the data analysis derived from an open-ended question was firstly planned to use simple qualitative data analysis of written text contents. The genuine answers from every respondent however were not come in rich written text. The researcher documented all the raw written text data that were linked to the research question and read through each response carefully to get a sense of the whole data. Then, the researcher developed categories for the main findings both similarities and differences and assigned at least one category to each response. The Excel program was used to arrange the responses in the adjacent column with the appropriate category. The next step was to see which of the categories had the most responses, therefore, representing the major themes. Finally, the researcher identified the patterns and trends in the data and the main issues rose from the respondents to reach certain conclusions.

## **CHAPTER 4**

### **RESULTS AND DISCUSSION**

#### **Results**

This chapter provides insights to explain the results of the four main issues of the study conducted among Acehnese women with breast cancer: (1) Respondents' characteristics including personal factors (age, ethnicity, marital status, educational level, economic status, family history, and clinical presentation); (2) Sociocultural factors including breast cancer awareness, cultural beliefs about breast cancer and its treatments, alternative therapy used, and social support; (3) Patient delay in consulting a medical doctor among Acehnese women with breast cancer; and (4) Personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehnese women with breast cancer.

#### **Respondents' Characteristics**

With regard to the characteristics and relevant clinical data of patient delay in consulting a medical doctor representing personal factors, the statistical analysis from 160 eligible respondents revealed that the average age of the respondents was 37 years with 31.9% under 30 years old and only three cases over 60 years. Most of the respondents were married (57.5%) with no family history of breast cancer (85.0%). The majority had attended senior high school or university (33.8%, 22.5%, respectively). As seen in Table 1, breast lump was used as general interpretation of the initial symptom (86.9%). The distribution of cancer stages was

mostly stage I (42.5%), followed by stage II (IIa and IIb) and stage III (28.8%, 25%, respectively).

Table 1

*Respondents' Characteristics (N = 160)*

Variable	<i>n</i>	%
Age (years)		
< 30	51	31.9
31- 40	35	21.9
41- 50	49	30.6
51- 60	22	13.7
> 60	3	1.9
<i>Mean (SD) = 37.42 (12.71)</i>		
Ethnicity		
Acehnese	160	100.0
Marital status		
Married	92	57.5
Single	50	31.3
Widowed	15	9.4
Divorced	3	1.9
Level of Education		
No schooling	10	6.3
Elementary school	30	18.8
Junior high school	30	18.8
Senior high school	54	33.8
University	36	22.5
Family history of breast cancer		
Yes	24	15.0
No	136	85.0
Monthly income (IDR)		
<i>Mean (SD) = 1,551,379.31* (877,376.63)</i>		
Insurance status		
Yes	159	99.4
No	1	.6
Place of residence		
Rural area	84	52.5
Urban area	76	47.5
First symptom		
Breast lump	139	86.9
Breast pain, nipple problem, and change of breast shape	21	13.1

*Note.* \* USD 1 ~ Indonesian Rupiah (Rp) 9,690

Table 1 (continued)

Variable	<i>n</i>	%
Stage of breast cancer		
I	68	42.5
IIa	24	15.0
IIb	22	13.8
III	40	25.0
IV	6	3.7

### Sociocultural Factors

Table 2 shows the sociocultural factors of the respondents including of breast cancer awareness indicated by warning signs of breast cancer, age pattern of breast cancer risk, early detection and frequency of standardized screening. This table also presents the respondents' use of alternative therapy, cultural beliefs regarding breast cancer, and social support.

With regard to breast cancer awareness, all of the respondents lacked awareness of every aspect of breast cancer with particular in mammography as such 100% of the respondents had rarely or never adhered to this screening procedure. Frequency of breast checking and breast self-examination was another concern as such 59.4% of the respondents rarely or never performed this simple test. Surprisingly, more than half of the respondents (52.5%) had visited a traditional healer as their first choice for healthcare. However, this decision was in conflict with the high positive scores of the respondents' regarding their cultural belief regarding breast cancer ( $mean = 110.44$ ;  $SD = 11.548$ ). The respondents' social support scores indicated most had good positive social support from their husband, mother, or son/daughter (Table 2).

Table 2

*The Sociocultural Factors of the Acehnese Women with Breast Cancer (N = 160)*

Variable		<i>n</i>	%
Breast cancer awareness			
Warning signs of breast cancer*	Do not know	72	45.0
	Only know 1-4 signs	74	46.3
	Know $\geq 5$ signs	14	8.7
Age-related risk			
	A 30 years old women	31	19.4
	A 50 years old women	36	22.5
	A 70 years old women	3	1.9
	A women of any age	90	56.2
Frequency of breast checking			
Breast self-examination	Rarely or never	95	59.4
	Every 6 months	21	13.1
	Monthly	18	11.2
	Weekly	26	16.2
Breast clinical examination	Rarely or never	140	87.5
	Every 6 months	14	8.8
	Monthly	6	3.7
Mammography	Rarely or never	160	100
Alternative therapy use	Use	84	52.5
	Not use	76	47.5
Cultural belief regarding breast cancer <sup>#</sup>			
	<i>Mean (SD) = 110.44 (11.548)</i>		
	Min = 78; Max = 142		
Social support			
	<i>Mean (SD) = 31.38 (3.45)</i>		
	Min = 22; Max = 40		

Note. \* Scattered list of 11 breast cancer symptoms provided (see Figure 4);

<sup>#</sup>Percentage of cultural beliefs provided (Table 3)



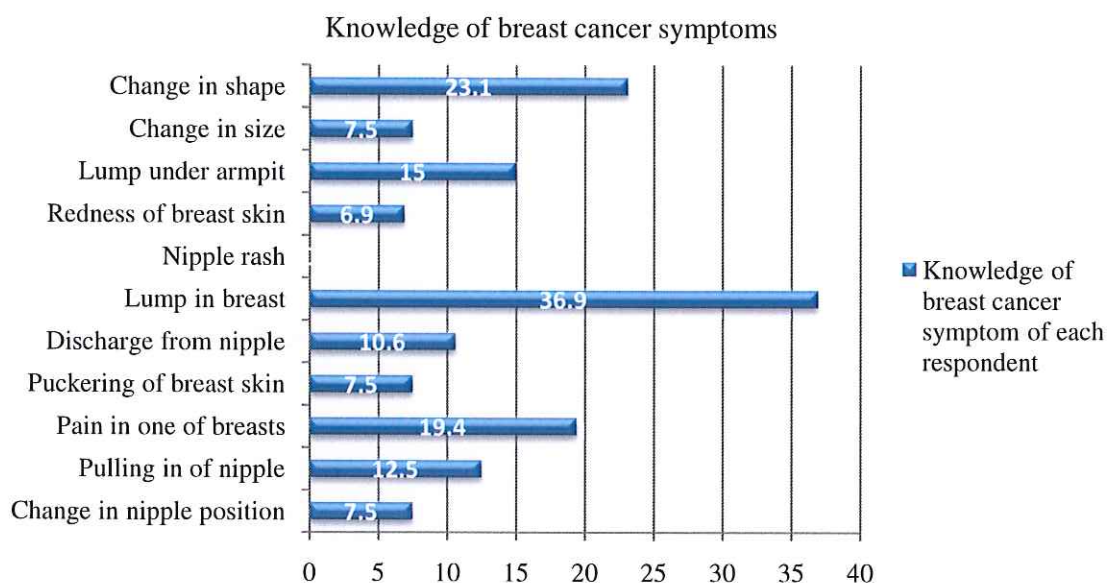


Figure 4. Proportion of respondents in identifying breast symptom from a set of 11 potential breast cancer symptoms (N = 160).

Table 3

*Frequencies and Percentages of Cultural Beliefs (N = 160)*

Item	Agree & strongly agree		Not sure		Disagree & strongly disagree	
	n	%	n	%	n	%
<b>Cultural belief of breast cancer</b>						
Breast cancer is fate and God's will, nothing can be done to stop getting cancer	97	60.6	8	5.0	55	34.4
Breast cancer always results in some kind of disfigurement and disability as a womanhood and motherhood	78	48.8	39	24.4	43	26.9
<b>Cultural belief of risks of developing breast cancer</b>						
Faith in God and destiny helps prevent breast cancer	90	56.3	16	10.0	54	33.8
Pressing of the breast will cause breast cancer	54	33.7	52	32.5	54	33.7
<b>Cultural belief of early detection and screening test of breast cancer</b>						
Being unable to pay for transportation and living allowance inhibit me to get medical services earlier	64	40.0	17	10.6	79	59.4
<b>Cultural belief of the treatments and outcomes of breast cancer</b>						
Treatments for breast cancer make the patient very painful	65	40.6	42	26.3	53	33.2

Simple qualitative data analysis based on data written from an open-ended question found that the dominant reasons underpinning the respondents' decision to consult a medical doctor were: a) to get a definite diagnosis and get well from illness; b) alternative therapies had not been successful; and c) when a breast lump became larger and was associated with pain.

### Patient Delay in Consulting a Medical Doctor

The median duration of patient delay (from first symptom to first consultation) was 90 days but with a high variation of delay time ( $IQR = 341$ ), ranging from 2 days to approximately 3 years. Above half of the respondents (51.2%) consulted a medical doctor within three months while 18.8% delayed consulting for 2 years (see Figure 2).

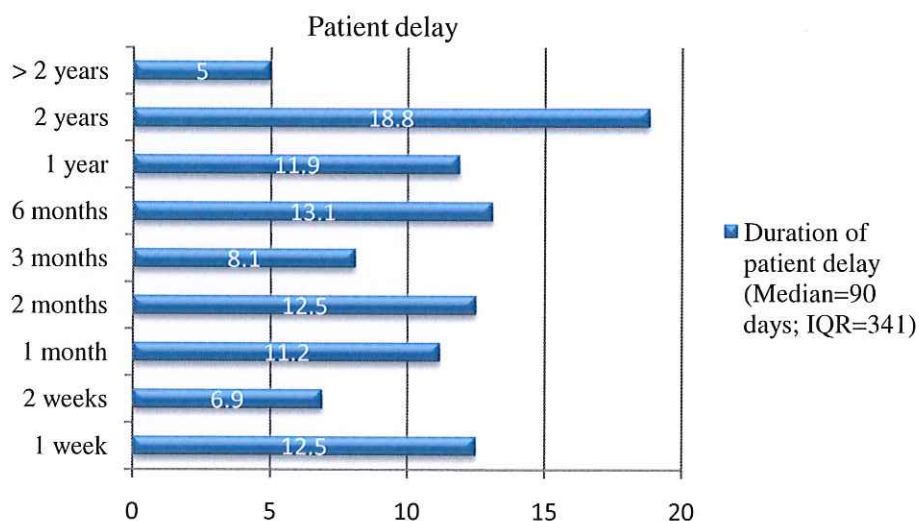


Figure 5. Duration of time from first symptom discovery to initial consulting a medical doctor (N = 160).

The independent variables that were in categorical level were dummy coded. As we can see in the Table 4 that the comparable number of subject in each

group either delay or not delay given almost the same sample size that can provide more accurate classification and hypothesis testing.

Table 4

*Dummy Coded Variables (N = 160)*

Variable	<i>n</i>	%
Marital status		
Married (0)	92	57.5
Single/ divorced/ widowed (1)	68	42.5
Family history of breast cancer		
Yes (0)	24	15.0
No (1)	136	85.0
Clinical presentation of breast lump		
Yes (1)	139	86.9
No (0)	21	13.1
Alternative therapy use		
Yes (1)	84	52.5
No (0)	76	47.5
Patient delay		
Delay (1)	78	51.2
Not delay (0)	82	48.8

### **Personal and Socio-cultural Determinants of Patient Delay in Consulting a Medical Doctor**

A two-step hierarchical binary logistic multiple regression analysis, with a set of personal factors, followed by a set of socio-cultural factors entered sequentially, was performed. The variable “ethnicity” and “breast cancer awareness” were not included in the regression model due to no variability of its response. The model goodness of fit, tested with the Hosmer and Lemeshow test, was satisfactory as indicated by a non-significant Chi-square (Chi-square = 2.938,  $df = 8$ ,  $p = .938$ ).

The findings showed that only two predictors significantly contributed to patient delay: stage of cancer ( $b = 1.14$ ,  $p = .000$ , Odds Ratio = 3.13) and alternative medicine use ( $b = 1.62$ ,  $p = .001$ , Odds Ratio = 5.07). In other words, the

respondents who had more advanced stage and had used alternative medicine were approximately 3 and 5 times, respectively, more likely to delay consulting a medical doctor. Younger age, married, low education, no family history of breast cancer, clinical presentation with non-breast lump symptoms, and low social support might have contributed to patient delay, but not in a significant way statistically. Altogether, the model explained approximately 58% of the variation in patient delay (Table 5).

Using the information of the regression analysis findings, the predicted equation was constructed as follows:

$$\text{Odds Ratio of patient delay} = -1.531 + 1.139 (\text{Stage of cancer}) + 1.624 (\text{Alternative medicine use})$$

Table 5

*Logistic Regression Predicting Patient Delay in Consulting a Medical Doctor among Acehese Women with Breast Cancer from Personal Factors and Sociocultural Factors (N=160)*

Predictor	B	SE	Wald $X^2$	<i>p</i>	OR	95% CI
Personal factors						
Age	-0.01	0.03	0.20	.653	0.99	0.93-1.05
Marital status <sup>a</sup> : Single	-1.23	0.85	2.09	.148	0.29	0.06-1.55
: Divorced	-1.41	1.09	1.66	.198	0.24	0.03-2.08
Education	0.11	0.25	0.21	.651	1.12	0.69-1.82
Income	0.00	0.00	0.65	.420	1.00	1.00-1.00
Family history of breast cancer <sup>a</sup>	0.42	0.64	0.43	.512	1.52	0.43-5.33
Clinical presentation of breast lump <sup>a</sup>	-0.12	0.74	0.02	.876	0.89	0.21-3.80
Stage of cancer	1.14	0.28	16.46	.000	3.13	1.80-5.42
Socio-cultural factors						
Cultural beliefs	0.01	0.02	0.05	.829	1.01	0.96- 1.05
Alternative medicine use <sup>a</sup>	1.62	0.50	10.39	.001	5.07	1.89-13.63
Social support	-0.03	0.08	0.18	.675	0.97	0.83- 1.13

Constant = -1.531; Chi-square = 83.45, *df* = 11, *p* = .000; Nagelkerke  $R^2$  = .583.

*Note.* OR = Odds Ratio; CI = Confidence Interval.

<sup>a</sup> = Dummy coded predictors: Marital status (married = 0, single or divorced/widowed = 1); Family history of breast cancer (yes = 0, no = 1); Clinical presentation of breast lump (no = 0, yes = 1); Alternative medicine use (yes = 1, no = 0).

Dummy coded dependent variable: Patient delay (not delay = 0; delay = 1).

## **Discussion**

This section explains the main findings of this study, which were the respondents' characteristics and sociocultural factors of patient delay in consulting a medical doctor among Acehese women with breast cancer. Also, this part explains the predictive power of personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer and the way these two factors influenced patient delays.

### **Respondents' Characteristics**

The average age of the respondents in this study was 37 years, which is higher than in years past, and reflects a trend in other Asian countries as well, as breast cancer rates have been rising and affecting younger women between 30 and 40 years of age (Agarwal et al., 2007). These rising rates have been connected to changing trends in diet and lifestyles of young Asian women adopted from western lifestyles as a result of the rapid growth of information technology and the internet bringing about new cultural paradigms and perspectives. Consequently, the number of modifiable cancer risk factors has been increasing, as well as the potential risk to exposure to cancer-linked substances from the environment (Bhikoo et al., 2011). Various studies from Western countries have shown a relationship between breast cancer and obesity, less physical activity than in past years, smoking, alcohol consumption, a diet higher in saturated fat than in earlier times, and the use of exogenous hormones (American Cancer Society [ACS], 2011). Reflecting these worldwide trends, the lifestyles of young Acehese women today has a diet rich in

animal fats and higher exogenous hormone exposures, as our society progresses towards a more developed country lifestyle. The findings of higher rates of new breast cancer cases in younger women in Aceh might therefore be best explained from considering the modern lifestyles of young Acehnese women today.

The finding of having only three elderly breast cancer cases (> 60 years old) in this study may be related to the traditional lifestyle of Acehnese elderly, and the cultural ways of life they used to interpret symptoms and responded to cancer as well as other health problems. Many older Acehnese women, as well as middle-aged post-menopausal women, generally perceive themselves to be at a lower risk of developing breast cancer compared to younger women. In accordance with Bish et al. (2005), many older women have less knowledge of breast cancer symptoms and believe that after menopause breast cancer is no longer a health concern for them. Although they found breast cancer symptoms, they were more likely to appraise that it was not a serious problem. Moreover, they also believe that cancer and its treatment may eventually cause disability, disfigurement, loss of income, and cost a lot of money. Such embedded beliefs may cause older Acehnese women to be disinclined to consult a medical doctor or seek help for breast symptoms in a timely fashion (Bish et al., 2005; Grunfeld et al., 2002). Consequently, the prevalence of new breast cancer cases among older Acehnese women in this study might not represent the actual numbers of new breast cancer cases who were absent from the breast cancer care in hospital. This issue poses to certain question about a culturally health care service to increase Acehnese elderly with breast cancer to harmoniously access to breast cancer screening and treatments in hospital.

The results regarding Acehnese women's age and the incidence of new breast cancer cases also support the influence of ethnicity on breast cancer. Ethnicity involves one's sense of identity as a member of a cultural group including sense of self and the lifestyle one chooses, which may have an impact on the risk of breast cancer and the way an individual responds to health concerns and healthcare professionals (Kagawa-Singer et al., 2010). With regard to Indonesian health beliefs and practices, there are a variety of alternative and traditional healers in Indonesia, many related to particular ethnic groups. Adherence to a particular cultural way of healing such as relying on a *Dukun* (Indonesian traditional healer) becomes the first option of an Acehnese's health seeking behavior. From this practice, they first select a traditional healer and trust the healer to diagnose and cure all illnesses, including breast symptoms. Beyond using traditional folk medicines and healing methods, taking care of sickness in the Indonesian elderly is usually the responsibility family members or other relatives, and it is also custom to keep illnesses, with particularly cancer, private or confidential.

Other than life styles and health beliefs as described above, the evidence for genetic predisposition to breast cancer risk is known to be higher in individuals with certain genetically determined syndromes, which must also be considered in any study of cancer in a particular ethnic group such as Acehnese women. Inherited mutations (alterations) in breast cancer susceptibility genes account for approximately 5%-10% of all female and male breast cancer cases (American Cancer Society [ACS], 2012). Two common mutations in breast cancer genes, BRCA1 and BRCA2, which are located on chromosomes 17 and 13 respectively, have been identified and account for a substantial proportion of very high risk

families (Washbrook, 2006). Therefore, individuals with a strong family history of breast cancer, or cancer at other sites, such as ovarian and colon cancer, should consider counseling to determine if genetic testing is appropriate. Then, prevention measures may be possible for individuals with breast cancer susceptibility mutations (ACS, 2012).

Although a family history of breast cancer places a woman in at higher risk than those without it (ACS, 2011), almost all respondents in the current study (85%) reported no family history of breast cancer. The first possible argument made to this finding is the Acehnese way of life. The people in Asian countries traditionally regard a diagnosis of cancer as a stigma which can bring shame to the entire family (Azaiza & Cohen, 2008; Karbani et al., 2011; Taha et al., 2012; Tsai et al., 2011), and thus some respondents in the current study may have regarded a history of cancer as private family affair.

Despite high rates of breast cancer in Indonesia and Aceh, breast cancer screenings and diagnosis had been slow to catch on as such evidence from the statistical analysis. Again, the social stigma attached to cancer might help best explain the reluctance to disclose their family history of breast cancer. In the study by Karbani et al. (2011) among South Asian breast cancer patients, they found that even saying the word “cancer” is believed to precipitate ‘bad luck’ or even bring cancer to speaker or their families. From this study, we may hypothesize that the majority of the respondents choose not to report their family history of breast cancer to others in order to avoid making stigma and bring bad luck to their families. A further worrisome derived from a perception of no family history of breast cancer is lack of awareness of having double risk in developing breast cancer when compared to



women with no family history. This unclear issue poses to the suggestion to further explore the issue of a family history of breast cancer among Acehnese women with breast cancer.

Another factor to be considered is that under Indonesian and Islamic culture, marital status and traditional gender roles have been found to be important factors associated with patient delay, which also further supported from the findings of this study (Harirchi et al., 2005; Ramennick, 2006). It has been argued that patient delay resulted from the central role as wife and mother of married women. The primary responsibility of Islamic women is fulfilling the role of wife and mother. Giving first priority and taking the whole responsibilities for their family members is therefore perceived as more important than being concerned about their personal health and well-being. They viewed the processes of cancer diagnosis and treatments as barriers which would disrupt their roles as wives and mothers, which would have a negative impact on the happiness and harmony of their family (Im et al., 2004; Taha et al., 2012).

In Islamic as well as Acehnese culture, even though being a wife and mother are considered the greatest achievement of a woman, and of great importance to her family, the woman is not the leader of the household. In Islam, the husband is the leader of the family, and the wife act as his supporter and consultant. With further regard to the role of the Muslim wife in marriage, considerable importance is given to good appearance, which includes smelling good and being physically beautiful and being compliant to the husband in all commands, and such imperatives make decision to visit a medical doctor or undergo a mastectomy. From this, breast cancer screening and treatments would be done under the permission of their husbands.

Even though gender roles play an important role on Acehnese women in making the decision to attend breast cancer screening, the majority of the respondents (71.3%) in this study presented with an early stage of breast cancer (stage I and stage II). In contrast to other studies within Islamic countries and other developing countries, the majority of women with breast cancer tend to present with an advanced stage of cancer (stage III and stage IV) (Alhurishi et al., 2011; Talpur et al., 2011; Yip et al., 2006). The characteristic of breast cancer was intrinsically less aggressive and low proliferation rate which might support this finding. As each breast cancer is unique, having its own characteristics and qualities, taking on so many configurations that no two breast cancers are ever exactly alike. Some grow faster and others slower. Some inhabit milk ducts and others the lymph nodes. Some are spurred to grow with exposure to estrogen, others through overabundance of a tumor-driving protein called Her2/neu (Healthsearches.org, 2006). However, as cancer spreads with the passage of time, and the prognosis worsens as the stage advances, it follows that delay must affect the outcome of the disease.

Beyond the cultural and religious factors, low economic status (mean monthly income was Rp.1, 577, 631.6 = USD 162.81) might act as another barrier for the respondents to access or adhere to breast cancer screening and treatments in a city hospital. Even though health insurance covers for all medical expenses at government hospitals for Acehnese people (99.4%), more than half of them live in a rural area (52.5%), as much as 120 miles away from the hospital. And also, if they do go to the hospital they have to pay their own expenses, such as travelling fees or gas and food and accommodation while away from home. This low income is thus another reason that women who have a symptom of possible breast cancer were more likely to wait

longer before seeking medical treatment and commonly present with an advanced stage (Ali et al., 2008; Talpur et al., 2011).

Similar to several previous studies, breast lump was the first noticeable sign and dominant symptom of breast cancer recognized by almost all the respondents (86.9%) (Kumari & Goonewardena, 2011; Meechan et al., 2003). Generally, a breast lump is recognized as a significant sign of abnormality and possible cancer and leads the affected woman to go for an early consultation (Kumari & Goonewardena, 2011). However, in this study even breast lump was still used as the first recognition of breast cancer but this did not accompany with early consultation. As discussed previously, the time of initial medical consultation among most of the respondents in this study (80.6%) was over one month and up to more than 2 years. This finding is considerably quite long delay when compared with other studies conducted in Asian developing countries which revealed the duration of delayed presentation ranged from 3 to 18 months (Lodhi et al., 2010). Here again, this might be another space to accept the strong influence of sociocultural factors.

Along with this finding, as discussed earlier the study results revealed that patient delay in consulting a medical doctor can result from many factors and have many aspects related to personal and sociocultural factors embedded in the Acehnese culture. A deeper examination sociocultural factors that might be associated with delays in seeking medical help is therefore addressed in the following section, to see if there is room for improvement in the area of delays in seeking appropriate medical advice.

## **Sociocultural Factors**

This study evaluated the practical importance of sociocultural factors in of Acehnese women with breast cancer on patient delay in terms of breast cancer awareness, alternative therapies used, cultural beliefs about breast cancer, and social support. Also, the discussion of the hypothesis testing is addressed at the end of this chapter.

**Breast cancer awareness.** As mentioned previously, the overall Acehnese respondents' awareness of breast cancer was relatively low. For instance, none of the respondents could identify five or more non-lump symptoms from the provided lists. Generally, better knowledge of the signs and symptoms of cancer would help people recognize possible cancer symptoms and therefore reduce delay time to seeking medical help (Simon et al., 2010). Accordingly, lack of individual interpretation and perception of breast cancer symptoms of the respondents in this study was accompanied with 1 week and extended to more than 2 year delay in consulting a medical doctor. A study conducted by Simon et al. (2010) also noted that in which they found that lack of breast cancer awareness or knowledge of breast cancer symptoms and attitudes towards help-seeking together increased the delay time in consulting a medical doctor.

In accordance with a large national survey conducted by Moser, Patnick, and Beral (2007) in United Kingdom, most of the respondents in this study reported a lack of awareness regarding the age-related risk of breast cancer. The results of this present study showed that over half of the respondents wrongly believed that cancer risk does not vary with age. Only 1.9% was correctly informed, understanding that the oldest group of women is at the greatest risk of breast cancer.

Misconception about this fact among the respondents might have been related to delays in the middle-age and elderly groups in consulting a medical doctor or seeking medical help such as breast cancer screening in a timely way. Inadequate knowledge of the age pattern of breast cancer risk and recommended frequency of standardized screening for early detection in different age groups therefore could be diagnosed here.

However differentiation age pattern of breast cancer risk between American and Asian countries might also have influenced this negative result. According to Siegel, Ward, Brawley, and Jemal (2011), in the USA, the estimated risk of breast cancer is higher for women aged 70 and older, while in women aged 39 and younger the probability of developing breast cancer is low. This fact is contrary to current studies concerning Asian countries, which have found that breast cancer occurs at a relatively young age with aggressive biological characteristics. The proportions of young age (< 35 years) were up to 25% in developing Asian countries (Agarwal et al., 2007). A high incidence among younger group of women could be the reason why the majority of respondents were not aware of and did not choose the age above 70 years to be most likely to get breast cancer.

The results of the study also highlighted inadequate knowledge of early detection and frequency of standardized screening, as evidenced from the percentage of the respondents who had never performed BSE (72.5%) or had a mammogram (0%). The phenomenon of low breast cancer awareness among Acehnese respondents is also supported by evidences from a previous study by Im et al. (2004), with regard to a screening program, some breast cancer women were not familiar with cancer screening as a preventive measure and they believed that a lower risk of developing

cancer was indicated from the absence of signs and symptoms, no family history of breast cancer, and had a healthy lifestyle. They tended to make the decision to delay seeking a medical diagnosis and treatment based on these factors.

The powers of personal and sociocultural factors of Acehnese women with breast cancer on the beliefs they hold about breast lumps, breast cancer screening and even expectations about what will happen to them and what a medical doctor and health care providers will do might take the whole responsibility for patient delay in this study. This finding supports the summary from a mini literature review made by Parsa and colleagues (2006) regarding the influence of personal and sociocultural factors on final decision-making of cancer patients to engage or not engage in cancer screening and to seek or to not seek medical attention.

**Alternative therapies use.** Initially seeking an alternative therapy has been found as one of the determinant factors of patient delay in making the decision to receive modern therapy among breast cancer women in Asian countries (Hisham & Yip, 2004; Malik & Gopalan, 2003). Similarly, more than half of respondents in this study (52.5%) relied on alternative therapy to deal with breast cancer prior to seeking modern medical care. Generally with other Acehnese people, when a breast lump or other possible cancer signs appear, the respondents in this study used a variety of traditional alternative treatments. They gave detailed information in using “benalu kopi”, soursop leaves, mangosteen rind, and other traditional ingredients, dukun (traditional healer), massage, and prayer. “benalu kopi” is a parasite plant that grows on and takes food from coffee bush, leading to the death of the plant if not removed. They have traditionally used this plant as a medicine because they believed that cancer was a kind of ‘parasitic’ disease the same as the plant parasite. Also, the

Acehnese respondents did not use only one type of alternative therapy but also used in combination as such visiting the “dukun” (14.4%) and prayer (31.3%).

Various reasons have been given by women when questioned about their use of traditional remedies for cancerous signs rather than seeking modern health care, many of which are rooted in the expectations about woman in traditional Aceh society. Previous studies have found that recommendations and general agreements about what should be done by family and friends, faith and trust in alternative therapies, previous bad experiences with hospital service, fear of loss competence after mastectomy, fear of embarrassment, and priority given to their work as wife and mother were among the main reasons many women preferred using traditional healers (Muhammad et al., 2011; Taib et al., 2007).

**Cultural beliefs about breast cancer.** Cultural and religious beliefs play a vital role in term of patient delay in consulting a medical doctor. Under the basic hierarchical structure of the Acehnese and others Asian countries, women traditionally have occupied a lower position which subordinated their own needs, including to health care needs to the needs of other family members (Cunningham, 2012; Taha et al., 2012). Aceh culture has emphasized the importance of family as central unit to be considered when women consider the decision to choose therapy options and consult a medical doctor (Appendix G). In order to not burden their family, most of the women did not give their attention to the symptoms they were experiencing and presented themselves as not sick, in general. Until today, the majority of Acehnese woman give first priority to roles of wife and mother. For instance, they take all the responsibility for all housework and taking care of the children, including supporting their husband’s work and religious activities.

Like other Asian women, fear of embarrassment is another enormous barrier for Acehese women making them reluctant to seek breast cancer screening. Accompanied by the fundamental Islamic belief that God decreed, Acehese Muslim women strictly cover their heads and bodies from the attention of men, and conservative and traditional attitudes towards body and bodily functions together make them unwilling to show their breasts to others, including to health care providers. An earlier study found that through the processes of CBE, women needed to expose their breasts to either male or female physicians, and as a result of the feelings shame and humiliation this causes them to feel, they refrain from further breast exams (Parsa et al., 2006). Since every oncologist in Aceh is male, facing with struggle was then happened with the Acehese respondents in this study. They need to reconcile their fear of death with their fear of embarrassment, and often the fear of embarrassment is stronger. Getting breast cancer screening and treatments from female medical doctor to fulfill their cultural needs was therefore impossible. Under the limitation of female oncologist as well as the strong beliefs regarding body, spiritual distress might be another big worrisome among Acehese women with breast cancer here.

In this study, the majority of the respondents (60.6%) believed that contracting breast cancer in the first place, and then the outcome of cancer treatment and care, is all God's will, and result from an unchangeable fate which cannot be prevented or cured, a belief which has been found in earlier studies conducted with Asian American, Israeli Arab, and Jordanian breast cancer survivors (Ashing et al., 2003; Azaiza & Cohen, 2008; Taha et al., 2012). Consequently, they may view or interpret cancer screening and treatment in hospital as not necessary and of little



benefit, and decide to not participate in initial screening, or later to not follow the recommended treatment (Ashing et al., 2003).

Azaiza and Cohen (2008) found that Asian women had different perception of the risk factors of breast cancer, depending on whether they followed traditional ideas, or if they had been exposed to biomedical views of the disease. In this study, culture also had an influence on the beliefs of the Acehnese women about risk factors for developing breast cancer. For instance, most of the respondents strongly agreed with the suggestion that chemicals in food can cause breast cancer, and that breast feeding can reduce the chance of breast cancer (83.8% and 51.9%, respectively), and 56.3% believed that the faith in God and destiny helped prevent breast cancer. Many of them had a strong belief in the power of prayer, and placed more importance on spirituality and prayer than on modern healthcare providers.

The majority of the respondents (48.8%) indicated a high level of agreement with the belief that breast cancer always results in some kind of disfigurement and disability, with negative impact on both womanhood and motherhood. According to a previous study, fear of disability or loss of the symbolic role of womanhood and motherhood were found as one of the barriers in seeking breast cancer treatment, in particular the fear of mastectomy (Im et al., 2004; Taha et al., 2012). The possibility of needing a mastectomy made women fear being unable to breastfeed their babies and being unattractive or unable to satisfy their husbands (Im et al., 2004). Seeking alternative treatments rather than consulting a medical doctor and receive modern cancer care in a hospital is therefore expected by the majority of breast cancer women in this study. The current study also found that their limited awareness of modern advances in breast cancer treatments was not strong enough to

overcome the women's strong cultural beliefs regarding breast health, breast cancer, management and outcomes modern cancer care.

The study found a considerable contrast between the respondents' awareness of BSE (57.5%) and rate of actual of the BSE performances (27.4%), which may raise some questions concerning the validity of the KAP (knowledge, attitude, practice) model, which suggest that changing behavior is an end product of having knowledge and the desired attitude. Our finding was similar to the study of Wong-Kim and Wang (2006), which also found that even though BSE awareness was high, BSE performances in their study group was much lower. The finding in the current study that more than half of the respondents had knowledge of BSE while hardly a fourth of them actually performed BSE might be another argument for the strong influence of sociocultural factors over knowledge and awareness.

Regardless of the cultural beliefs, the poor scores of the items "breast cancer is an incurable disease", "pressing of the breast can cause cancer", and "detecting a small lump in breast is not serious and you do not need to hurry to seek care and treatment" (Appendix G) might reflect to inadequate knowledge among the Acehnese respondents regarding the benefits of breast cancer screening or instruction in how to perform a BSE. This finding might lead to a serious concern in term of breast cancer screening as well as early breast cancer detection since BSE is a simple and effective method for early detection of breast cancer.

The study conducted by Juanita et al. (2012) with 76 nursing students from the Public Nursing College in Aceh supported the current concern of this study. According to Juanita et al. (2012) even though breast cancer campaign has been implemented in most of Aceh provinces, the prevalence and mortality rates of breast

cancer among Acehnese women remain the same. The wrong perceptions and misconceptions about breast cancer and early detection of breast symptoms among Acehnese communities might best take responsibility for this situation (Juanita et al., 2012). Accordingly, the study results from this study also evidently supported the important role and influence of local Aceh culture on health behaviors and breast self-examination practices. In order to succeed increase the number of Acehnese women to engage or access and adherence to nation breast cancer screening and treatment program, a culturally sensitive breast cancer screening program is needed to be developed based on both Islamic culture and traditional culture of Aceh (Juanita, Jittanoon, & Boonyasopun, 2012).

In this present study, the dominant reasons underpinning the Acehnese respondents' decision-making to visit a medical doctor were to get a definite diagnosis and get well from their illness as well as when alternative therapies were not successful. Increased size of breast lump accompanied with pain together enhanced the Acehnese respondents initial engaged in cancer treatments from hospitals. This finding was consistent with others studies, which found that the first symptoms of breast cancer are usually ignored by breast cancer patients and kept waiting until new symptoms appear, or the initial symptoms worsens. In addition, conventional medical therapy was initiated traditional treatments failed. Most breast cancer patients eventually presented at a more advanced stage of cancer (Farooqui et al., 2011; Norsa'adah et al., 2011).

**Social support.** In this study almost all of the respondents received the positive support from their families, primarily spouses, mothers, siblings, and children. Many respondents reported that a family member, usually a spouse, mother,

sibling, or child, accompanied them to most of their medical care visits for their breast cancer. They would not choose treatments from medical doctor, if their significant others in their family did not bless. This is somewhat in contrast with previous study in Pakistani Muslim women found that breast cancer is often viewed as a socially unacceptable disease that may result in a negative response from family members, discouraging many women from seeking active medical treatment for the disease, or attempting to hide the diagnosis as the disease will affect the whole family and may cause unnecessary financial problems (Banning & Hafeez, 2009).

In the Indonesia context, the family is very important. The family plays an important role when one of its members becomes sick, in providing the physical, physiological, and emotional support. The family endeavors to find information on where to seek treatment for the ill family member, either traditional or modern treatment. Some members of the family also accompany the patient during treatment and stayed with her if patient was hospitalized. So from this, we see that even if there is some reluctance to acknowledge the disease or seek diagnosis or treatment at first, once the disease is recognized and accepted, social support from family members becomes one of the facilitating personal factors enhancing Acehnese respondents to access and adhere to breast cancer screening and treatments from hospitals.

### **Personal and Sociocultural Determinants of Patient Delay**

In this study, Hypothesis 1 stated that personal factors (age, ethnicity, marital status, educational level, economic status, family history, clinical presentation) have direct effect on patient delay in consulting a medical doctor. The statistical analysis revealed significant associations between delayed presentation and

late stage disease ( $p = .000$ ). The respondents with higher stage of breast cancer were three times more likely to have delayed consulting a medical doctor than those with a lower stage. These results were congruent with a previous study (Montazeri et al., 2003) which found that women who presented late had a significantly bigger tumor size and an advanced stage of disease.

The other personal factors (age, marital status, education, monthly income, family history, and initial symptoms) examined were not significantly associated with patient delay time, which is somewhat in contrast with previous systematic reviews which found that older age, lower educational level, and low income status were found to have a strong correlation with late presentation (Alhurishi et al., 2011; Sharma et al., 2012). However, even though they were not statistically significant associations, this study found a higher percentage of patient delay in the late adult group (41-50 years old), married women, monthly income lower than Rp. 1,000,000 (USD 102.73), and no family history of breast cancer, findings which have also been noted in various earlier studies from developing Asian countries, i.e. Thailand (Bhosai, Sinhusake, Miwa, & Bradley, 2011); Pakistan (Lodhi et al., 2011; Talpur et al., 2011), Malaysia (Norsa'adah et al., 2011); India (Ali et al., 2008), and Iran (Harirchi et al., 2005; Montazeri et al., 2003).

The second hypothesis stated that sociocultural factors (breast cancer awareness, cultural beliefs about breast cancer and its treatments, alternative treatment use, social support) have direct effect on patient delay in consulting a medical doctor. The hierarchical binary logistic multiple regression analysis revealed significant associations between alternative therapy use and patient delay ( $p = .002$ ), as the respondents who first tried traditional therapy were at five times greater risk of delay

in consulting a medical doctor than those who had not tried traditional therapy. Previous studies have found the same thing that the alternative therapy was a significant reason for many patients and their delayed diagnosis of breast cancer (Malik & Gopalan, 2003; Norsa'adah et al., 2011).

As discussed earlier, traditional healers have been embedded and prioritized first in Aceh culture for illness with no exception for breast cancer. Generally, traditional healers provide hope and faith for Acehnese people, and in regard to breast cancer, traditional healers treat these patients as ones who can be cured without undergoing surgery. Further, traditional healers use personal and intimate relationships to treat and communicate with patients and their families (Farooqui et al, 2011). Therefore, traditional healers become an everlasting therapy for Aceh people as well as Acehnese women with breast cancer. As the 'golden period' for dealing successfully with cancer is dependent on detection and treatment in early stage of cancer, delay caused by seeking unsuccessful traditional treatment before seeing a medical doctor are undoubtedly linked to detection in later stages and poorer outcome (Parsa et al., 2006).

Incongruence with many previous qualitative studies that have explored the contributions of cultural beliefs and social support in patient delays in seeking medical advice, in this study, the statistical analysis revealed no significant associations between cultural belief and social support with patient delay time (Azaiza & Cohen, 2008; Farooqui et al., 2011; Im et al., 2004; Karbani et al., 2011; Kwok & White, 2011; Potrata, 2011).

In conclusion, this study found that stage of breast cancer and alternative therapy use was significantly associated with duration of patient delay. The

respondents with a more advanced stage of breast cancer and traditional therapy use were three and five times more likely, respectively, to have delayed in consulting a medical doctor than those who presented with a lower stage of cancer or who had not tried traditional therapy first. The other personal and sociocultural variables (age, marital status, educational level, economic status, family history, initial symptom, cultural belief of breast cancer, and social support) examined were not significantly associated with the duration of patient delay.

## **CHAPTER 5**

### **CONCLUSION AND RECOMMENDATIONS**

This chapter presents the conclusions and recommendations which are inextricably linked to all previous chapters. The recommendations derived from the firsthand experiences in conducting this study and the study results, including the possibility of implications to nursing practice and education with a particular focus on the associations of personal and sociocultural factors on breast cancer screening and treatments. The strengths and limitations are also addressed at the end of this chapter.

#### **Conclusion**

This descriptive cross-sectional study was designed to examine the personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehese women with breast cancer. The study was undertaken based on one of the three vital concepts of patterns or types of delay in breast cancer treatments proposed by Hansen (2008), personal and sociocultural factors associated with delays in breast cancer treatment proposed by Sharma et al. (2012), and Acehese women's traditional culture, cultural attitudes and beliefs toward health and cancer.

Data collection was conducted at the surgical and chemotherapy units of dr. Zainoel Abidin General Hospital and Ibu dan Anak Hospital, Aceh, Indonesia, from November 2012 to February 2013. One hundred and sixty respondents with breast cancer who met the inclusion criteria were recruited. As detailed in Chapter 3, a



structured questionnaire consisting of two parts was employed to collect the data used in this study. The validity was approved by the 3 experts, the reliability of the Cultural Belief regarding Breast Cancer and Cancer Care Questionnaire and the Social Support Questionnaire was .74 and .84 respectively. The open-ended question was also employed to further examine the reason/s to initial consult a medical doctor. For testing the hypotheses, hierarchical binary logistic regression was performed. The data derived from an open-ended question was analyzed using simple qualitative data analysis of written text contents.

The study findings were the mean age of new cases was lower than 40 years, most had a low economic status, and more than half were married. In this study, the majority of the respondents had no family history of breast cancer, and almost half (42.5%) presented at stage I. The duration of patient delay ranged from a week to more than two years. A breast lump was the most commonly recognized first of possible breast cancer. The statistical analysis found low level of breast cancer awareness and the number of women who were familiar with breasts self or clinical examination, and none had ever had a mammogram. Essentially, embarrassment accompanied with absence of female oncologist was reported as an enormous barrier for Acehnese women to access to breast cancer screening.

The majority of the respondents had a high positive score regarding cultural belief regarding breast cancer and social support. However, almost all the respondents had tried traditional therapy prior to seeking medical care. The statistical analysis revealed five times greater risk for delay of the Acehnese respondents who used traditional therapy than those without using traditional therapy. Under Indonesian and Islamic culture, breast cancer and the outcome of cancer treatment and

care were viewed by the Acehnese respondents as God's will. Consequently, the power of religious prayer was believed to be more important than hospital services and health care providers. The perception that breast cancer treatment might involve some kind of disfigurement also made many respondents disinclined to seek modern medical treatment. There were no significant associations between social support and patient delay time. Consulting a medical doctor was done once they experienced and increased in size of a breast lump accompanied with viewing their alternative therapies as having failed. The major goal of consulting a medical doctor was to get a definite diagnosis and get well from their illness.

The powers of personal and socio-cultural factors of Acehnese women with breast cancer on the beliefs they hold about breast lumps, breast cancer screening and expectations about what might happen to them and what a medical doctor and health care providers would do, could together explain almost all of the patient delay in consulting a medical doctor in this study. The statistical analysis also revealed significant association between stages of breast cancer and alternative therapy use with patient delay. Even though the other sociocultural factors did not reveal significant associations with patient delay time, the data showed some congruence between the respondents who were older, married, had a low income, and no family history of breast cancer.

### **Strengths and Limitations**

This study concerning personal and sociocultural determinants of patient delay in consulting a medical doctor among Acehnese women with breast

cancer had certain strengths and limitations. In terms of the generalizability of the findings, this study was conducted at the biggest government hospitals which serve as the top referral centers for Aceh province, and therefore represent the entire province. The generalization must be limited to women of Aceh ethnicity, however, since only Aceh ethnic women participated in this study, with an unexpected absence of Gayo, Alas, Singkil, Tamiang, and Simeulu ethnic respondents.

The second major strength of the study lies in the method of data collection, which involved not only self-reported questionnaire, and perusal of medical record, but also face-to-face interview to ensure rigorous study results. Also, the better results from this study may be claimed according to the appropriateness of three concepts as conceptual framework to develop the research questionnaire can represent the whole picture of sociocultural factors.

In spite of these strengths, some limitations were noted. With regard to the actual duration of patient delay, since the respondents were interviewed after being diagnosed at a hospital rather than at the time of initial recognition of symptoms, the error of reported duration of patient delay might take into consideration. The validity of the findings of duration of patient delay might rely on the effectiveness of patients' recall of the dates and times from the first symptom experienced and first medical consultation. Method used to collect duration of delay therefore might have information biased, with a particular for some respondents with a longer delay. Another potential weakness in the data might involve the findings of positive attitudes towards conventional therapies. Since the interviews were conducted following the decision to receive cancer treatments at a modern hospital, the positive feelings concerning the benefits of cancer treatment could be related to

feelings of helplessness, plus negative feelings towards traditional treatments which had not been successful, or experiencing non-relievable pain.

A final point that should be noted concerning the findings is that cultural views of cancer in families regarding the perceived stigma of the disease, as well as belief-based reluctance to use the term 'cancer', might have resulting in lower reporting of a family history of breast cancer than was the actual case. Here, another limitation regarding cultural sensitivity in using sensitive terms of 'cancer' in questionnaire might responsibility for this finding.

### **Implications and Recommendations**

The highest goal in conducting this study was to infer and imply the study results to develop culturally sensitive strategies to shorten the duration of patients' delay in consulting a medical doctor with particular focus in the Acehese context. In providing appropriate cultural care, health care provider should attempt to harmoniously integrate the patients' specific cultural needs such as different cultural and religious practices, health practices, and daily living practices into nursing care. Health care provider should show sensitivity and respect to all aspects of patients' needs, as well as during the communication process to provide a sense of trust and respect which further improve good relationships between two parties and the positive perception regarding breast cancer service in hospital

The evidence generated from this study on the associations and influences of sociocultural factors in the Aceh context particularly low breast cancer awareness is important when attempting to change the pattern of these women in

seeking breast cancer screening and appropriate treatments. Importantly, advanced development of modern cancer care as well as today's campaigns cannot overwhelm breast cancer services without concerning a particular distinct Aceh culture. Here, the study examines knowledge and breast self-examination skills, and other breast cancer screening including mammography among Acehnese women should be taken into consideration. Also, the focus should be given to each single item of breast cancer awareness. Shortening patient delay of Acehnese women with breast cancer therefore can be enhanced through educational programs of modern cancer care with a need for congruence with the sociocultural context of Acehnese culture, indeed.

The result found that Acehnese women with breast cancer used a variety of alternative therapy types for a variety of reasons. Health care providers should screen or assess details about the use of alternative therapy in each patient so that nursing counseling would be more appropriate on an individual basis. In addition, this issue needs further investigation to explore the perspectives of individual decision making and reasoning for using alternative therapy as well as their beliefs about screening, diagnosis, and treatments of breast cancer among Acehnese women. Essentially, under Acehnese culture of preference for traditional healer (dukun) which becomes the central trust for Acehnese people in terms of health and illness before seeking modern medical care. Here, 'dukun' will become the important person to be incorporated into cancer diagnosis in order to inform or persuade suspected new breast cancer cases to access and adhere to breast cancer services and cares in hospital.

The study's finding about the associations and predictive power of personal and sociocultural factors raise a major concern should be for Acehnese

nurses and every health care provider. Strategies need to be developed refining cultural cancer care competency, included cultural cancer care sensitivity. Increasing the number of modifiable cancer risk factors as well as increasing the potential risk of exposure to cancer-linked substances from changing trends in diet and lifestyles of young Acehnese women leads to further studies regarding this issue. Moreover, family history of breast cancer in Acehnese women with breast cancer is an issue that seems to need more study, as many of the women in the current study were unclear about this, and thus the numbers given not reliable. The study also brings broad recommendations to Indonesian nursing education as the vital agent in producing cultural cancer care competency, included cultural cancer care sensitivity for Acehnese student nurses.

Importantly, the study results also reflect the potential association of system or provider delay and patient delay. Future study regarding total delay is suggested. Moreover, since some patients may not have presented to a hospital, instead preferring alternative treatment, a future population-based study could be useful. Lastly, financial support for travelling to a hospital, including living allowance, as well as increasing the number of government breast cancer care hospitals with particular in rural Aceh areas might also improve the percent of women seeking timely medical advice for potential breast cancer.

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**APPENDICES**



## **Appendix A**

### **Informed Consent Form**

My name is Nurleli. I am a master nursing student from Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a thesis entitled identify and investigate factors underpinning or influence your decision making to consult medical doctor or initiate treatments and care in hospital. The data derived from your participation will be kept confidentially and will be used only for improving care in a hospital and service. Importantly, deciding to participate with my study is freely and voluntarily. Even you have already made decision to participate with this study, you can freely decide to not continue participating at any time without getting any effect to care and service. If you decide to participate voluntarily, you will be asked about your personal information and health history. I will give a set of questionnaires to be completed. This may take you about 20 minutes.

#### **Risk and discomforts:**

There is no evidence shown risk related to responding to the questionnaires. However, there is a possibility that some questions may make you upset. Please do not hesitate to let me know, if you feel so or need further help. If you decide not to continue your involvement in the research at any time, for any reason, you may discontinue without getting penalty and any of your contributions can be withdrawn too. I intend to write a thesis and I may present the study at conference, and possibly publish a paper in an academic journal.

#### **Benefits:**

The basic information derived from this study will further initiate Indonesian nursing staff and others health care provider to have better understanding of how to manage patient and to find strategies that fit with Acehese culture in order to enhance Acehese women with breast cancer to receive appropriate treatment as a result in increasing their well-being.

**Confidentiality:**

All information and your responses in this study will remain confidential. Only the researcher and the advisors are eligible accessing the data. Neither your name nor any identifying information will be used in the reports of the study. 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 of the research information.

**Participation and withdrawal:**

Your participation in this study is voluntary. Returning the forms given indicates that you understand what is involved and you agree to participate in this study. You have the right to withdraw from participation anytime without any problems prior to completion of data collection.

Thank you for expressing interest in this study. If you have questions, you can contact me by mobile phone 081269772581 or by email at: [nurleliramli@yahoo.com](mailto:nurleliramli@yahoo.com). Your signature on the form will indicate that you understand what is involved and that you consent to participate in this study.

_____	_____	_____
(Name of respondent)	(Signature of respondent)	Date
Nurleli		
_____	_____	_____
(Name of researcher)	(Signature of researcher)	Date

**Appendix B**  
**Personal Characteristics and Disease-Related Data Form**

No. Respondent :  
 Date and time :

Please check (√) the box that is relevant to you

1. Age .....years old
2. Ethnicity
 

<input type="checkbox"/> (1) Aceh	<input type="checkbox"/> (2) Gayo
<input type="checkbox"/> (3) Alas	<input type="checkbox"/> (4) Singkil
<input type="checkbox"/> (5) Tamiang	<input type="checkbox"/> (6) Simeulu
3. Marital status:
 

<input type="checkbox"/> (1) Married	<input type="checkbox"/> (2) Single
<input type="checkbox"/> (3) Widowed	<input type="checkbox"/> (4) Divorced
4. Level of Education:
 

<input type="checkbox"/> (1) No schooling	<input type="checkbox"/> (2) Elementary school
<input type="checkbox"/> (3) Junior high school	<input type="checkbox"/> (4) Senior high school
<input type="checkbox"/> (5) University	
5. Family history of breast cancer:  (1) Yes  (2) No
6. Income: .....IDR
7. Insurance status:
 

<input type="checkbox"/> (1) Government	<input type="checkbox"/> (3) Charity
<input type="checkbox"/> (2) Private insurance	<input type="checkbox"/> (4) Do not have any insurance
8. Place of residence:  (1) Rural area  (2) Urban area

Clinical presentation (*question no. 9-13 will be filled in by the researcher*)

9. First symptoms:
 

<input type="checkbox"/> (1) Breast lump	<input type="checkbox"/> (2) Breast pain
<input type="checkbox"/> (3) Nipple problem	<input type="checkbox"/> (4) Change of breast shape
<input type="checkbox"/> (5) No symptom	<input type="checkbox"/> (6) Others.....
10. Stage of breast cancer:
 

<input type="checkbox"/> (1) I	<input type="checkbox"/> (2) IIa
<input type="checkbox"/> (3) IIb	<input type="checkbox"/> (4) III
<input type="checkbox"/> (5) IV	T___N___M___
11. Tumor size:.....

12. When you had first thought of it as potential illness : date\_\_\_month\_\_\_year\_\_\_

13. When you had decided to contact health professionals: date\_\_\_month\_\_\_year\_\_\_

**Appendix C**  
**Breast Cancer Awareness Measure (BCAM)**

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

Yes  No

*If yes, please circle the signs you know below*

1. Which statement are the warning signs of breast cancer?

Change position  
of nipple

Pulling in of  
the nipple

Pain in one of  
breasts or armpit

Puckering or  
dimpling of  
breast skin

Discharge or  
bleeding from  
nipple

A lump or  
thickening in  
breast

Nipple rash

Redness of  
breast skin

Change in the  
size of breast  
or nipple

A lump or  
thickening  
under armpit

Change in the  
shape of breast  
or nipple

*Please tick (✓) one answer only*

2. In the next year, who is most likely to get breast cancer?

A 30 years old women

A 50 years old women

A 70 years old women

A women of any age

3. How often do you check your breasts?

Type of breast cancer screening used	Rarely/ never	At least once every 6 months	At least once a month	At least once a week
Breast self-examination				
Mammography				
Clinical breast examination				



### Appendix E

#### Alternative Therapy Use Questionnaire

(i) Types of alternative therapy use

Type	Items	Yes	No
	<ul style="list-style-type: none"> <li>- Herbs</li> <li>- Natural therapies such as blessing drinking water, etc</li> <li>- Massage</li> <li>- Prayer</li> <li>- Go to dukun</li> <li>- Others.....</li> </ul>		

(ii) Main reason of alternative therapy use

Item	Yes	No
1. More effective than modern medicine		
2. More benefits		
3. Because I want to be in control of my treatment		
4. I had strong beliefs and used it as the last hope		
5. I had bad previous experiences in modern treatment		
6. ....		
7. ....		
8. ....		
9. Other,.....		

**Appendix F**

**Social Support Questionnaire**

This questionnaire is asked you whether you get support from your husband or other family members.

*First, please check who are the main persons who provide you support (check  $\checkmark$  all that apply)*

Husband     Mother     Son     Daughter

Item	Not at all	Some times	Often	Very often
1. She/he asked about my symptoms				
2. She/he took the initiative to talk about my concerns				
3. She/he advised me to talk to my doctor				
4. She/he tried to calm me				
5. She/he talked directly about cancer				
6. ....				
7. ....				
8. ....				

**Appendix G**  
**Additional Analysis**

Table 6

*Frequencies and Percentages of Cultural Beliefs of Breast Cancer and Cancer Care*

(N = 160)

Item	Agree & strongly agree		Not sure		Disagree & strongly disagree	
	n	%	n	%	n	%
<b>Cultural beliefs of breast cancer</b>						
1. Breast cancer is fate and God's will, nothing can be done to stop getting cancer	97	60.6	8	5.0	55	34.4
2. Breast cancer is incurable disease and equal death	13	8.1	18	11.3	129	80.7
3. Openly discuss about breast cancer is shameful	49	30.6	18	11.3	93	58.2
4. Mentioning the word "breast" is taboo, so no need to disclose your breast cancer to other person	40	25.0	7	4.4	113	70.7
5. Breast cancer always results in some kind of disfigurement and disability as a womanhood and motherhood	78	48.8	39	24.4	43	26.9
<b>Cultural beliefs of risks of developing breast cancer</b>						
6. Cancer caused by evil eye of envying neighbors	4	2.6	15	9.4	141	88.1
7. Faith in God and destiny helps prevent breast cancer	90	56.3	16	10.	54	33.8
8. Pressing of the breast will cause breast cancer	54	33.7	52	32.5	54	33.7
9. Breast feeding can reduce the chances of breast cancer*	83	51.9	43	26.9	34	21.3
10. Chemical in food can cause breast cancer*	134	83.8	21	13.1	5	3.1
11. Breast cancer will not happen if no family member has history of cancer	19	11.9	51	31.9	92	56.3
<b>Cultural beliefs of early detection and screening test of breast cancer</b>						
12. Detecting a small lump in breast is not serious and need not to hurry to seek care and treatment	29	18.1	20	12.5	111	69.4
13. Breast self-examination (BSE) can early detect breast cancer*	92	57.5	26	16.3	42	26.3
14. Breast self-examination is easy to practice*	86	53.8	34	21.3	40	25.0



Table 6 (continued)

Item	Agree & strongly agree		Not sure		Disagree & strongly disagree	
	n	%	n	%	n	%
15. Breast cancer screening is needed to be done without presenting any signs and symptoms*	112	70.0	23	14.4	25	15.6
16. Female cannot expose their breast and be examined by male doctor	31	19.4	32	20.0	97	60.6
17. People have responsibility to protect their body and have to take the best possible care of it*	156	97.4	2	1.3	2	1.3
18. Visiting a medical doctor and being diagnosed with breast cancer is a stigma for you and your daughter and will become ostracize from social	14	8.7	12	7.5	134	83.8
19. Women's role as mother and wife to take care of my child(ren) or family is a reason for not being able to get free time to visit a medical doctor	55	34.4	27	16.9	78	48.8
20. I will firstly looking for medical treatment although the distance from hospital is far away from my home*	139	80.6	17	10.6	14	8.8
21. Being unable to pay for transportation and living allowance inhibit me to get medical services earlier	<b>64</b>	<b>40.0</b>	17	10.6	79	59.4
<b>Cultural beliefs of the treatments and outcomes of breast cancer</b>						
22. Traditional therapy is more effective than modern treatment in hospital	21	13.1	44	27.5	95	59.4
23. Traditional healer (dukun) is the first choice once you detect abnormal symptoms of your breast	26	16.2	14	8.8	120	75.0
24. You will not choose treatments from medical doctor, if everybody in your family does not bless you	36	22.6	17	10.6	107	66.9
25. The treatments in a hospital either surgery, chemotherapy, or radiation for breast cancer will help regardless of how advanced the disease is	<b>89</b>	<b>55.7</b>	54	33.8	17	10.7
26. Surgery will spread tumor to the whole body	15	9.4	41	25.6	104	65.1
27. Effects of chemotherapy were worse than breast cancer itself	23	14.4	73	45.6	64	40.0
28. Treatments for breast cancer make the patient very painful	<b>65</b>	<b>40.6</b>	42	26.3	53	33.2
29. A women who has had treatment for breast cancer can enjoy a good quality of life*	127	79.4	26	16.3	7	4.4
30. Feeling less respect and unfriendly from hospital staff	35	21.9	19	11.9	106	66.3
31. Health professionals are always in hurry and do not have time for their patients	44	27.5	16	10.0	100	62.5
32. Health professionals are not compassionate for what their patients are going through	37	23.1	17	10.6	106	66.3

Note. \* Positive question

Table 7

*Frequencies and Percentages of Types of Alternative Therapy Use (N = 160)*

Items	Use		Not use	
	n	%	n	%
Herbs	62	38.8	98	61.3
Natural therapies such as blessing drinking water, "benalu kopi", soursop leaves, mangosteen rind	34	21.3	126	78.8
Massage	27	16.9	133	83.1
Prayer	50	31.3	110	68.8
Go to Dukun	23	14.4	137	85.6
Go to Shinse	2	1.3	158	98.8

Table 8

*Frequencies and Percentages of Main Reasons of Alternative Therapy use (N = 160)*

Item	n	%
More effective than modern medicine	24	15.0
More benefits	20	12.5
Because I want to be in control of my treatment	39	24.4
I had strong beliefs and used it as the last hope	23	14.4
I had bad previous experiences in modern treatment	18	11.3
I felt that traditional healers more friendly	16	10.0
Alternative therapy is also easily available and affordable	38	23.8
I believed it was helpful to recovering, healing, and improving health	33	20.6
Boosting the immune system	22	13.8
Reducing side effects of conventional treatments	29	18.1
To improve emotional health	26	16.3
To increase the feeling of control	28	17.5
Reducing physical and psychological distress	22	13.8
To cure or treat cancer	57	35.6

## **Appendix H**

### **List of Experts**

Three experts had examined the content validity index of the questionnaires

1. Assist. Prof. Dr. Khomapak Maneewat

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

2. Assist. Prof. Dr. Hathairat Sangchan

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

3. Dr. Srila Samphao, M.D

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

## VITAE

**Name** : Mrs.Nurleli  
**Student ID** : 5410420033

### Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Nursing Science	Faculty of Nursing, Syiah Kuala University, Aceh, Indonesia.	2008

### Scholarship Awards during Enrolment

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### List of Publication and Proceeding

Nurleli., Maneewat, K., Petpichetchian, W. (2013). Patient Delay in Consulting a Medical Doctor among Acehnese Women with Breast Cancer. *The 2010 International Nursing Conference on Health, Healing, Harmony: Nursing Values*, Phuket, Thailand. May 1-3, 2013