Illness Perceptions of Indonesian Women with Breast Cancer

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ABSTRACT

A descriptive study was conducted to explore illness perceptions of Indonesian women with breast cancer. The conceptual content cognitive map (3CM) method and additional interview were utilized to capture Indonesian women's perceptions of their illness. By using descriptives, frequencies, and content analysis, seven categories of forty Indonesian women's perceptions of breast cancer emerged namely description of breast cancer, causes, consequences, time-line, cure/controllability, coping, and support. The descriptions of breast cancer category portrayed physical sign and symptoms of breast cancer, breast cancer as a test, a warning, and a punishment from God, breast cancer as a shame, a serious disease, and a bitter life experience. The informants perceived several causes of breast cancer which were modifiable and unmodifiable consisted of food related causes, behaviors, attitude, birth-control, petrified milk, frozen blood, germ or virus, genetic, and black magic. Beside the negative consequences of being diagnosed with breast cancer in terms of social life; making burden; family disruption; physical impacts; financial problems; negative psychological responses and progress of the disease, the informants also described positive consequences that by being sick with breast cancer made them totally rest and gave them time for personal activities; breast cancer brought an improvement of relationship among family members and also with relatives; and breast cancer generated positive psychological responses. All women perceived breast cancer as a chronic illness which needed long term treatments as an effort to deal with it. The women perceived breast cancer as both a curable and incurable disease. Treatment modalities of breast cancer to control breast cancer including medical and non-medical treatment were also disclosed. While the consequences category dominated the negative perceptions (50%), more than half (56%) informants perceived coping category brought positive perceptions of breast cancer. The women perceived covering some parts of body; doing self-care to prevent recurrent; seeking treatment; religious practice;

positive reframing; acceptance; and fighting spirit could lessen their suffering from breast cancer. The rest, support from support from family, health care provider, neighbors, religious-group, and other patients were perceived positive by the informants regarding breast cancer diagnosis. The findings from present study support the component of illness perceptions found in western country but the contents of each category are different. This present study demonstrated the integration of illness perception, psychological responses or emotion and coping. The findings also described the uniqueness of culture which included religion, past experience, environment, and symptom experiences that take role in constructing Indonesian women's perceptions of breast cancer. The 3CM method was able to capture the structure and the contents of the informants' illness perceptions accurately while avoiding inadvertent biases that may be created by using a method that has not been normed in an Indonesian population, while additional interview is used to clarify and to find in depth the data gathered from the 3CM method. The research findings can be used as a baseline data for future research regarding illness perceptions and guidance of nurse practitioners to determine nursing interventions for restructuring illness perceptions of Indonesian women with breast cancer to adjust and live with their illness.

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CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

Cancer is one of the leading causes of deaths worldwide. In 2005, cancer killed approximately 206,000 people in Indonesia under the age of 70 years. Breast cancer is the leading cause of female cancer deaths in Indonesia, accounting for 26 of 100,000 female deaths (WHO, 2008).

Being diagnosed with breast cancer is a traumatic event for women. They face two issues in one time. Firstly, they face uncertainty about the possible spreading of cancer, suffering, and death and secondly, the women will face the femininity issue (Heskestad & Tjemsland, 1996 as cited in Landmark & Wahl, 2002). Breast is a symbol of femininity and sexuality for women. Loss of breast can change women's perception of their own body. It also can change the way in which they experience and understand themselves and relationship with other close relatives. Losing breast means losing femininity and sexuality. It leads to the feeling of degradation in relation with men (Landmark & Wahl, 2002). Hence, they need to respond both cognitive and behavioral strategies in order to employ them for adjusting and living with their illness.

Many factors can influence patients' outcomes. One important factor is cognitive responses of health threat which we called illness perception. Several studies have been conducted to explore and understand illness perception in chronic diseases but only a few studies have been conducted in cancer area (Degner, Hack, O'Neil, & Kristjanson, 2003; Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking, 2003; Anagnostopoulosa & Spaneab, 2004; Kritpracha, 2004; Lehto, 2004; Millar et al, 2005; Sarna et al., 2005; Llewellyna, McGurkb, & Weinman, 2007). Most of studies were developed based on the Leventhal's Self-Regulation Model (Leventhal, Nerenz, & Straus, 1982) and used the Illness Perception Questionnaire (IPQ) which was developed by Weinman, Petrie, Moss-Morris and Horne (1996) to assess patients' illness perceptions. The Self-Regulation Model posits that a person employs a cognitive representation, consisting of an interaction between cognition and emotion to understand the health threat and to guide responses. There are five components of illness perceptions (Lau &

Hartman, 1983; Leventhal et al., 1982) namely identity, cause, consequences, time-line, and cure/ controllability.

Some studies (Degner et al., 2003; Wallberg et al., 2003 & Sarna et al., 2005) used the meaning of illness instrument which was proposed by the concept of Z.J. Lipowski (Lipowski, 1970 as cited in Degner, Hack, O'Neil, & Kristjanson, 2003). Lipowski had described eight categories for the meaning of illness particularly in North American culture. The categories were challenge, enemy, punishment, weakness, relief, strategy, irreparable loss, and value.

Two studies (Kritpracha, 2004; Lehto, 2004) used the Conceptual Content Cognitive Map (3CM) method besides the IPQ. The 3CM method is one method to assess patients' illness perception which was developed by Kearney and Kaplan (1997) based on a person-environment perspective which emphasizes the critical role that environments, which includes culture, play in the development of illness perceptions. By using the 3CM method, the researcher can capture the structure and the content of illness perceptions accurately while avoiding inadvertant biases that may be created by using a method that has not been normed in one population because the individuals are asked to identify the concepts that they believe are important to explain their view of particular issue and asked to organize each concept in a way that depict how they perceive the issue. Therefore the result will show a visual display which express an individual's perception (Kearney & Kaplan, 1997).

One study was developed in the United States of America (Lehto, 2004) and other was in Thailand (Kritpracha, 2004).Through the 3CM method, the findings of Lehto (2004) fully supported the components of illness perceptions that were proposed by Lau & Hartman (1983) and Leventhal et al. (1982). But Kritpracha's (2004) study only partially supported these components where the time-line component did not come up and interestingly, there was a contradictory finding about the cure/controllability component. The 3CM method indicated that the majority of the patients perceived that breast cancer is not curable, but results from the IPQ suggested that the patients tended to perceive their illness is curable. Kritpracha (2004) also added other components namely, emotion, coping, and social support which were found from the 3CM method.

Findings from the previous studies support that culture plays an important role in constructing individuals' perception of their illness. Culture constrains the perceptual,

explanatory, and behavioral options that individuals have at their disposal for understanding and responding to their illness (Angel & Thoits, 1987). Only few studies have been done to explore illness perceptions of breast cancer in different cultures. The studies were conducted in the Egyptian women, Arab women in Israel and Buddhist women in Thailand (Ali & Khalil, 1996; Azaiza & Cohen, 2008; Kritpracha, 2004). The rest of studies were mostly conducted in western culture. Thus, the results could not be generalized to apply in Indonesian breast cancer patients in Indonesia who has different cultural background. Indonesia is a predominantly Muslim country where has recently undergone a transition from an aggressively westernizing regime to one in part supported by traditionalist Islamists (Bahramitash, 2002). The family and the women's roles in Muslim societies has been affected by various laws and cultures in different countries in addition to the social, economic, and financial factors (Sechzer, 2004).

The present study aimed to examine the illness perceptions of Indonesian women with breast cancer. Better understanding about illness perception can help nurses in providing effective interventions to help patients for managing their responses to breast cancer.

Objective of the Study

The objective of the study was to describe the structures and the contents of illness perceptions of Indonesian women with breast cancer.

Research Question

What are the structures and the contents of illness perceptions of Indonesian women with breast cancer?

Definition of Terms

Illness perception in this study was defined as the patients' understanding about breast cancer which consisted of structures and contents of illness perceptions. The structure of illness perceptions consisted of cognitive and emotional structure regarding breast cancer diagnosis which called category of illness perception in this present study. Here, the content of illness perception was the detail of patients' cognitive and emotional structures. Both of structure and

content of illness perception were addressed by using 3CM method. Additional interview was used to clarify and to find in-depth the contents of informants' illness perceptions.

Significance of the Study

The outcome of the study can contribute to nursing practice and nursing research in Indonesia:

1. For the nursing practice, the research findings can be used as guidance for nurse practitioners to determine nursing interventions for restructuring patients' illness perceptions so that they can adjust and live with their illness.

2. For the development of further research, the study can be used as a basic data to develop patients' self regulations to adjust and live with their illness.

Scope of the Study

This study focused only on exploring the informants' illness perceptions which included the structures and contents of the illness perceptions. Forty Indonesian women who had been newly diagnosed with breast cancer and admitted in Dr. Mohammad Hoesin Hospital in Palembang, Indonesia, were recruited in this study.

CHAPTER 2

LITERATURE REVIEW

The literature review section focuses on theoretical reviews and research findings regarding: (a) concepts of illness perception; (b) roles of illness perceptions contributing to patients' outcomes; (c) factors related to formation of illness perceptions; (d) illness perceptions of patients with breast cancer; (e) illness perceptions in Muslim culture; and (f) measurements of illness perceptions.

Concepts of Illness Perceptions

The diagnosis of illness is a pivotal life event that can transform an individual. This information can activate the information-processing mechanism in indivual's mind including how the individual perceive the illness. Many definitions of illness perception have been given by experts. Illness perception is defined as parallel cognitive and emotional representations in response to illness and other health threat which, in turn, gives rise to the problem-based and emotion-focused coping procedure, respectively (Leventhal et al., 2001 cited in Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). Illness perception is also defined as an organized set of beliefs regarding how the illness affects the body, its likely impact on life and experiences, whether it can be cured or not and so on as the reaction of illness-related information (Cameron & Moss-Morris, 2004). Finally Kearney and Kaplan (1997) defined illness perception as a cognitive structure which embodies individual's assumptions, beliefs, facts, and misconceptions about the illness. The structures occur at numerous levels of abstraction and each content in a higher level map represents the lower level map.

Synonyms of illness perceptions include illness cognitions, illness representations, illness beliefs, illness schemata (Cameron & Moss-Morris, 2004), cognitive maps (Kearney & Kaplan, 1997) and meaning of illness (Degner, Hack, O'Neil, & Kristjanson, 2003).

Based on the Self Regulation Model which was developed by Leventhal and colleagues (1982), the illness perception reflects the operation of underlying information-processing mechanism which is designed to regulate the individual's response or behavior. The purpose is to utilize information and needed as a feedback for self regulation.

There are four assumptions of information-processing mechanism which may influence the way it deals with illness episodes as follows:

a. Stages of processing. The information-processing system has three stages. They are: (1) a stage of interpretation where the information is analyzed and given meaning, (2) a stage of action planning (also called coping stage) where someone generate and execute appropriate response to the stimuli, and (3) a stage of appraisal where the result of the second stage is evaluated in relation to the desired outcome.

b. Parallel construction. The information-processing system occurs through parallel routes. There are objective perceptions and interpretation which is distinct from subjective informational processing. The parallel construction is generated with a varying degree to respond to health threat.

c. Hierarchical processing. The information is enriched or progressively more deeply processed by hierarchical levels of the nervous system. The hierarchy varies from the simplest level which is an automatic mechanism that makes use of very concrete stimulus features, the intermediate level which is more abstract in perceptual memory, and the conceptual level process which forms the most abstract level. The conceptual level offers a high medium to arrange information, appraising environment and people, and anticipates the outcome of future actions.

d. Deliberate versus automatic processing. Some information processing automatically developes underlying experience and behavior. Emotional reaction usually generates automatic behavior sequences whereas long term planning or coping will involve complex sequences of conscious imagery and thought.

This model explains that health related behavior is a result of repeated process of integrating internal and external stimuli with existing cognitive structure to give meaning to individual's experience. The processing system changes over time. It becomes more complex within and across illness episodes.

Five components of illness perceptions (Lau & Hartman, 1983; Leventhal et al., 1982) are as follows:

a. Identity

It is the label or name given to the condition and the signs or symptoms those appear to go with it. Being told that someone has illness will make that person generates symptomatology for searching the physical symptoms to make sense of illness labels. This action may involve talking to other people to find-out if they have similar symptoms or were exposed by similar events and then compare them with the symptoms they feel. The need for information and the tendency to seek labels will be reduced if the symptoms fit what one's earlier defined as a perceptual memory.

b. Cause

It is the individualistic ideas about the perceived cause of the condition, which may not be completely biomedically accurate. The representations are based on personal experiences as well as the opinion and discourses of significant others, health professionals and media sources, reflecting issues such as stress, environmental pollution and other pathogen

c. Time-line

It is the predictive thought about how long the condition might last whether it is an acute or chronic one.

d. Consequences

It is the individuals' thought about the consequences of the condition and how this will impact on them physically, socially, and economically and emotionally.

e. Curability/controllability

It is the thought about whether the condition can be cured or kept under control and the degree to which the individual plays a part in achieving this.

Bishop (1991) suggested that in disease, symptoms define illness and illness is understood in terms of the involved symptoms. When people experience physical symptoms, they will interpret the symptoms by retrieving from memory prototypes of various diseases. The symptoms are interpreted as representing the disease whose prototypical symptoms are most likely the one that has been currently experiencing.

Individual's perception of illness can bring positive and negative feeling into their minds. A study of Petrie and colleagues (1999) on myocardial infarction and breast cancer patients showed that 60% of each patients group reported positive changes as the impact of their illness and the reporting of such changes was unrelated to illness severity. The finding suggested that psychological variables may be paramount in this process. The most common themes reported by breast cancer patients were improved close relationships with others followed by greater appreciation of health and life, a change in personal priorities, improved empathy, and healthy life style change. Another study of 217 female patients with lung cancer from Sarna et al. (2005) found that most of the women (64%) perceived lung cancer as positive meaning. More than half of them chose challenge as their meaning of lung cancer. Lung cancer as a value was chosen by 10% of women and as a relief by only 1%. The rest (36%) chose lung cancer as enemy, irreparable loss, punishment, and weakness. Although lung cancer is a disease which is associated with tobacco use, few of them (7%) perceived it as a punishment. Regarding the findings of negative meaning of lung cancer, a few of them (18%) perceived it as an enemy. These findings may be because many lung cancer patients experienced stigma, shame, and blame from others since they had lung cancer (Chapple, Ziebland & McPherson, 2004). The lung cancer patients felt stigmatized because the disease is strongly associated with smoking although some of them did not or had stopped smoking years before diagnosis of lung cancer and television advertisement which purpose was to prevent young people from smoking described a dreadful death of people with lung cancer. Finally this condition was perceived affected patients' relationship with family, friends, and doctors.

Turk et al. (1986) proposed a 38-item Implicit Model of Illness Questionnaire (IMIQ) to operationalize constructs developed by a previous study. Tthey also include personal responsibility and disruptiveness. The informants were divided into three groups consisting of diabetic educators with RN degrees, diabetic patients, and college students. A 38-item scale that ranged from "strongly agree" to "strongly disagree" (range 1 – 9) was used. The informants were randomly sampled to obtain ratings of two kinds of illnesses. One was personally salient which was diabetes and another one was non salient which was cancer (a disease with which they were familiar but had a little direct experience).

The result confirmed four dimensions of implicit model of illness which were: (a) seriousness, (b) personal responsibility, (c) controllability, and (d) changeability. The first dimension, seriousness, described the seriousness of the illness. It represented individual's knowledge about the degree to which the illness is contagious, difficult to cure, long-lasting and require medical attention. The second dimension, personal responsibility, described the degree to which an individual perceived her/himself as responsible for the cause of illness and took responsibility to cure her/himself from the illness. The third dimension, controllability, described the extent to which the illness is controllable by the individual or outside agents. The last dimension, changeability, described an individual's knowledge about whether the symptom and other aspects of illness change over time.

Schiaffino and Cea (1995) then applied the IMIQ to a larger sample of informants with three different illnesses (rheumatoid arthritis, multiple sclerosis, and human immunodeficiency virus). The finding which emerged was not consistent with the structure identified by Turk et al. The researchers found out four-factor structure. The first structure was curability factor, which was a combination of Leventhal's causes, cure, and time-line dimensions. This factor reflected informants' beliefs that the illness is curable, temporary, and not chronic. Personal responsibility was the second factor which also included causes of illness, consequences, and identity components that referred to the extent to which the person was responsible of the illness. Symptom variability was the third factor structure. It reflected the Leventhal's time-line dimension and Turk et al.'s control and changeable factors. The last factor was the serious consequences. It concerned with the severity of illness. This study described the value of IMIQ in assessing illness perception and suggested that illness perceptions differ as a function of personal experience and personal relevance.

Another concept of illness perception comes from Kearney (1994). In this concept illness perception is described as cognitive map. It posits that there is a cognitive structure in someone's mind which is called prototype building cognitive map. Prototype is an abstraction of someone's experience with an exact object or concept in the world. When new information comes which has common similarity or features then it can activate the stored prototype and be integrated easily together in someone's cognitive map. On the other hand if the new information is quite different or less in common similarity with the stored prototypes then usually the information will be

ignored. It means someone's experience about one particular object or concept influence how tight the corresponding prototypes become and how easy the prototypes are activated. Therefore it is reasonable to suppose that cognitive structures in different individuals' minds will show variation.

The prototype model suggests that the closeness of fit between the symptom information and available prototypes should affect the speed with which people process that information. A closer fit between a set of symptoms and an available disease prototype should lead to more rapid processing of symptom information. When people process the illness information, they will do their best to relate symptoms to a given disease entity and, when successful, they make association to the overall set of symptoms. When unsuccessful in relating symptoms to a specific disease, individuals will continue efforts to understand their symptom experience, but will do so on the basis of individual symptoms. Thus, when faced with serious symptoms that do not fit a known pattern, individuals try hard to produce labels for the condition, but are at a real loss to figure out what is causing the symptoms (Bishop, 1991).

Cognitive map can occur at many levels cognitive structure. Each content of structure in a higher level map representing an entire lower level map resulting a hierarchical structure (Kearney & Kaplan 1997). Once a prototype is activated, it will link to another associated prototype in mind. Through this way someone is able to a make plan before making decision and action. When a person is less comfortable with the information, he will be less confident of its use, and less competent to apply the information to the real situation.

Role of Illness Perceptions Contributing to Patients' Outcomes

Many studies were developed to measure patients' outcomes. From those studies, researchers revealed significant roles of illness perception in forming patients' outcomes. One study from Degner, Hack, O'Neil, & Kristjanson (2003) measured 159 patients' perceptions about the meaning of breast cancer with their psychosocial functioning by using the Beck Depression Inventory, the Spielberger Anxiety, and the EORTC Functional Scales. The findings described that women with positive perception of breast cancer (perceived breast cancer as challenge or value) at the time of diagnosis had significantly less trait anxiety at the follow up assessment which took place 3 years after time of diagnosis. The women who perceived negative

meaning of breast cancer also had higher levels of depression and anxiety and reported poorer levels of emotional functioning and quality of life at the follow up assessment.

Another study from Sarna et al. (2005) investigated the relationship between meaning of illness in 217 female patients with lung cancer and their quality of life (QOL) using the meaning of illness instrument (Degner, Hack, O'Neil, & Kristjanson, 2003) to assess the meaning of lung cancer and used a cancer-specific and generic quality of life instrument (QOL-Patient). The results supported findings from (Degner, Hack, O'Neil, & Kristjanson, 2003) that showed the power of patients' MOI conceptualization to their QOL. The women who perceived more negative meaning of lung cancer had poorer QOL. It is also supported by finding from Fowler and Baas (2006) who conducted their study in forty-two patients with chronic kidney disease found that the consequences component of illness perception had significantly negative correlation with quality of life. It means as the perceived consequences increased, the quality of life of the patients will be decreased.

The last, Groarke and colleagues (2005) conducted a study in 75 women with rheumatoid arthritis and they found that the more perceived illness identity and more serious perceived illness consequences were associated with poor physical function, higher pain and more depression and anxiety. Lower perceived illness cure/control was also associated with more pain, depression, and anxiety. These result demonstrated that there was a consistent association between illness perceptions and psychological and functional adjustment in illness.

Factors Related to Formation of Illness Perceptions

Many factors are related to formation of illness perceptions. These factors are age, gender, stage of disease, past experience, education, personality, symptom experiences, and culture.

Age

Age is an important factor in individual's illness perceptions as the perception is based on information people acquire over time. Degner, Hack, O'Neil, & Kristjanson (2003) studied the meaning of illlness of 1,012 Canadian women with breast cancer and they found that younger women (less than 50 years) were likely to perceive their illness more negatively than older women. Most of them viewed their illness as enemy, punishment, weakness, and irreparable loss.

Older women (more than 50 year old) considered themselves lucky to have breast cancer in this age because from this event they could draw strength (perceived breast cancer as a challenge). It indicated that it might be more difficult for them to view breast cancer as a challenge if they would be younger. Similar to another study, Wallberg and colleagues (2003) conducted study in Sweden with 187 women with breast cancer. They found that women in the middle age (51-65 year old) were more likely to perceive breast cancer as challenge compare to younger and older women. Women with older age (more or equal to 66 year old) were the most group who perceived breast cancer as giving intrinsic value to them or growing them in some way.

Kritpracha (2004) who studied illness perceptions in Thai women with newly diagnosed and early stage of breast cancer by using the 3CM method and the IPQ also suggested the influence of age in the formation of illness perception. The results revealed that older patients were more likely to perceive less cure and controllability of breast cancer.

Gender

Lehto (2004) found that there was a difference in between male and female patients' perception of lung cancer. Female patients with lung cancer experienced more symptoms perceptions prior to surgery, and males had more symptoms perceptions following the surgery.

Stage of disease

Progression of cancer gives more complication to patients' body. Symptom of illness will occur more in the last stage than in earlier stage. Therefore, stage of cancer influence patients' perceptions of illness. Women who faced the more progressive illness (late-stage of cancer) perceived more negative meaning compared to earlier-stage one (Degner, Hack, O'Neil, & Kristjanson, 2003 & Wallberg et al., 2003). They perceived breast cancer as enemy/ punishment/ weakness/ irreparable loss.

Past experience

Illness perception may develop from several sources including direct experience of illness and medical care, experience of illness through family, friends, and media. Rees, Fry, & Cull (2001) described the experiences of women with a family history of breast cancer were likely to have impact on the perception of consequences, cure, and controllability of breast cancer.

Degner, Hack, O'Neil, & Kristjanson (2003) also explained the perceived negative meaning from the women with breast cancer seemed was obtained as the influence of previous experience in their lives such as marital breakdown, discomfort of treatment, and unresolved anger about something that had occurred before diagnosis. The women also emphasized the role of previous life experience to help them constructing the positive meaning to confront their cancer.

Education

Education is an important factor for an individual in forming illness perception by determining the ability to access, obtain, and interpret information. Amtmann (1996 as cited in Kearney & Kaplan, 1997) explored the relationship between cognitive structures as measured by the 3CM method and level of expertise. The result suggested that experts (in this case, the topic of the study was wild and scenic rivers) tended to have more structured arrangements (a greater number of concepts, more categories, and more clearly defined relationship between categories) than the novices' cognitive structures.

Kritpracha (2004) found years of education play an important role in predicting how the women with breast cancer in early stage perceived cure or controllability and whether the illness would last for short or long time. She described that women with higher years of education were more likely to think that their illness will last for a shorter time, and more likely to think that their illness will be cured or controlled.

Psychological condition

Lehto (2004) studied worry and cognitive representations of illness on 42 lung cancer patients. She found that worry is a significant problem in the early period following the diagnosis of lung cancer. The higher intensity and more frequent worry were associated with the formation of cognitive representations of illness with more negative and threat-related thought contents. The intensity and frequency of worry may reinforce perceptions that the treatment will not be effective and that the personal effort towards managing the illness are also not effective. In contrast, the lower intensity and less frequent worry would be associated with the formation of cognitive representations of illness with more positive contents. The higher intensity and frequency of worry may reinforce a cognitive representation of illness with less coherent and detailed structure.

The study also found that patients' state anxiety emerged as a contributor to multiple dimensions of the cognitive representation of illness in its early development. Optimism and perceived effectiveness in cognitive functioning were found strongly related to the cognitive representation of illness following the surgery of lung cancer.

Symptom experiences

Symptoms are subjective reports by patients indicating a change in normal function or sensation due to disease or treatment (Burkett & Cleeland, 2007). Symptoms play a central role in illness perceptions (Keller, Ward & Baumann, 1989 as cited in Baumann & Keller, 1991). People will be motivated to find a set of symptoms to monitor a disease state and evaluate progress in controlling it (Meyer, Leventhal & Gutmann, 1985 as cited in Baumann & Keller, 1991). The following studies revealed symptom experiences from women with breast cancer in various stages.

Bender, Ergun, Rosenzweig, Cohen, and Sereika (2005) conducted studies to assess symptoms in breast cancer across 3 phases of the disease. Study I had 40 women with the phase of early-stage breast cancer (ductal carcinoma in situ (DCIS), stage I or stage II) following primary surgery for the disease and prior to the initiation of adjuvant therapy. Study II had 88 women with phase of disease on stage I, II, or III breast cancer who have completed surgery and adjuvant chemotherapy and maybe receiving hormonal therapy. Study III had 26 women with phase of metastatic breast cancer with mild anemia. The studies revealed symptoms in breast cancer across 3 phases of the disease which included fatigue, feeling lack of energy, decreased physical strength/ weakness, headache, sleeping difficulty, feeling depressed or blue, feeling anxious and nervous, problem with memory, and loss of concentration. Other symptoms (hot flushes or flashes, aching muscle, joints and backaches, and night sweating) were only found in study I and II.

Twenty women, who underwent surgical excision of a primary lesion and adjuvant chemotherapy consisting of 4 cycles of Adriamycin and Cyclophosphamide (AC), followed with 4 cycles of paclitaxel (Taxol) experienced their feeling of disfigured and/ or lopsided and numbness in the chest wall, in the axillary area, or the upper arm area. The feeling was described as more uncomfortable than incision pain. Another concern focused on their body image. The women also felt a "pulling sensation" as well as swelling that made a noticeable difference. While

receiving the AC, the women complained of severe nausea and hair loss whereas while receiving Paclitaxel, the women complained intense bone and joint pain, numbness and tingling of their fingers and toes, taste changes which altered the ability to determine the freshness of foods and to take enjoyment out of eating. Beyond the physical symptoms, the women also described cognitive changes during various treatments (Boehmke and Dickerson, 2005).

Bower (2008) reviewed behavioral disturbances experienced by breast cancer patients, including fatigue, sleep problems, depression, and cognitive disturbance. Several factors may contribute to cancer-related fatigue including direct effect of breast cancer, adverse effect of cancer treatment, psychosocial factors, co-morbid physical symptoms, and co-morbid medical conditions. Sleeping difficulty had been reported before, during, and after treatment with radiation and/ or chemotherapy and among women with both early stage and metastatic disease. The main precipitating factor of sleeping difficulty is the occurrence or exacerbation of menopausal symptom caused by hormonal or chemotherapy treatment. Other precipitating factors are pain, biological changes associated to cancer, and psychological stress. The occurrence of depression in breast cancer patients is more strongly influenced by psychosocial and physical factors, rather than severity of the disease or treatment regimen. Depressed mood is correlated with fatigue and sleep disturbance in the context of breast cancer. On the other hand, women with breast cancer experience cognitive disturbance. Subjective cognitive complaints are not correlated with objective cognitive performance in breast cancer patients but correlated with subjective reports of fatigue and depressed mood. The biologic mechanism of effects of chemotherapy on cognitive function is unknown.

Culture

Illness perceptions are highly linked with surrounding culture. Culture provides a framework within which illness perceptions develop. Culture constrains the perceptual, explanatory, and behavioral options in response to an individual's illness (Angel and Thoits, 1987). There are two differences in the pattern of perceptions of illness held by society with socio-centric cultures (usually Eastern) and egocentric culture (Western) (Cameron and Moss-Morris, 2004).

Socio-centric cultures view health as the balance or harmony among physical, psychological, social, and spiritual factors. The cultures share that disease is a result of imbalance

among these factors. It holds holistic view that a person is seen as existing in relation to others, the environment, and spiritual forces. No difference between mind and body, self and others, human and environment, and science and spirituality. Socio-centric cultures include Asian, Native American, Latino, and Central American cultures.

On the other hand, egocentric cultures, which include European and American cultures, view illness in terms of physiological process and emphasize the individual. The cultures distinguish illness from emotional, social, and environmental events.

The causal component of illness usually varies across cultures. Generally it can be divided into three categories: natural causes (such as infection and accident), supernatural causes (such as karma and bewitchment), and emotional causes (such as stress and fear). Kritpracha (2004) in her study found that Thai women with breast cancer mentioned the causes of their cancer were diet; stress; pollution; behavior such as lack of health care, not breast feeding their babies; milk stored in breast; hereditary factor; fate/chance; contraceptive; and Karma. The ascription of Karma reflects Buddhist's unique perception where Thailand is a predominantly Buddhism country.

Findings from Degner, Hack, O'Neil, & Kristjanson (2003) added the importance of culture influence in forming illness perceptions. English-Canadian women with breast cancer were more likely to perceive their illness as a challenge or as having value more than Canadian women who came from other ethnicity (continental Europe, namely: Ukrainian, French, or Germany). The findings showed that socio-cultural variables, including ethnicity, are important factors which influence the identification of and response to illness (Angel & Thoits, 1987).In some continental countries usually patients are protected from knowing diagnosis of cancer because the value of "hope" and "cancer" are mutually exclusive. This may explain why non-English-Canadian women in that study perceived more negative meaning of breast cancer.

Illness Perceptions of Patients with Breast Cancer

Breast cancer is a dreadful diagnosis for women. Women with breast cancer face double reactions (Heskestad & Tjemsland, 1996 as cited in Landmark & Wahl, 2002). Firstly, they face uncertainty about the possible spreading of cancer, suffering, and death and secondly they face the femininity issue. A qualitative study of Landmark and Wahl (2002) with 10 Norwegian

women who were newly diagnosed with breast cancer without distant metastasis found that there was extensive diversity of emotion related to female identity. Loss of breast through surgery can change women's perception of their own body. It also can change the way in which they experience and understand themselves and relationship with other close relatives. Losing breast means losing femininity and sexuality. It led to feeling of degradation in relation with men. Another study from Oluwatosin (2006) was conducted in rural area of Ibadan, Nigeria with 407 women participation. It indicated that the women perceived breast cancer was the most severe cancer compared to all cancers. The reasons were "it kills fast" (35.9%), "it affects the breast" which is considered the source of life (28.3%); and 11% said "it is very painful". They labled breast cancer with "infection of the breast" (mastitis), "that which devours", and "that which swells". This information shows there was misconception of breast cancer in this population where breast cancer was mixed up with mastitis. Various causes of breast cancer were perceived by the women. They were breast-feeding factors (when breast-feeding, when the child bite mother during breast-feeding, and breast-feeding for a long time); breast-related factors (putting money in brassiere, always wearing brassiere, fondling with breast during lovemaking, scratching of breast, and size of the breast); parity-related factors (multiparity, nulliparity, and menopause); health related factors (dirty habits, Guinea worm infestation, and careless about one's health); and mystical-related factors (attack from the "enemy" and wrath of God).

A study of Degner, et al. (2003) used the meaning of illness (MOI) instrument which describes eight categories of meaning of illness: challenge, enemy, punishment, weakness, relief, strategy, irreparable loss, and value to assess the meaning of illness of 1,012 Canadian women with breast cancer. Time since diagnosis was irrespective. After being asked to choose one of 8 categories which had the closest meaning as they perceive, the patients asked by researchers to explain why they chose those categories.

The findings described that majority of the patients (57.4%) chose "challenge" or "value" (27.6%) as the meaning of their cancers. The rest chose "enemy" (7.8%) or "irreparable loss" (3.9%) or other categories which were less than 2 percent. Those women, who perceived breast cancer as a challenge, perceived themselves as strong persons that had ability to overcome breast cancer and other challenges. Though they agreed the importance of support from husbands or children but they did not rely on them to maintain their strength of character.

Degner et al. (2003) reported the women who viewed breast cancer as a challenge when received diagnosis of breast cancer tried to compare this traumatic experience with any other significant experience of their lives such as losing child, death of beloved ones, divorce, or other serious problems. If they did not have significant traumativ event, they imagined something worse, for example how if they will lose their significant persons in their lives. The result of this process concluded that having breast cancer had made them to be stronger persons so that they can be role models for others by confronting their illness in a positive manner, and can have good lives and feel fortunate when they compare themselved with others.

Women who viewed breast cancer as a value perceived that the diagnosis of breast cancer had made them to look at their lives differently. They tried to reorder the priorities in their lives, considered their relationship with God, feel more sensitive to nature, and finally led to perceive each day as a precious commodity. They began to change their pattern of interaction with others, to become more assertive, confident, expressive, understanding, and more compassionate with others particularly who experiencing illness, and to improve relationship with husband and other family members. They also tried to focus more on themselves and to do things they wanted to do and to become spiritually stronger or morally strengthen. Unlike women who chose "challenge" as their meaning category and perceived that they had the character as strong persons before they had been diagnosed, these women were less sure of themselves and considered that the breast cancer played an important role in their personal development.

The women who perceived breast cancer as an enemy described the illness as an attack, a violation, or an invasion of their bodies. They thought they did not deserve breast cancer and that the illness had robbed their womanhood. They knew that they needed to fight the illness but they were not sure about their ability.

The women who perceived breast cancer as an "irreparable loss" were women who had experience of recurrence, who concerned of probability of recurrence and who concerned about dying. They worried about their family future after their deaths. Other women associated irreparable loss with loss of part of their bodies through surgery or loss of relationship with their husbands.

The women who perceived breast cancer as a weakness described that they had loss of control. They loss physical strength and failed to fight the illness or infection. On the other hand

women who perceived breast cancer as a punishment described that the illness is a result of being bad in past time of their lives, such as did not see mother in hospital during the last few days of her life, not having the kind of life they should have, etc. All the perceptions were speculations and it was not clear to what extent the women believed on their own stories.

Only very small number of women chose "relief" and "strategy" as meaning category of breast cancer. The women thought that breast cancer is positive to them because they are relieved from family or work responsibilities. Those who chose "strategy" also saw a positive meaning. They described that others are more attentive and watchful towards them since the development of breast cancer.

Degner et al. (2003) conducted a 3 year follow-up study of the 1,012 women who were within 6 months of their cancer diagnosis at the time of the first study. The sample in the follow-up study was 234 eligible women. This study aimed to see the changes in the meaning of breast cancer. The findings suggested that most of Canadian women in this study maintained positive meaning of breast cancer as challenge or value. Only a small number of women shifted meaning from positive to negative or vice versa. The women who perceived negative meaning at both time described that breast cancer as an enemy initially felt attacked and invaded, then came to see it as something to fight against in order to survive. Breast cancer as a weakness was associated with losing control over what was happening in their bodies and in relation to treatment. For punishment category, the women still felt breast cancer as something unfair to them.

Similar findings had come from Wallberg and colleagues (2003) who conducted study in Sweden with 187 women with breast cancer. Majority of the women chose challenge as the meaning of their breast cancer. The women in this study were asked to choose one of 8 meanings of illness categories as described in meaning of illness instrument. They were asked whether they need an explanation of one or more categories before choosing, in which case the research assistant would read the abbreviated interpretation to them. Otherwise the women would use their own interpretation and choose one of the meaning categories. It is quite different from the previous study (Degner et al., 2003) which asked all of the women to read through a brief description of each category before selecting one of category to describe their perception of breast cancer. When fourteen women did not find any of the categories that matched with their perception of breast cancer, they were not included in study.

The women in Wallberg and colleagues' study interpreted "challenge", "enemy", "irreparable loss", "punishment", "weakness", and 'value" congruently with Lipowski's conceptualization of meaning of illness (Lipowski, 1970 as cited in Degner, Hack, O'Neil, & Kristjanson, 2003). Two categories in this study namely "relief" and "strategy" were interpreted differently from Lipowski's by the women. The women interpreted "relief" as "to know what was wrong", "not to need radiotherapy", "to get rid of it", and "that it is over" whereas Lipowski described "relief" as They interpreted "strategy" as rest from responsibilities or demand when being well, or interpersonal crisis, or economic problem. The women interpreted "strategy" as attitudes of resistance and adjustment: "you have to consider–it means changes–think about how to handle situation" and "it is close to challenge" whereas Lipowski described "strategy" as a way to seek others' attention, support, or compliance.

Findings from both studies using the meaning of illness instrument to find out patients' perceptions of breast cancer in Canadian and Swedish women with breast cancer supported culture of western people which encourages fighting spirit. These findings also suggest the interpretation of words (the meaning categories) between researchers and patients might be different although both parties had used the same language and come from the same culture. It is important to clarify the words which patients use to describe their perception of breast cancer to prevent misinterpretation by researcher.

Kritpracha (2004) studied the influences of cognitive representations of breast cancer on emotional responses and coping in Thai women who newly diagnosed with breast cancer. The study was conducted in Thailand with 45 newly diagnosed breast cancer patients in early stage. The researcher used the 3CM (Conceptual Content Cognitive) method and Illness Perception Questionnaire (IPQ) to explore patients' cognitive representations of illness.

The findings of structures and contents of cognitive representations confirmed the components of illness perceptions (Lau & Hartman, 1983; Leventhal et al., 1982). There was a strong association between the disease labels and concrete symptoms and then the earliest role of symptoms created suspicion for an individual to discover the disease. Then, the finding explained that specific culture is an important source of information that can form cognitive representation.

The patients perceived that their illness will last a longer time or represent a more chronic time-line. Further, there were more consequences cited as a result of breast cancer, and

interestingly, there was a contradictory finding about the cure/controllability component. The 3CM method indicated that the majority of the patients perceived that breast cancer is not curable, but results from the IPQ suggested that the patients tended to perceive that their illness is curable. Findings from the 3CM method only partially supported the illness perception components (Lau & Hartman, 1983; Leventhal et al., 1982) where the time-line component did not arise but through this method the researcher found three other components, namely, emotion, social support, and coping. These findings suggest that there is a limitation of the IPQ and the 3CM method. Through the IPQ the patients need to choose concepts which were generated by researchers that might be not a part of their perceptions. Moreover, founders of the IPQ made this questionnaire based on their specific culture (western culture) which is really different from eastern culture where this study took place. Another thing, by using the 3CM method only, the researcher cannot find the detail of patients' illness perception. Therefore, additional interview based on results of patients' 3CM map was conducted in this study to make the researcher understands in depth the patients' illness perceptions.

Illness Perceptions in Muslim Culture

Islam is a culture and a complete way of life, a system to be followed, a code of ethics and a constitution to be applied in the daily life of Muslim (Athar, 1993 as cited in Rajaram & Rashidi, 1999). Muslims believe that all aspects of life are borne by religious teachings and they attempt to keep God as the center of of their consciousness, intentions, and actions (Shaikh, 2005, p. 10 as cited in Miklancie, 2007).

Someone's destiny has been ordained since creation but prayer can sometimes change destiny (Miklancie, 2007). Muslim patients understand that illness is a part of life and a test from Allah (God of Muslims) (Rassool, 2000). They consider illness as atonement for their sins and dying and suffering as a part of life. However, they are strongly encouraged to seek care and treatment (Athar, 1998). Health and illness is seen as a part of a continuum of being, and prayer keeps on the salvation in health and illness (Miklancie, 2007; Rassool, 2000). Muslims believe that God has a plan for each individual including life and death. According to death they believe it is the way to be reunited to God in heaven (Miklancie, 2007).

Khan (1986 as cited in Ashy, 1999) described that disease in Islamic culture is divided into four types: spiritual, functional, structural, and superficial. Spiritual disease is the most severe disease, for example schizophrenia. Functional disease is the disturbance which is manifested in imbalance of temperament. Structural disease is a disease which affects the size, number, or form of organs. Superficial disease is a disease of skin or hair and usually it hide an underlying disease.

Islamic cultural and religious practice mandates on gender and modesty consideration which include a requirement for women to cover their body since they reach puberty except their face and hands (Rajaram & Rashidi, 1999). Part of breast and other area of body of women with breast cancer are exposed during examination and treatment (intervention). Health care providers often are unaware of their discomfort due to this type of bodily exposure and they often may not be sensitive to their modesty requirement. However, this barrier can be overcome by giving special consideration to provide privacy. Another discomfort may arise when women receive care from health care providers of the opposite gender. Islam does not allow getting treatment from a care provider of the opposite gender, unless it is impossible to locate a health care provider of the same gender.

Women in Muslim culture have restricted access to health information outside their community (Rajaram & Rashidi, 1999). Women, particularly older women, are less likely to work outside the home due to traditional cultural norms and the high value placed on the role of women as mother and house-wife (Meleis & Hatter-Pollard, 1995 as cited in Rajaram & Rashidi, 1999). While illness perception reflects information-processing system, thus these issues may influence the formation of illness perceptions in Muslim women.

The practice of religion in many ways is helpful for health. For example, praying five times a day will help to reduce psychological stress and to keep structure and discipline in the life of individual. It also gives a chance to express feelings, hopes, and needs to Allah. It offers strength in times of hardships through belief in a powerful God (Ashy, 1999). Once a Muslim get sick, the family members and friends have a religious obligation to visit that person. Usually they bring foods and then pray for the ill person. The ill person must be taken care and pampered by other family members (Miklancie, 2007).

One study of Ali and Khalil (1996) in Egypt (predominantly Muslim country) with 99 Muslim Egyptians revealed that there is a social stigma about cancer where being diagnosed with cancer means death. Individuals who are diagnosed with cancer imply that they have done bad deeds in life and have not followed a straight path. For this reason, the health care professionals as well as the general public avoid using the term "cancer" in communication. The term "tumor" is commonly used by professionals; however, the phrase, "the bad disease" or "the serious disease" is commonly used by the general public. The informants expressed that it would be socially unacceptable and painful to disclose personal, family, or friends diagnosis with cancer. The informants were also asked in an open-ended question to describe the leading causes of cancer. There was a substantial awareness among informants that cigarette smoking and food pollution are the leading causes of cancer. Finding from this study also revealed that people had a great respect for physicians and they surrendered their minds and bodies to them, left the treatment decisions to physicians and did not argue or discuss with them. The physicians were perceived as the experts, and patients gave their faith to them to make the right medical decisions (Ali & Khalil, 1996).

The knowledge of the causes of breast cancer was found as the combination of modern biomedical views and traditional concept on 51 Arab women in Israel (Azaiza & Cohen, 2008). Most of the women were Muslim; three were Christian and one was Druze. They mentioned the hereditary factors, environment and the modern way of life such as cellular phone and antennas; air pollution; chemical in foods; a high-fat diet; and hormones in meat as the causes of breast cancer. A traditional view of the cause of breast cancer was the issue of an evil eye of envying neighbors emerged all together with modern causes. The women also perceived that giving birth and breast-feeding are protective factors against breast cancer. Some of the women perceived that breast cancer was a punishment for improper behavior when they lived out of the religion's commandments. Other than that the women viewed breast cancer as a test from God to see their patience as a part of God's love.

Indonesia is the world's largest Muslim country. Population of Indonesia in the year of 2000 was 206.3 million. Eighty-six percent of the population in Indonesia is Muslim and mean years of schooling is 7.3 (Statistics Indonesia, 2008). Indonesia is a developing country which is consisted of thirty provinces from many different islands (Statistics Indonesia, 2008). According

to WHO (2006), most of causes of death for Indonesian in 2002 were infection and cardiovascular disease. Cancer frequently is not perceived as a serious health problem in developing countries where the threat of infectious disease, perinatal or maternal mortality receives more attention (Ali & Khalil, 1996; Boffetta & Parkin, 1994).

The family and the women's roles in Muslim societies has been affected by various laws and cultures in different countries in addition to the social, economic, and financial factors (Sechzer, 2004). Indonesia has recently undergone a transition from an aggressively westernizing regime to one in part supported by traditionalist Islamists (Bahramitash, 2002). In Islamic traditional law, men are regarded as the head of the household and are responsible for family maintenance (required to pay *nafigah*, or housekeeping money, to their families) and the women play a role as a housewife to raise their children. In Indonesia, women employment is increasing per year (Bahramitash, 2002). It shows a change of roles of women in Indonesia particularly in a country with Muslim society.

No study has been conducted to explore patients' illness perceptions of breast cancer but there is one qualitative study that some part of findings described the meaning of illness as perceived by patients. It was conducted in Bandung, Indonesia to describe the lived experience of stroke survivors (Kosasih, 2004) which was applied on ten stroke survivors by using hermeneutic phenomenology approach. Four main themes occurred to describe meaning of being a stroke survivor. The first theme was being obedient to the doctor regarding the treatment of stroke. The second theme was regression to childlike status where the patients had many disabilities and could not perform their task independently. The third theme was being under supervision and assistance, and the last theme was being tested from Allah. Those findings mainly focus on the consequences and cause of illness. We can see from the findings there was a spirituality issue came up from the last theme which may different from other population. It explains the influence of culture in forming illness perception in different population.

Measurements of Illness Perceptions

Meaning of Illness Instrument

Degner, Hack, O'Neil, & Kristjanson (2003) developed Meaning of Illness (MOI) Instrument to assess patients' meaning of illness that can be applied in a large number of samples using a semi-structured measure. The instrument can be completed in a few minutes and consist of rich data about ascription of meaning in the context of cancer.

Degner and colleagues (2003) proposed the instrument based on the work of Canadian psychiatrist Z.J. Lipowski who suggested that coping strategies are directly related to the meaning of illness, injury, or disabilities (Lipowski, 1970 as cited in Degner, Hack, O'Neil, & Kristjanson, 2003). Further, Lipowski described eight categories for the meaning of illness particularly in North American culture. The categories are: (1) challenge, illness is perceived as tasks or any other life situations which need effort to be mastered by using available resources; (2) enemy, illness is perceived as opponent that invades from internal or external and need to be fought, or it also can be a feeling of helplessness and readiness to surrender; (3) punishment, in this category the illness is perceived as proper/improper or justice/unjustice to the individual; (4) weakness, illness is perceived as failure or feeling of loss of control or shame; (5) relief, illness is perceived as rest from responsibilities or demand when being well, or interpersonal crisis, or economic problem; (6) strategy, illness is perceived as a way to seek others' attention, support, or compliance; (7) irreparable loss, illness is perceived as a great loss that cannot be replaced; (8) value, illness is perceived as giving intrinsic value to someone or growing someone in some way.

Degner and colleagues (2003) used eight laminated cards which contained meaning categories as described before to assess the meaning of breast cancer of 1012 women with breast cancer. Each title of the meaning category was typed in a large typeface and then they were put randomly on a table in front of patients. The patients were asked to select one category which was closest to their meaning of breast cancer after they read through a brief description of each category. Next, the patients were asked to explain reasons for their selections. The statements were recorded in writing by researcher and then analyzed.

This instrument could capture meaning of illness of patients with breast cancer (Degner, Hack, O'Neil, & Kristjanson, 2003; Wallberg et al., 2004) and women with lung cancer (Sarna et al., 2005). All of those studies took place in western countries. Lipowski postulated the eight

categories for the meaning of illness based on culture of North American people which encourages fighting spirit and patients' roles in their illness. The categories may not fit with the eastern culture which is definitely different from western culture. Even in western population itself, study from Wallberg et al. (2004) found that some of Swedish women (7%) in their sample did not find any of the categories which matched with their perceptions of breast cancer. Therefore, using this instrument in Indonesian women might produce inadvertent biases because the culture of people in Indonesia is obviously different from people in western countries.

The Illness Perception Questionnaire

The illness perception questionnaire (IPQ) is one of instruments to assess individual's perception of their illness which was developed from the original work of Lau & Hartman (1983) and Leventhal et al. (1982). Previously, Leventhal and colleagues used open or semi-structured interviews to facilitate a deeper understanding of individual's illness perception but this method was time consuming and expensive to collect and analyze and difficult to be applied in large sample size.

The items in IPQ were theoretically derived to assess each component of illness perceptions (identity, cause, consequences, time-line, and cure/controllability). The internal consistency and test-retest reliability of the separate scales, concurrent, discriminative and predictive validity of the instrument are encouraging. Expected correlations were obtained between IPQ scales and established measures of disability, coping, self-rated health status and health distress (Weinman, Petrie, Moss-Morris, & Horne, 1996). Using this questionnaire in Indonesian population may force the informants to choose the concepts which are not a part of their perceptions because the IPQ was made based on the western population. Since culture is one significant factor which influences someone's perception to information, the researchers did not choose this questionnaire to be used in the present study.

The Conceptual Content Cognitive Map (3CM) Method

From the cognitive map concept which was explained previously, Kearney and Kaplan (1997) developed one methodology to capture cognitive structure and content in someone's mind map which is called the conceptual content cognitive map (3CM) method. In this method individuals are asked to identify the concepts that they believe are important to explain their view of particular issue and then are asked to organize each concept in a way that depicts how they

perceive the issue. The result will show a visual display which expresses an individual cognitive structure.

The 3CM method is a valid measure of cognitive structures and contents (Kearney & Kaplan, 1997). It can provide the environment which allows individuals to make contact with their knowledge and express it effectively. Since the 3CM method generates a kind of arrangement that is compatible with human information processing, then it appears to facilitate the thought process. The use of cards to externalize the thought process takes advantage for solving the problem of limited channel capacity of the mind. The cards allow individuals to generate and organize a large number of concepts without losing track of them.

The informants are asked to write down the important things across their minds on stickers when being asked to tell someone who is unfamiliar with breast cancer about the issue. Each idea is written on separate sticker. Then, the informants are asked to code each idea with a positive (good feeling) or negative (bad feeling) according to how they perceive it by themselves. They organize the ideas into groups and give a label to each group that describes the area of concern. They are free to add new items to the list any time and there is no restriction for the number of organization and no time limitation to complete the task.

The 3CM method is able to capture the structure of the informants' illness perceptions accurately while avoiding inadvertent biases that may be created by using a method that has not been normed in an Indonesian population. Further, in this method the researcher does not miss important concepts that are a part of the informants' perceptions. Thus, we can obtain an accurate account of the informants' illness perceptions. Therefore, researcher used the 3CM method as an instrument to assess illness perception of Indonesian women with breast cancer in this study. Additional interview was conducted following the 3CM method which was used to clarify contents of informants' illness perceptions and to find in-depth data regarding the contents from the 3CM.

In summary, the diagnosis of breast cancer threatens an individual's thought of both structures and contents. Only small number of studies conducted in breast cancer area and mostly used MOI instrument and IPQ to gather women's perception of breast cancer which have not been normed in an Indonesian population. This study uses a person-environment perspective that emphasizes the critical role that environments, which includes culture, play in the development of

illness perceptions. Based on this perspective, individuals build mental models that contain interactive components from the internal and external environment (Kaplan, 1983; Kearney & Kaplan, 1997). While a cancer diagnosis is a universally aversive, or incompatible environment, differences in illness perceptions develop in response to cancer among groups from different cultures.

CHAPTER 3

RESEARCH METHODOLOGY

Design of the Study

The descriptive study was conducted to explore illness perceptions of Indonesian women with breast cancer in Indonesia. The 3CM is a research instrument which falls somewhere between traditional quantitative and qualitative methods (Kearney & Kaplan, 1997).

Population

The population of this study was Indonesian women who were diagnosed with breast cancer in Palembang, Indonesia.

Sample

The sample of this study was recruited from the women who were diagnosed with breast cancer in Palembang, Indonesia. The number of sample was forty which was based on the sample size of similar prior studies that used the 3CM method (Kritpracha, 2004 & Lehto, 2004). It was a suitable number of sample size for this study because it was an exploratory study for a new population of study that never been studied before in Indonesia.

Forty Indonesian women with breast cancer who attended the health care service at Dr. Mohammad Hoesin Hospital in Palembang, Indonesia were recruited. It took two months for the recruitment of eligible informants who met the inclusion criteria. The inclusion criteria for the recruitment were as follows: (1) women who have been diagnosed with breast cancer and under primary treatment (treatment to treat the breast cancer itself); (2) age 18 years old and above; (3) able to communicate in Indonesian language or Palembangnese; (4) able to read and write in Indonesian or Palembangnese; (5) have no previous history of breast or other cancer; (6) no alteration of consciousness; (7) no cognitive impairment; and (8) able to provide voluntary consent.

Setting

The study took place in the Dr. Mohammad Hoesin Hospital in Palembang, Indonesia which is a regional government hospital in Palembang, South of Sumatera Province, Indonesia. This hospital   provides 877 beds which are distributed into 5 classes of service, namely Super VIP (7 beds), Utama (72 beds), Class I (99 beds), Class II (184 beds), and Class III (497 beds). The differences among those classes of service are the room and treatment facilities. The government of Indonesia provides health insurance for poor citizen which is called Jaminan Kesehatan Masyarakat (Jamkesmas). Cancer patients who use this insurance will be free of charge when they are hospitalized (in Class III ward). In Class III ward the patient must share one room with other 3 until 7 patients depends on the size of the room. The space between beds is approximately 1 meter. The insurance also includes medication, advanced diagnostic examination, and specialist clinic for consultation. Dr. Mohammad Hoesin Hospital also serves patients with this insurance from government. This hospital is also an education and medical and health science research hospital.

Patients with breast cancer usually come to the hospital to the general outpatient department and then referred to the breast cancer clinic. In this clinic the patients are examined and when further advanced diagnostic examination is needed the patients will be referred to the department which handles that examination. After diagnosing the patients, the physician will explain the plan for treatment to them. Breast cancer clinic in outpatient department is held once a week every Monday. No specific health education regarding to breast cancer or other specific activity for breast cancer petients.

Instrumentation

Instruments and Methods

The instruments and methods which were used in this study to capture illness perceptions of Indonesian women with breast cancer were as follows:

1. A demographic and health related data form was used to collect information including age, education level, years of education, marital status, number of children, number of family members in household, residential area, household income, insurance status, employment status,

occupation, religion, history of cancer in family, stage of breast cancer, type of treatment, time since diagnosis, and symptom experience.

2. The Conceptual Content Cognitive Map (3CM) method developed by Kearney and Kaplan (1997) used open-ended questions which were used to understand in-depth the important conceptions of the illness perceptions of informants who were diagnosed with breast cancer.

3. An interview method was conducted following the 3CM method to clarify and to find in-depth the contents of informants' illness perceptions. The informants were asked questions based on their responses that were listed by using the 3CM method. This interview aimed to increase the understanding of the researcher regarding the illness perceptions as provided by the Indonesian women who are facing breast cancer. During the interview, the researcher recorded new findings related to the 3CM content on a separate sheet of paper when the informants rejected being voice-recorded. At the end of the interview, the papers were affixed to the 3CM map.

4. A voice recorder was used for recording data in additional interview session.

Validity of the instruments

Construct validity from the 3CM method comes from the examination whether the method assess the construct it is meant to assess. High validity is indicated by the following (Kearney & Kaplan, 1997): (a) the measure performs in accordance with theoretically derived expectations; (b) the measure shows the expected relationships with other measures. Construct validity for this method has been established in healthy populations (Kearney & Kaplan, 1997), in new parents (Sink, 2001), in lung cancer patients (Lehto, 2004), and in breast cancer patients (Kritpracha, 2004).

The previous studies using the 3CM method suggested that the informants were able to differentiate idea that they "own" from they do not. The 3CM method facilitated discovery, as informants repeatedly comment on the utility of the process in helping them clarify their own understanding of the issue. The researcher also obtained this issue when applying the method in pilot study to one Thai female with breast cancer in Songklanagarind Hospital, Thailand. After completing the card arrangement the participant said that this technique help her to discover what was her main concerns due to her illness. The researcher also tried out the methods of this study with 1 Indonesian patient the actual data collection using Indonesian language. This pilot testing was considered as face validity of the method.

Translation of the instrument

The researcher translated the 3CM method into Indonesian language before applying to Indonesian women using back translation technique. Three bilingual translators who had ability in English and Indonesian language were in translating proccess of the 3CM method. The first bilingual translator translated the instrument from English version into Indonesian language. Then, the second bilingual translator translated the instrument from Indonesian version into an English version. Finally, the third bilingual translator evaluated, clarify, and discuss the discrepancy between the two versions with other translators.

Trustworthiness

In qualitative research, the concept of credibility, dependability, confirmability, and transferability have been used to describe various aspects of trustworthiness (Polit & Hungler, 1999; Graneheim & Lundman, 2004).

Credibility

Credibility refers to confidence in truth of the data meanings how well data and processes of analysis address the intended focus (Polit & Hungler, 1999). The researcher built trust relationship with the informants before assessing their illness perceptions. To gather the amount of data necessary to answer research question, the researcher used the 3CM method and additional interview. The researcher had done pilot study to assess illness perceptions of one Thai woman with breast cancer and also tested the method with 1 Indonesian woman with breast cancer. This would be considered as researcher credibility in assessing illness perceptions of Indonesian women with breast cancer.

Dependability

The dependability of qualitative data refers to the stability of data over time and over conditions (Polit & Hungler, 1999). In the present study the researcher transfered the findings to a tentative note and try to immerse with data. The researcher did not postpone time to clarify to patients when clarification was needed and member check technique was used by bringing the stickers (used in the 3CM method) that showed patients' statements when the researcher needed clarification of the patients' words or phrase. These showed the stability of the data over time.

Confirmability

Confirmability refers to the objectivity or neutrality of the data, such that there would be agreement between two or more independent people about data relevance or meaning (Polit & Hungler, 1999). In the present study the researcher sought agreement with 2 experts in Prince of Songkla University for analyzing the data.

Transferability

Transferability refers essentially to the generalizability of the data, meaning the extent to which the finding from the data can be transferred to other settings or groups (Lincoln & Guba, 1985 as cited in Polit & Hungler, 1999). The researcher had given a clear and distinct description of culture and context, selection and characteristic of informants, data collection and process of analysis.

Protection of Human Rights

The researcher asked approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University and Dr. Mohammad Hoesin Hospital before collecting data. When the proposal was approved, the researcher asked help from the nursing staff in Dr. Mohammad Hoesin Hospital to approach the potential informants who met the inclusion criteria of this study. The staff explained the study briefly, and then asked their permission verbally whether they agreed to participate in this study. Therefore, if the potential informants disagreed then the confidentiality of their diagnosis was still obtained.

When the potential informants agreed, the nurse informed to the researcher and the researcher approached to the potential informants, gave information verbally in detail to them about the purpose of the study, the plan procedure for gathering data, and the possible benefit of the study and risk to them.

The informants were informed that they were free to choose to participate or not to participate in this study, that they were free to withdraw from the study at any time with any reason. The researcher also assured the informants about their data confidentiality. Their anonymity was strictly protected, and also another data were protected. Then, the informants were asked to sign or verbally agree to the consent form before the data collection was performed.

There were minimal risks related to being in this study namely time spending, effort taken to answering the questions, and also this study might make informants think about some difficult things that may make them feel uneasy. It might develop psychological effects during doing 3CM method and interview because these methods would remind the informants about the issue of breast cancer diagnosis.

Plans were prepared if the risk happen to the informants. The plans included: (1) the researcher would stop gathering data at that moment; (2) be attentive to the participant's expressions and tried to understand what they were experiencing; (3) as a nurse, the researcher would try to alleviate the problems related to the psychological effects occurred.

By taking part of this study, the informants had an opportunity to think about important things that affect them and how they understand their illness. Their thoughts and concerns as a volunteer in this study could contribute to knowledge that might help improve understanding and care of future breast cancer survivors.

Data Collection Methods

The steps of data collection were as follows:

1. Preparation phase

    a.   The researcher asked for a letter from the Dean of the Faculty of Nursing Prince of Songkla University in Thailand for collecting data at Dr. Mohammad Hoesin Hospital in Palembang, Indonesia.

    b.   The researcher asked for permission from Dr. Mohammad Hoesin Hospital in Palembang, Indonesia.

    c.   The researcher explained to the Head of Research and Education Affair and staff at Dr. Mohammad Hoesin Hospital in Palembang, Indonesia, about the objectives of this study, the methods of data collection, and asked for cooperation.

2. Implementation phase

The steps of the implementation phase were as follows:

    a.   The staff identified potential informants who met the inclusion criteria.

    b.   The staff explained the study briefly to potential informants and then asked their permission verbally whether they agreed to participate in this study.

c. When the potential informants agreed, the nurse informed to the researcher and the researcher went directly to them, gave information verbally about the purpose of the study, the plan procedure for gathering data, and the possible benefit of the study and risk to them.

d. The potential informants were asked their consent by signing the informed-consent form or by giving verbally consent.

e. The researcher asked the informants questions of demographic and health related data and used medical record to complete all questions.

f. A private environment was provided as good as possible to facilitate thinking process of the informants while exploring the illness perceptions. The researcher also provided sticky notes and table to stick the sticky notes on it in front of the informants.

g. The informants were then asked to write down on the sticky notes anything across their minds when they were going to explain someone about breast cancer in separate notes. Every time after writing, the sticky notes were put on table in front of the informants. The informants then were asked to code each statement with positive (good feeling) or negative (bad feeling) sign according to how they feel about it, grouped them in a way that makes sense in their minds, and then labeled each group with word or phrase that describes the area of concern. Some informants asked for example how to label the group. Therefore, the researcher gave example how to label the group with some ideas which were not related to the issue of breast cancer. The informants were free to add more items at any time.

h. After finishing the 3CM method, which spent time for about 20 until 30 minutes, the informants were interviewed by the researcher and were voice recorded when they gave permission. The informants were asked questions based on their responses listed using the 3CM method. One difficulty occurred for specifying the probing questions at the additional interview session to refer to the final category of all informants because the researcher did not finalize the category of all informants yet at that moment. During the interview, the researcher recorded any new findings related to the 3CM content on a separate sheet of paper when the informants did not

grant voice recording. At the end of the interview, the papers were affixed to the 3CM map. The interview itself spent time between 30 until 180 minutes which vary depended on the informants' responses to the questions.

Data analysis

The researcher used descriptives, frequencies, and content analysis to analyze the 3CM and additional interview data. The steps of data analysis were described as follows (Graneheim & Lundman, 2004):

1) Selecting the unit of analysis. Unit of analysis is a whole interview that is large enough to be considered a whole and small enough to be possible to keep in mind as a context for the meaning unit (Graneheim & Lundman, 2004). Unit of analysis here was whole data gathered from 3CM and additional interview;

2) Selecting the meaning unit. Meaning unit defined as words, sentence, or paragraphs containing aspects related to each other through their content and context (Graneheim & Lundman, 2004);

3) Translating the meaning unit from Indonesian language into English. The researcher translated the data by herself and asked two other bilingual translators who were fluent in Indonesian and English to translate the Indonesian written data separately. The researcher also provided informations about the background of the informants to the other translators;

4) Comparing English version of data from three translators and then the researcher justified which translations that were closest to the real meaning of informants' perceptions;

5) Making sense of the data and learning what was going on and obtained sense of whole (Morse & Field, 1995; Tesch, 1990; Burnard, 1991 as cited in Elo & Kyngäs, 2008). The aim was to become immersed in the data;

6) Organizing the contents into descriptive categories. Findings from the interview were then analyzed to determine if they provided further substantive information about Indonesian women's illness perceptions related to diagnosis of breast cancer.The researcher compared data from one informant with others and then finally made an abstraction of the data. Abstraction means formulating a general description of the research topic through generating categories and then each category were named using content-characteristic words (Elo & Kyngäs, 2008). Three

informants were not able to make any groups of the contents gathered from the 3CM method although the researcher had given example how to make a group, therefore the researcher read and made sense of available data (3CM contents and additional interview) and compared the data with other informants' then made decision to put each content within appropriate category;

7) The contents in each 3CM map were counted to determine the extent (elaboration) of the cognitive structure;

8) Numbers of positive contents (rated as +) were counted;

9) Numbers of negative contents (rated as -) were counted;

10) The researcher asked two nursing experts faculty of Prince of Songkla University and discussed together to review and analyze the data until agreement achieved. This increased trustworthiness of the 3CM method in an Indonesian sample of women with breast cancer.

CHAPTER 4

RESULTS AND DISCUSSION

Results

This descriptive explorative study described the illness perceptions of forty Indonesian women with breast cancer in Palembang, South of Sumatera, Indonesia.

The findings are presented in two parts followed by tables and figures.

1. Demographic and health related data

2. Illness perceptions of Indonesian women with breast cancer

Demographic and Health Related Data

Majority of the informants were younger age of breast cancer survivors, year of education about 9.5 years, and were in the level of elementary school (40%). More than 75% were married and had more than 3 children with more than 4 family members living in household. Majority the informants lived in rural area with the household income per month less than or equal to Rp 750,000. Majority came to hospital to get treatment by using social insurance for poor citizen, being a home maker. All informants were Muslim. Majority of the women did not have history of cancer in family, being staged III breast cancer, underwent chemotherapy, were diagnosed less than 6 months and majority experienced 6 symptoms of breast cancer with the most frequent symptoms were: pulling sensation and hair loss (50%); numbness in chest wall or in the axillary area of upper arm and numbness or tingling of fingers and toes (47.5%); difficulty in sleeping (45%); and fatigue (42.5%) (Table 1).

Table 1

Demographic and health related data of the informants (N=40)

Variables	n	%	M (SD)	Min – Max
1. Age			48.3 (9.7)	31 – 73
2. Year of education			9.5 (4.0)	4 – 17
3. Level of education				
Elementary school	16	40		
Junior high school	7	17.5		
Senior high school	10	25		
Undergraduate	7	17.5		
4. Marital status				
Married	31	77.5		
Single/ widowed/ divorced/ separated	9	22.5		
5. Number of children			3.2 (1.9)	0 – 8
6. Number of family members in household			4.9 (1.8)	1 – 10
7. Residential area				
Rural	23	57.5		
Urban	17	42.5		
8. Household income per month				
Less than or equal to Rp 750,000	17	42.5		
Rp 751,000 – 1.5 million	11	27.5		
Rp 1.51 million – 2.5 million	8	20		
Rp 2.51 million – 3.5 million	2	5		
More than Rp 3.5 milion	2	5		
9. Insurance status				
Social insurance for poor citizen	29	72.5		
Government insurance	7	17.5		
Do not have any insurance	4	10		

Variables	$\underline{n}$	%	$\underline{M}$ (SD)	Min – Max
10. Employment status				
Employed outside home	7	17.5		
Housewife	19	47.5		
Retired	1	2.5		
Unemployed	13	32.5		
11. Religion				
Islam	40	100		
12. History of cancer in family				
Yes	11	27.5		
No	29	72.5		
13. Stage of breast cancer				
Stage I	2	5		
Stage II	11	27.5		
Stage III	23	57.5		
Stage IV	4	10		
14. Current treatment				
Mastectomy	8	20		
Chemotherapy	26	65		
Radiotherapy	4	10		
Hormone therapy	2	5		
15. Time since diagnosis (days)				
Less than 6 months	26	65		
Between 6 until 12 months	9	22.5		
Between 12 until 24 months	5	12.5		

Variables	n	%	M (SD)	Min – Max
16. Symptom experiences			5.9 (3.5)	0 -12
Fatigue	17	42.5		
Headache	8	20		
Difficulty in sleeping	18	45		
Feeling depressed or blue	2	5		
Feeling anxious and nervous	16	40		
Hot flushes or flushes	11	27.5		
Aching muscle and joint	14	35		
Backache	16	40		
Night sweat	4	10		
Numbness in the chest wall or in the axillary area of upper arm	19	47.5		
Feeling disfured and/or lopsided	12	30		
Pulling sensation	20	50		
Nausea	9	22.5		
Hair loss	20	50		
Numbness and tingling of fingers and toes	19	47.5		
Taste changes	9	22.5		
Difficulty in breathing	4	10		
Cough	2	5		
Pain in breast	10	25		
Weakness or paralysis of extremity	2	5		
Lymphedema of arm	5	12.5		

Illness Perceptions of Indonesian Women with Breast Cancer

Eighteen categories came up from the total contents (N = 309) which were gathered from the 3CM methods which described Indonesian women's perception of breast cancer consisted of positive and negative contents. However, after the researcher read and re-read each category, the contents, and the data from additional interview in detail, trying to make sense and comparing the data among each informants' data, finally the researcher found similarities and merged the 18-categories into seven categories. They are: (1) description of breast cancer, (2) causes, (3) consequences, (4) time-line, (5) cure/controllability, (6) coping, and (7) support (Figure 1). The seven categories which are revealed in this study reflect all the 18-categories as mentioned previously by the informants.
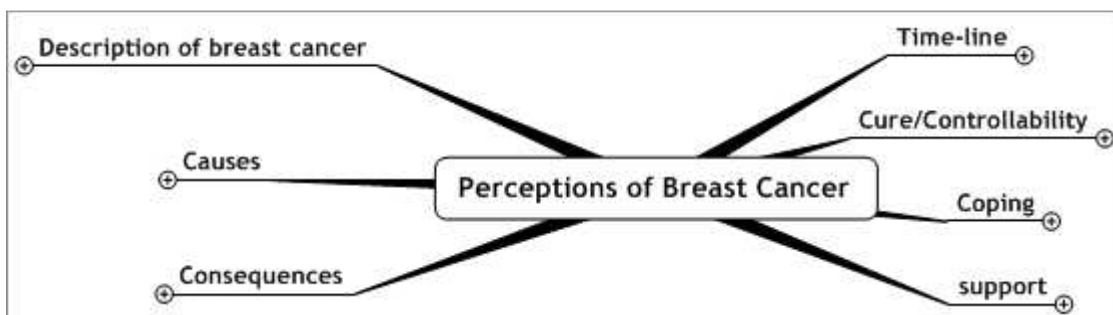

Figure 1 Perceptions of reast cancer

The categories were perceived by the informants generated positive and negative feelings to their mind with exceptions of some categories. The detail can be seen in Table 2. Among all categories, consequences of being sick with breast cancer and coping dominated the contents of informants' perceptions. Interestingly while consequences were perceived to create most of negative perceptions to informants' minds (50%), coping to breast cancer was perceived vice versa where more than half (56%) of informants decribed coping generated positive perceptions. The detail of contents within categories which were perceived as positive and negative are provided in Table 3 and 4.

Table 2

Frequency of all contents within categories

Category	Total content items (N = 309)	Positive (n = 107)	Negative (n = 202)
Description of breast cancer	40 (12.94%)	7 (6.54%)	33 (16.34%)
Causes	32 (10.36%)	0	32 (15.84%)
Consequences	115 (37.22%)	14 (13.08%)	101 (50%)
Time-line	6 (1.94%)	0	6 (2.97%)
Cure/controllability	25 (8.09%)	7 (6.54%)	18 (8.91%)
Coping	60 (19.42%)	60 (56.07%)	0
Support	31 (10.03%)	19 (17.76%)	12 (5.94%)

Table 3

Frequency of positively coded contents within categories (N = 107)

Category	Sub-category	n	%
Description of breast cancer (n = 7)	A test from God	6	85.7%
	A warning from God	1	14.3%
Consequences (n = 14)	Changes in life	9	64.3%
	Progress of disease	5	35.7%
Cure/controllability (n = 7)	Curability	4	57.14%
	Modality of treatment	3	42.86%
Coping (n = 60)	Cover some parts of body	7	11.67%
	Self-care to prevent recurrence	7	11.67%
	Seeking treatment	6	10%
	Religion	17	28.33%
	Positive reframing	13	21.67%
	Acceptance	2	3.33%
	Fighting spirit	8	13.33%
Support (n = 19)	Family	15	78.95%
	Neighbors	2	10.53%
	Religious-group	1	5.26%
	Being a supporter to others	1	5.26%

Table 4

Frequency of negatively coded contents within categories (N = 202)

Category	Sub-category	n	%
Description of breast cancer (n = 33)	A shame	1	3.03%
	A serious illness	2	6.06%
	A bitter life experience	3	9.09%
	A punishment from God	3	9.09%
	Physical sign and symptoms	24	72.73%
Causes (n = 32)	Modifiable	26	81.25%
	Unmodifiable	6	18.75%
Consequences (n = 101)	Changes in life	97	96.04%
	Progress of disease	4	3.96%
Time-line (n = 6)	Long-term illness	6	100%
Cure/controllability (n = 18)	Curability	3	16.67%
	Modality of treatment	15	83.33%
Support (n = 12)	Family	3	25%
	Health care provider	6	50%
	Neighbors	3	25%

Category 1: Description of breast cancer

The descriptions of breast cancer category reflected both positive and negative feeling of the informants. Positive feeling was brought by perceiving breast cancer as a test and a warning from God whereas breast cancer as a shame, a serious disease, a bitter life experience, a punishment from God, and physical sign and symptom of breast cancer were perceived carrying negative feeling to the informants. The detail of each subcategory will be presented as follows:

1.1 Breast cancer is a test from God

The informants perceived breast cancer was a part of love from God because God wanted to see how they responded to the illness and He would improve their status if they could deal with the illness patiently and sincerely. This idea is supported by the following statements:

> *"I accept the God's test by this illness. It shows kind of God's love to me because He will improve my status in front of Him as long as I am patient and accept this sincerely (P6)."*

> *"This illness is a test for me and my husband. God wants to see us whether we can accept it patiently (P34)."*

1.2 Breast cancer is a warning from God

Breast cancer was perceived a turning point to change to be a better person in life after committed sins for not being obedient with God's rules. Therefore, the informants named it as a warning from God. This issue is supported by the following statement:

> *"Allah warns me to apologize for my sins that I have committed because I usually teach Islamic religion to people, but I am not really close to God (P13)."*

1.3 Breast cancer is a shame

A woman with breast cancer was stigmatized as a bad woman. For that reason the informant described breast cancer is a shame which ought to be covered. This is supported by the statement as follow:

> *"I am embarrassed with my illness. It is a shame which I must cover. I don't want anyone think that I am not a good woman because usually someone who gets this disease is the one who has affair with men. In fact, I have always been loyal to my husband (P11)."*

1.4 Breast cancer is a serious disease

Breast cancer was perceived by the informants as a serious disease because of its life-threatening impacts and took a long time to deal with. The statements which support that idea are as follows:

"Breast cancer is not easy to be cured because it needs a long term treatment. More than that it is a serious disease and threatens life (P27)."

"This illness is very serious unlike others ... Other illnesss can be cured in a week but this one needs long time to be cured (P30)."

1.5 Breast cancer is a bitter life experience

The informant described life as a continuing condition consisted of sweet and bitter experience. She labled her disease as a bitter life experience where having breast cancer was perceived as unwanted condition in her life. This impression is supported by the statement below:

"I consider this disease as my bitter life experience. As we know each person has some part which is not smooth in her life. Sometimes we are on top but in another time we are at the bottom. Just like in my condition right now, I am at the bottom (P20)".

1.6 Breast cancer is a punishment from God

Being committed sins in life was described by the informants as the reason which made God angry with them. They thought God gave them this disease to punish them as the result of the sins. These ideas are supported by the following statements:

"I think this is a punishment from Allah for me because I used to leave my child for working when I was healthy and maybe it was also because of my arrogance of talents which I owned (P16)".

"It is possible that this illness is a punishment from Allah because maybe I committed a big sin in my past life unintentionally (P3)."

1.7 Sign and symptoms of breast cancer

Sign and symptoms of breast cancer as perceived by the informants consisted of physical changes, sensation, location, time occurrence, association between symptoms and severity of illness, precipitating factors, factor which increase severity. These ideas are supported by the following statements:

"I have felt the lump since long time ago in my right breast. At beginning it was only as small as quail's egg. I thought it was a common lump, not a disease ... like a lump you got after eating eggs, but the longer the bigger and it felt as bad as being bladed (P1)".

"I have been feeling numbness on my both hands and body for about 1 month. Maybe it happens because my illness is getting worse (P3).

"I would get throbbing pain on my left breast when I worked hard such as lifting up heavy stuffs. Perhaps it was caused by stretched tumor when I lifted up the heavy thing (P8)."

"The lump in my left breast is painful. It is throbbing pain and will be worse when I work hard (P32)".

In summary, Figure 2 depicts informants' perception of description of breast cancer category. Seven subcategories were perceived by the informants generated positive and negative feelings in their minds.
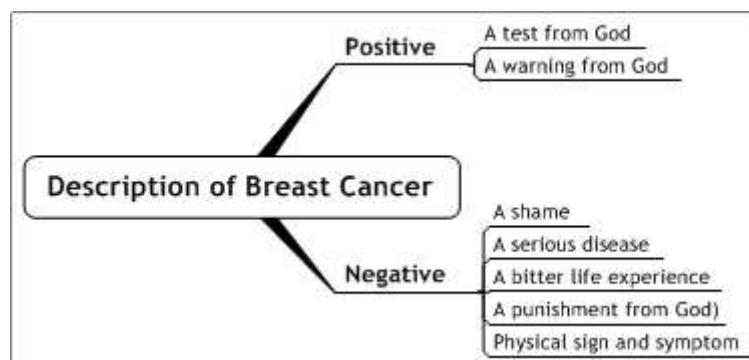

Figure 2: Description of breast cancer category

Category 2: Causes

The informants perceived several causes of breast cancer which were modifiable and unmodifiable. All causes were resulted in negative feelings to informants. The detail will be presented as follows:

2.1 Modifiable causes

Modifiable causes were perceived causes of breast cancer that were changeable. They were foods which contain additive ingredient to strengthen the taste and additive colors, farmed chicken, fatty foods, some kind of fruits, coffee, and chocholate. This information is supported by the statements as follows:

> *"If we can avoid chemical-contaminated foods and farmed-chicken then we will be safe from cancer including breast cancer. Chemical foods include additive ingredient to strengthen the taste (MSG) and additive colors (P8)."*

> *"Fatty foods which are like coconut milk can cause this disease ... (P30)."*

> *"I may not eat pineapple, durian, red meat, cabbage, jackfruit, mango, coffee, and chocolate because they caused and will make my illness become worse ... (P36)."*

Being under stressor and using birth-control shots were also perceived as the cause of breast cancer development. It is strengthen by the statements below:

> *"I think stress makes my disease become worse. Maybe that is the cause of my disease... (P33)."*

> *"After delivering the second baby I started to use birth-control shots and maybe that is the cause of the lump. Perhaps I am not compatible with the shots and have to change to other methods (P32)."*

Some behaviors in daily life were also perceived by the informants causing the development of breast cancer. They are pulling out the armpit hairs, wearing tight dress, wearing sponged bra, wearing bra during sleeping, being wicked to anyone, and smoking. This information is supported by the following statements:

> *"In my opinion the causes of breast cancer are pulling out the armpit hairs ... wearing tight dress, wearing bra with sponge, and wearing bra during sleeping (P27)."*

> *"I have never been wicked to anyone ... why me? Why not anyone else who is wicked? (P16)."*

> *"I have read that female smoker is predominantly to get cancer compared to female who does not smoke. I also smoke maximum 3 cigarettes per day (P8)."*

The rest, the informants perceived that germs, viruses, petrified milk which was described as stored milk because the informants did not breastfeed their babies for some reasons, and frozen blood which was described as bleeding inside breast caused by being hit incidentally by head of baby, door, or during have accident were also the cause of breast cancer. These ideas are supported by the following statements:

> *"I do not know what the cause is but maybe it was because I did not keep the hygiene of my right breast nicely so that the germs live there and caused the abnormality (P7)."*

> *"Breast cancer is caused by malignant viruses ... therefore I need chemotherapy to kill them totally (P12."*

> *"Breast cancer maybe caused by petrified milk. Petrified milk is hardening milk. When my youngest child was a baby, he did not want to suck my milk. So, maybe the milk was stored and become harder and then petrified ... (P9)."*

> *"I think the cause of my disease is the bleeding inside my breast. About 11 years ago my son's head hit my breast when I breast-fed him and it happened many times. Another thing is my breast happened hit a door too. Maybe the bleeding inside my breast led to develop a lump and then became a cancer (P34)."*

2.2 Unmodifiable causes

Unmodifiable causes were perceived causes which were unchangeable. They included gland, family history of cancer, and black magic. Here are the supported statements:

> *"The smaller lump can be treated with traditional healing with spoiled saliva because it can decrease the size of gland which causes cancer (P14)."*

> *"One of factors which cause cancer is history of cancer in family. So, when someone has family member who has cancer usually another family member will get cancer too. My father has tumor in intestine and my cousin also has breast cancer. Perhaps those are factors why I got cancer this time (P8)".*

"I went to see shaman for the treatment and he said that this illness was sent from someone who does not like me. I think it might happen in that way (P31)".

In summary, Figure 3 depicts the causes of breast cancer as perceived by the informants. All subcategories, namely modifiable and unmodiafiable causes, resulted in negative feelings to the informants. None of positive perception of causes of breast cancer emerged in this study.
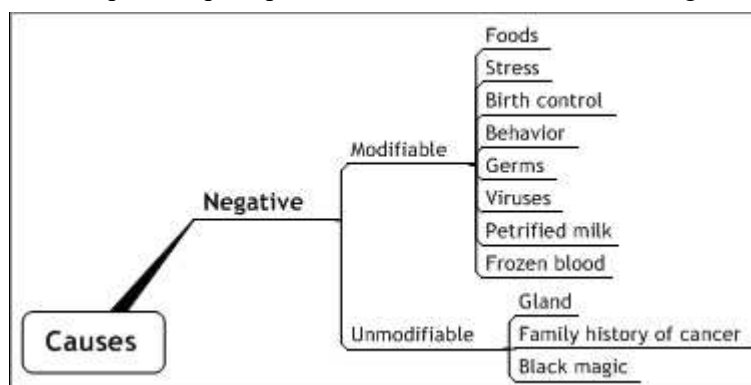

Figure 3: Causes category

Category 3: Consequences

The informants perceived changes of their lives and progress of disease as the consequences which ought to be faced after being diagnosed with breast cancer. Positive and negative feeling emerged in those both subcategories. The detail will be presented as follows:

3.1 Changes in life

The positive changes happened in terms of personal life, family, and psychological responses. The informants described that by being sick with breast cancer made them totally rest and gave them time for personal activities; breast cancer brought an improvement of relationship among family members and also with relatives; and breast cancer generated positive psychological responses which was feeling glad by the outcome of treatment. These ideas are supported by the following statements:

"This illness makes me totally rest ... I had worked hard to raise my children and take care of the family. I am getting older and this is the right time for me to rest now (P6)."

"I have time for my self because of the illness. I do not need to take care of the house and work anymore. Now, I can join the religious group activities, listen to the radio, or go outside for sightseeing. I never have time for those activities before I got sick (P6)".

"I feel the atmosphere of the house is calmer and each family member help one another (P17)".

"Before being sick, I was not really close to my husband's family. Since then, I have been closer to them (P5).

"I feel glad to see my breast now because the wound is dry since I got the first chemotherapy (P24)."

Negative changes of informants' lives were perceived in terms of social life, making burden, family disruption, physical impacts, financial problems, and negative psychological responses. The informants perceived by being sick with breast cancer limited their activity in social life due to hospitalization and breast cancer symptom experienced. As supported by the statements below:

"I usually join Islamic-learning group 2 times a week but have stopped for about a month because of the hospitalization (P28)."

"The blood spread to my dress so that the dress stinks of blood. I am reluctant to be close to anyone because of the stink (P28)."

Being sick with breast cancer was a perceived making burden to others due to leaving family for getting treatments in hospital and limitation of activity as an effect of breast cancer symptoms. The following statements support this idea:

"When I am admitted in the hospital, I have to leave my youngest child alone at home. My daughter takes care of him, but she cannot give full attention because she has her own family and lives in another house (P7)."

"I want to be able to sit and get up by myself. I make burden to others by being unable to move alone because my arm is very heavy (P31)."

The disruption of family harmony between informants and their spouses happened due to physical changes of women with breast cancer. The informants also mentioned about the presence of another woman in their marriage life after being sick with breast cancer. Moreover, side effects of treatments including chemotherapy and radiotherapy both during and after receiving treatments and losing breast from surgery created additional problems to women. These ideas are supported by the following statements:

"I feel meaningless in front of my husband because I am not perfect. He is not interested in me anymore because of my illness. My breast is wet, produces pus and putrid. He is reluctant to be close to me. I cannot make him happy with my condition right now. He gets angry and emotional easily. As a wife, I feel meaningless and our family is not perfect anymore (P2)."

"I have a thought that my husband may find another woman because he is still in young age. With my condition right now, I will not surprise if he has a mistress already. I cannot carry out my responsibility as a wife anymore, but I am sincere if he wants to marry another woman (P18)."

"I actually found improvement as a result of chemotherapy ..., nonetheless, I also experience many symptoms such as nausea, vomit, hair loss, blackish nails, and feel hot on body (P18)."

"Sometimes I feel my body is warm, nausea, and chilling, let alone after receiving radiotherapy (P4)."

"This illness is extremely difficult and excruciates women. I will not be perfect anymore as a woman. I am going to have my breast removed ... (P2)."

Finally, financial problems could not be avoided by the women with breast cancer which regarded to hospitalization and expensive treatments of breast cancer. The following statements support this idea:

"In past time I had paddy field and motorcycle, but they were sold to pay the treatment. All properties lasted for being sold out to get the treatment (P1).

"My husband has not worked since I am sick because he is accompanying me here. We do not have income when I am admitted in hospital (P19)."

In additon, some informants perceived psychological responses were created by lack of self-confidence as a result of the symptoms of breast cancer, physical changes, and social support. These ideas are supported by their statements as follows:

"I am easily to get offended now. Each time people whispered I thought they were talking about me. I thought maybe they were abhorrent with the smell from my breast because the wet wound has dried partly and it stank (P9).'

"I am shy to be in front of people. After undergoing surgery I use a wedded sponge into my bra, so that my breasts will be looked like normal (P12)."

"Neighbors came to my house giving me foods and fruits. They also gave some money for the treatment for me. I am so ashamed to be sympathized by them and have been considered as a poor person by them. I am offended by what they have done to me (P36)."

Shame was one issue which the informants repeated many times. They expressed losing femininity, body exposure, symptom experience, and being unable to fulfill responsibility. For losing femininity the informants described as being imperfect to be a woman when they had their breast removed and losing hairs as a result of the treatment. One informant described her feeling ashamed when the health care provider exposed her body during examination. These concepts are supported by the statements as follows:

"I am ashamed that as a woman I am not perfect anymore. I only have one breast and I am also bald ... (P18)."

"I am embarrassed. My hairs have dropped off since I received chemotherapy. I cried frequently because it is sad to lose everything. I lost my breast and then now I also have to lose my hairs but I cannot do anything ... (P24)."

"I am ashamed to open my dress and then examined by doctor. I am ashamed the doctor and others see my breast (P19)."

It is also supported by observation of researcher during gathering data from informants in the hospital. In the class III ward, where the patient must share one room with other 3 until 7 patients depends on the size of the room and the space between beds is approximately 1 meter, the

health care providers hardly used curtain or other equipment to maintain privacy of patients

during physical examination or when health care providers offered health care at bedsides.

The symptoms of breast cancer which were experienced by informants brought about

feeling ashamed to interact with other people. The last, being unable to fulfill responsibitily, both

as a wife and a mother, when having breast cancer was portrayed as the source of shame. These

impressions are supported by the statements below:

> *"I am ashamed to meet and chat with neighbors because of the stink of my wound, so that, I rarely go out from home since being sick (P33)."*

> *"I am ashamed of this disease, when the wound is wet, bad smell is coming out from it, that thing makes me less confidence when I close to people (P23)."*

> *"I am ashamed with my husband and others. I cannot do anything now. I cannot carry out my responsibility as a wife or take care of my child anymore (P16)."*

The informants mentioned their fears of death, progress of the disease, and the treatment

of breast cancer including surgery and chemotherapy created negative psychological responses to

them. This idea is supported by the following statements:

> *"I am scared of death. I am afraid this disease cannot be cured. I still have small children and husband to be taken care. If I die, who will take care of my family? (P1)."*

> *"I am scared of the peril of breast cancer. People say the cancer can spread throughout the whole body when it is getting severe (P12)."*

> *"Actually I have felt that I got lump since years ago. The fact is I was scared of surgery. If the doctor offered surgery, I wouldn't accept it. I am afraid of death when the surgery fails (P3)."*

Other psychological responses of having breast cancer perceived by the informants were

uncertain about the curability of cancer, about the next treatment regimen, and also about their

family lives. This issue is supported by the statements below:

> *"I am anxious with this illness, whether I am curable or not. I only can pray to God to recover from my illness (P29)."*

> *"I can not understand why this illness does not go out from my body, emm..I don't know what should I do next. Various therapies have been applied to remove the illness, yet they seem not to work properly, is there any best therapy available for such illness?"*

> *"What I am thinking now is my child. His age is still 7 year old. If only I die, with whom he will live. Who will take care of him? (P4)"*

Finally, being sad because the women could not take care of their children since they

were sick, getting bored with the treatment regimen, and feeling hopeless with breast cancer also

generated negative psychological responses to the informants. This is supported by the following statements:

> "I feel sad when I remember my child at home. I couldn't take care of him since I have been sick (P20)."

> "I feel bored to get treatment and being admitted in hospital … (P2)."

> "I have tried all the treatments including alternative medicine but the illness is getting worse. I had herbal therapy for 3 months, but it caused problem on my leg. It can't move. I also did not find significant improvement after undergoing the first chemotherapy. It seems this illness does not have its remedy. My mother died because of breast cancer (P16)."

3.2 Progress of the disease

Another consequence of having breast cancer as perceived by informants was a progress of disease. They perceived the progress both in positive and negative manner according to symptoms which were experienced at the moment data were gathered. These issues are supported by statements as follows:

> *I feel many improvements after receiving chemotherapy. The wound of surgery has dried and I never feel pain on my right breast anymore (P40).

> *I have had difficulty in breathing for a week, my left arm is getting bigger and also my left leg is also difficult to be moved now. I do not know why my condition became like this but maybe my disease is getting worse (P26).

Figure 4 portrays the consequences of breast cancer to the informants. They include changes in life and progress of the disease which brought positive and negative feeling to the informants' mind.
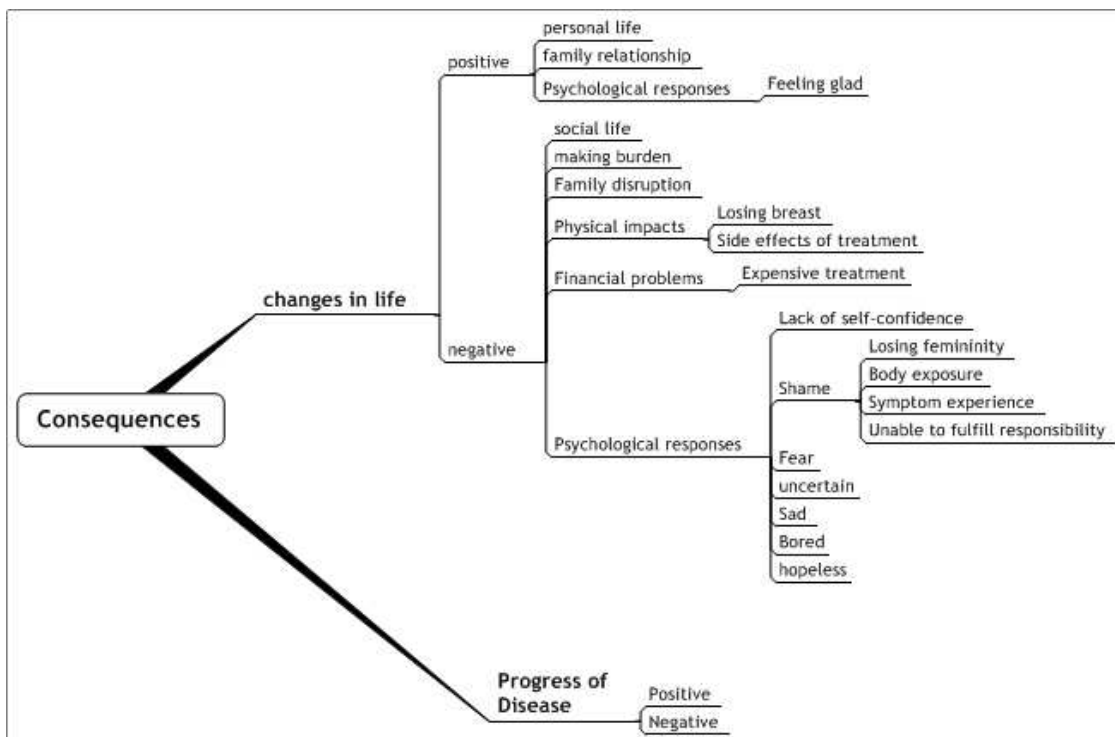
Figure 4: Consequences category

Category 4: Time-line

The informants perceived breast cancer as a chronic illness which needed long term

treatments as an effort to deal with it. All informants described this issue as negative perception

(Figure 5). Supporting statement is provided as follows:

> *"I have completed six cycles of chemotherapy within 6 months, moreover, I
> also have to undergo operation, check it regularly, and take medicine
> completely. I really have to be patient from this long-term suffering (P6)."*

> *"The chemotherapy takes a long time. I must receive chemotherapy every 21
> days for 6 times which means I have to be hospitalized and leave my children
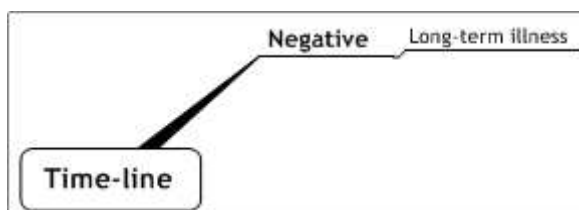> for that long (P34)."*

Figure 5: Time-line category

Category 5: Cure/Controllability

The cure/controllability category indicated the extent to which the informants believe their condition was amenable to cure or control by any treatment of breast cancer.

5.1 Curability

The informants described positive perceptions of this category when they perceived breast cancer was a curable disease and could be controlled by treatments. Negative perceptions regarding cure/controllability of breast cancer described breast cancer was an incurable disease and nothing to do to control this disease. These ideas are supported by statements below:

> *"Nowadays the treatments of breast cancer are advanced, so that we do not need to be worried. As long as we are not too late to get the treatments, I mean when the lump is small, then the chance to recover will be higher (P14)."*

> *"I have tried all the treatments including alternative medicine but the illness is getting worse ... It seems this illness does not have its remedy. My mother died because of breast cancer (P16)."*

5.2 Modality of the treatment

Getting along with treatments with two modalities consisted of medical and non-medical was perceived as an effort to control breast cancer. Some informants experienced non-medical treatments or traditional healing such as herbal therapy, acupuncture, reflection massage therapy, spoiled saliva, spelled water, batu giok therapy, dzikr therapy and others from folk healer or shaman prior to medical treatments. That happened because they believed in alternative treatments and afraid of medical procedure in hospital. After finding these treatments did not work then they started to seek medical treatments in hospital. These ideas are supported by statements as follows:

> *"I am scared and not ready for the surgery yet. Actually, I am scared of the operative room. Actually, I have noticed the lump since last year, but since I know surgery is usually administered for this illness then I looked for alternative medicine before seeing doctor. I got reflection massage therapy, but when the lump leaked I decided to see doctor because I thought the alternative medicine was not enough for my illness anymore (P11)."*

> *"I went to see shaman for the treatment and he said that this illness was sent from someone who does not like me. I think it might happen, so I followed the advice from the shaman to wipe my breast with my husband's black underwear everyday. Then, the lump became smaller since then. I came to the hospital because my left arm was swelling and difficult to move, but the doctor said that I had breast cancer. He said the swollen arm was also because of the cancer. I have to receive chemotherapy to treat this problem (P31)."*

Hence, all informants perceived non-medical treatment was negative after experiencing its outcome. From the previous information, it is clear that the informants perceived breast cancer could not be controlled by non-medical treatment.

Different findings from non-medical treatment when the informants perceived medical treatment was both positive and negative. They perceived it was positive because of the possibility to recover from breast cancer, on the other hand it was negative because they perceived the treatment aimed to treat severe cancer, thus they found that their condition was severe. These ideas are supported by statements below:

> " I went to go to see doctor and underwent surgery. Now I only have one breast, but actually it is fine for me as long as I can recover (P27)."

> "Chemotherapy is used to treat severe breast cancer. The patient does not need chemotherapy when the lump is small. I have received chemotherapy for 8 times and going to receive the 9th (P18)."

Figure 6 portrays the cure/controllability of breast cancer perceived by the informants. Two subcategories namely curability and modality of the treatment brought about positive and negative feeling to the women.
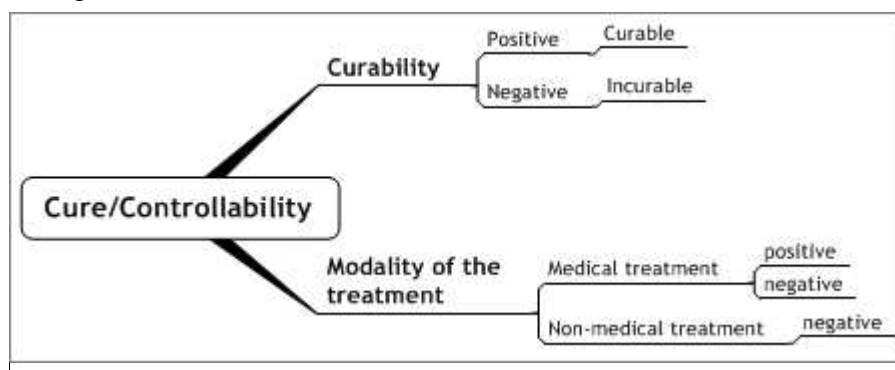

Figure 6: Cure/controllability category

Category 6: Coping

Seven subcategories arose from the informants' coping with breast cancer. These were: cover some parts of body; self-care to prevent recurrent; seeking treatment; religious practice; positive reframing; acceptance; and fighting spirit (Figure 7).

6.1 Cover some parts of the body

Covering some parts of body was an effort of the informants to deal with physical changes which was one of consequences of being diagnosed with breast cancer. They tried to cover their heads, which were mostly hairless because of the side effect of chemotherapy, with

hood. They also tried to put wad which was made from soft material into their brassiere, so that they would look normal. The statements to support these ideas are as follows:

"My hairs have dropped off since I received chemotherapy ... I, at last, bought a hood to cover my head, so that no one know I am bald (P24)."

"... I went to go to see doctor and underwent surgery. Now I only have one breast, but actually it is fine for me as long as I can recover. I still can hide the lost breast by putting wadded clothes into my brassiere when I go outside (P27)."

6.2 Self-care to prevent recurrent

Performing self care had been done regarding to an effort of the informants to prevent worse condition in the future. It consisted of performing breast examination, avoiding the causes of breast cancer, and maintaining personal hygiene. These ideas are supported by statements below:

"By performing self-breast examination each time when we take a bath then we will know early if there is an abnormality with our breasts. Therefore, we will recognize the lump since it is still small so that it will be easier to be cured (P8)."

"I have to avoid some foods so that the disease will not re- emerge again. I have to avoid chicken's stomach and liver, cow's meat and liver and also additive ingredient to strengthen the taste of food). Otherwise the disease will come back again (P39)."

6.3 Seeking treatment

Seeking treatment was described as an effort to recover from breast cancer. For some informants, it was also a part of overcoming the test from God, as they labeled breast cancer was a test from God previously. These ideas are supported by statements below:

"... I want to get treatment continuously until totally cured although it will take a long time, but the most important thing is I will be healthy and be able to do activity as before being sick (P17)."

"... I have to endeavor with the treatments of breast caner because He wants to see my efforts to face the test which is given by Him to His creature (P6)."

6.4 Religious practice

Religious practice was perceived as a means to getting along with God by praying, reciting God's names (dzikr), and being surrendered to God. This strategy brought about positive feelings to the informants. They felt calmer, being stronger and more patient to face the illness. The supporting statements are as follows:

"Before being sick with breast cancer, I seldom pray but since then my husband and I have started to be closer to God. It makes my heart is more calm and surrender to God's will (P4)."

"I always remember Allah while doing dzikr. I do so, to calm down my mind in order to be patience and able to adapt the reality of the incurable disease (P23)."

> *"... I am sure whatever happens later, it will be the best for me and my family from Allah. As a Muslim we have to accept everything which has been fated by Allah. I surrender to Him (P35)."*

Interestingly, the informants perceived active coping explicitly seeking treatments had to be accompanied with getting along with God by praying and being surrendered to His almighty. In their perceptions the one who could cure their illness was God with health care provider as the mediator. These ideas are supported with the statements as follows:

> *"I believe God is the owner of every thing including myself. It is very easy for Him when He allows me to recover from this illness. Besides surrendering myself to Him, I have to endeavor with the treatments because He wants to see my efforts to face the test which is given by Him to His creature (P6)."*

> *"I put efforts to seek the treatments and I also keep prayer to Allah because He is my lord and He is the only one who is able to cure this disease with doctor as mediator (P9)."*

> *"I have tried my best to get treatment. I wish God blesses upon me a recovery. I definitely depend on Him to cure me after taking treatment and pray to Him, and I believe He listens to my prayer (P20)."*

6.5 Positive reframing

Positive reframing was perceived as one coping strategy which brought about positive feelings to the informants by thinking positively about their condition at that time. They described by being sick with breast cancer their sins would be forgiven by God, trying to compare themselves with other patients and reliazed that they were in much better condition, and they also thought that they gained knowledge since being sick with breast cancer. Other informants tried to think about their family and recovering from breast cancer. To be together with family was perceived would bring happiness to the informants because of the support from family. Further, thinking about recovery from breast cancer also constructed positive feelings in their minds by reasons of discontinuing burden other people as a consequence of their condition. Another reason was by being recovered from breast cancer hopefully would bring back part of informant's life as before suffering from breast cancer.These impressions are supported by statements below:

> *"I am sure my sins will be forgiven when I am patient and sincere to accept this disease (P6)."*

> *"I met many patients from various backgrounds in government hospital. I realized that I am luckier than most of them because lots of patients here came late to get medical treatment because they lived in rural area or they did not have money for the treatment (P14)."*

> *"Now I know more about health matters. I become more careful of foods that I and my family usually eat every day ... (P21).*

"Even though my family is poor but as long as we are together I am happy. I only have simple foods to eat, but when my children are around, they can cheer me up and make me happy. They are meaningful to me (P3)."

"If it is still possible, I want to recover from my illness. The most important thing is I can walk and never burden my children and anyone else. I am so dependent on them right now which only make burdens to them (P3)."

"I wish one day I am able to work with catering again because I love to cook, but since I received chemotherapy I got tired easily. I wish to recover soon after the sixth chemotherapy (P40)."

6.6 Acceptance

The acceptance of being sick with breast cancer came by time after passing other coping strategy previously and as a human being they ought to accept any kind of illness given by God sincerely. This issue is supported by statement as follows:

"Previously, I used to wear breast imitation made from wadded cotton of underwear to form my breast in order to look normal, but now, I never do that anymore. I think, I am able to adapt the reality of my bodily appearance without any feelings of inferior (P21)."

"As a creature of God we have to accept all kind of illness sincerely. No need to regret anything. Crying is useless because we will not get well by doing that, therefore we have to be sincere to accept this (P38)."

6.7 Fighting spirit

All informants perceived fighting spirit, in terms of getting along with breast cancer treatments and having family as a source of spirit to deal with breast cancer treatments, created positive feelings to their minds. Getting along with treatments of breast cancer described their struggle to keep on continuing the treatments with all problems went along with it to reach the aim of recovering from breast cancer, whereas, thinking of family was perceived as the source of spirit to overcome the problems affected by breast cancer treatments. These impressions are supported by statements as follows:

"Sometimes I got bored when receiving the long treatment or I had another business at the same time of the schedule of treatment, so that the treatment ought to be postponed. I always remember I have to recover and have to fight this disease. I do not want to be a loser. Finally, I continue the treatment process until now. I will keep on continuing the treatment until it is complete (P10)."

"I will not give up and keep continuing my treatments although my financial is scattered. I will try all my best though I must borrow some money from others for the cost. The most important thing is my recovery. If I do not get the treatments, my disease will get worse and no one can take care of my children (P5)."

Figure 7 depicts seven coping strategies which were used by the informants to deal with their cancer. All coping strategies were perceived creating positive feeling to the informants' minds.
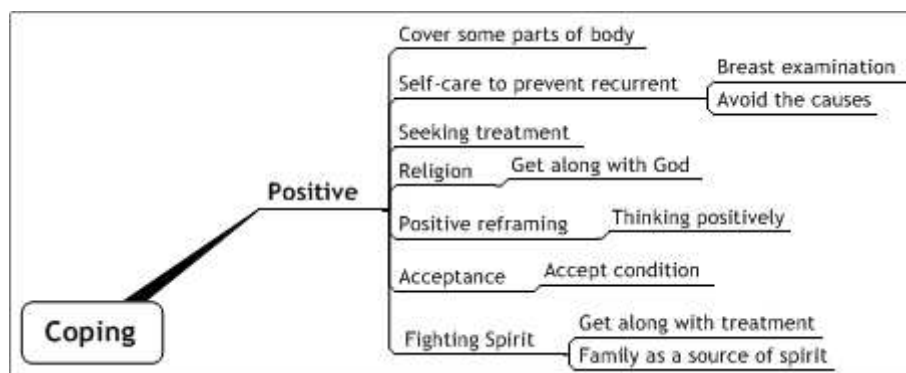

Figure 7: Coping category

Category 7: Support

Support was perceived by the informants as any actions which were given from others to women who suffer from breast cancer. In this category the informants described the sources of support namely family, health care provider, neighbors, religious-group, and the informant herself as a supporter to other patients.

7.1 The family support

Family was perceived as a source that could lessen the suffering of informants by providing material and spiritual support, hence they described family support as positive feeling. Conversely, one informant perceived support from family as negative because she described her husband and children tended to ignore her illness. Another informant perceived being accompanied by children at hospital, which was one of support, resulted in negative feeling because it caused another problem to the children. These ideas are supported by statements as follows:

> *"... My husband always takes and accompanies me to go to hospital. He pays attention closely on my needs. I think he loves and takes care of me. He does not let me down and desperate because of this disease. He knows that I do not like to go to doctor and hospital. That is why he always accompanies me (P17)."*

> *"... My relatives support my treatment cost and also my family needs. Otherwise, it would be impossible for me to come to hospital and get the treatment because I cannot afford it ... (P5)."*

> *"My husband does not care of my condition. He does not want to know that I am sick. He does not want to help me on work (P27)."*

"My children do not want to help me to work at home and they do not obey me (P27)."

"My children have not gone to school since I am admitted in the hospital … They want to see me and accompany me in the hospital … (P19)."

7.2 The health care provider support

In terms of support from health care provider, all informants described negative feelings due to some issues which were the lack of hospitality of health care provider, service differentiation and unsatisfied facility and information provided in hospital. The ideas are supported by statements below:

"I have to face unfriendly health care providers in the hospital. Well, I cannot do anything except accepting it because I am the third class patient, then I must deal with this condition (P27)."

"I have been here for 2 days already but no medical treatment since I came here. I have to clean my wound by myself … It is so different from the past time when I used my own money for the treatment comparing to now that I am using insurance from government for poor citizen (P36)."

"I do not have family in this city, so that when my relatives from village came to visit me then they have to sleep in hospital under my bed. I feel pity to see them suffer from cold (P19)."

"In my opinion cancer patients need to be given motivation from the health care providers. They also sometimes do not know what the next treatment is and are too reluctant and shy to ask to the doctors and nurses here (P14).

7.3 The neighbors support

Neighbors did not only support materially but also gave information about treatments of breast cancer which were perceived resulted in positive feeling to the informants. On the other hand, the support was percieved negative because some of neighbors gave inappropriate information regarding to breast cancer. These issues are supported by statements below:

"Neighbors in my village are so keen. The one who could not lend me money but willing to help gave me her dress in order I can use it while I am admitted in hospital in Palembang (P15)."

"… The sympathy also came from my neighbours who live near from my house. They informed me several kinds of treatment which they knew to cure cancer to me (P20)."

"The neighbors scared me. They said that my illness was incurable though I had surgery. I was influenced by them at that time. Therefore I tried to seek alternative medicine …but my illness became worse. Finally I went to see a doctor but the neighbors kept on influencing me … (P4)."

7.4 The religious-group support

Religious-group was also one source of support for the informant by encouraging her to

seek medical treatment in hospital. This is supported by statement below:

> *"Since I was sick, I have been actively join religious activities … My religious group-friends encouraged me to get medical treatment. Now I know who the real friends are (P4)."*

7.5 The patient's support

There was an interesting finding in this category which was one informant took a role as

a source of support to other patients during waiting for the treatment of breast cancer in hospital.

This issue is supported by statement below:

> *"I want to help and encourage other patients. I do hope other cancer patients do not give up and stop the treatments to achieve optimal cures as much as they can. I usually chatted with other patients when I was on queue during waiting for radiotherapy and encouraged them (P14)."*

Figure 8 represents the sources of support for the women with breast cancer consisting of

support from family, health care provider, neighbors, religios-group, and patients themselves.

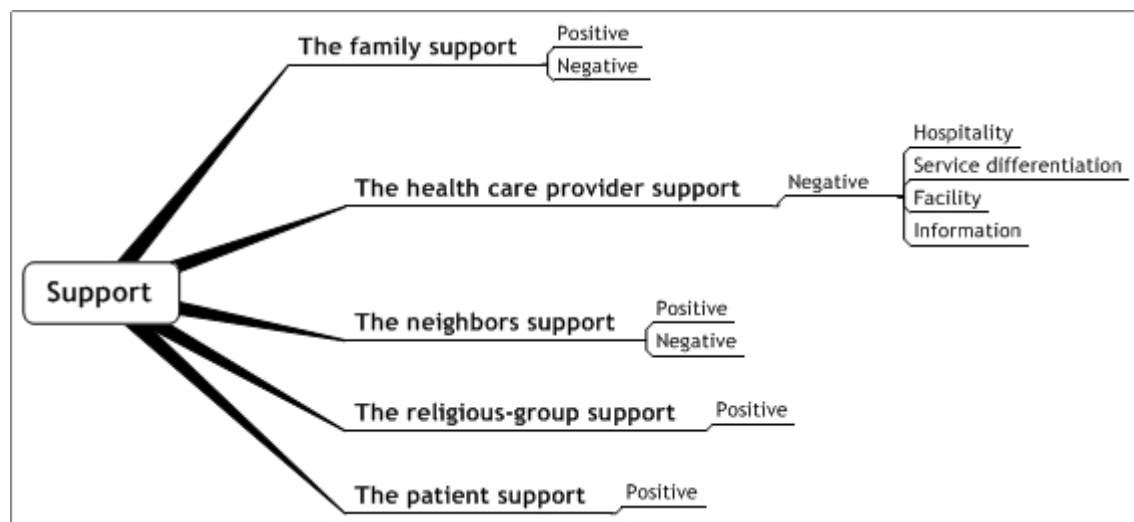This category led to positive and negative feeling to the informants.

Figure 8 Support category

Discussion

Characteristic of informants

Forty Indonesian women with breast cancer who were taking treatment in Dr. Mohammad Hoesin hospital, Palembang, Indonesia, participated in this study. The mean age of informants was 48.33 years old, ranging from 31 – 73 years old, comparable to the previous study which was 46.4 ± 9.7, ranging from 20 – 79 years old (Wakai, Dillon, Ohno, Prihartono, Budiningsih, and Ramli, et al., 2000). The mean year of their education was 9.5 years and the level of education for most of informants (40%) was elementary school which is comparable to the statistic of population in Indonesia where most of population (52.44%) was educated at elementary school level (SCB, 2006). The researcher found difficulty when applying the step of the 3CM method to 3 informants. Although the informants had been given some examples regarding how to label each group they had made to the items with a word or phrase to describe the area of their concern but they still could not make it. All those 3 informants were in elementry school level with 4 year of education. This information may support the influence of education in forming the more structured someone's cognition as Amtmann (1996) cited in Kearney & Kaplan (1997) suggested experts tended to have more structured arrangements (a greater number of concepts, more categories, and more clearly defined relationship between categories) than the novices' cognitive structures. Finally, the data showed that more than fifty-seven percent informants were living in rural area with 42.5% informants' household income per month was under Rp 750,000 or equal to approximately US$ 75 as compared to data from World Health Organization (2005) most of Indonesian (52%) were living in rural area with income US$ 710 per year.

Perceptions of breast cancer

The aim of this study was to describe the structures and the contents of illness perceptions of Indonesian women with breast cancer.

The structure of illness perception of Indonesian women with breast cancer

The structures of illness perceptions in this study described seven categories which consisted of description of breast cancer, causes, consequences, time-line, cure/controllability, coping, and support. It is interesting, beside the same findings with the illness perception in western country which suggested five components of illness perceptions namely identity, causes,

time-line, consequences, and cure/controllability as described by Lau and Hartman (1983) and Leventhal et al. (1982), the researchers found two more categories namely coping and support. Although the informants in the present study labled the first category as description of breast cancer but it has the same definition with identity component.

Leventhal and colleagues (1982) separated coping from illness perception. They described coping as further stage of information processing system after the stage of interpretation of illness where the perception of illness activated. The stage of coping is also called stage of action planning where the appropriate responses to the health information, in this case is breast cancer diagnosis, are generated and excuted. Coping in the present study was defined as behavioral and emotional processes to resolve the uncomfortable feeling associated with breast cancer. Once the informants thought about the uncomfortable feeling regarding to breast cancer, it would trigger them directly to think about what they did to response the uncomfortable feeling. It shows that coping is an integration part of the informants' perception of illness. The findings of this study are in accord with Kritpracha's (2004) which found three additional components of illness perceptions consisted of emotion, coping, and social support. Emotion in Kritpracha's study emerged as a new component of illness perceptions whereas Leventhal and colleagues (1982) separated it into another construction of self-regulatory system which described the subjective informational process of event. In present study the psychological responses or emotion was included in consequences category because the informants perceived it as a part of the impacts which they got by being sick with breast cancer.

Most of the women in the present study mentioned about the consequences of being diagnosed with breast cancer (37.2%) as the most frequent issue came to their minds (Table 2). When consequences of being diagnosed with breast cancer was perceived as the one which brought the most negative feeling to the informants (Table 4) including the changes in life (96%), the women perceived coping, mainly religious practice (28.3%) and positive reframing (21.7%), as the most category which brought positive feeling to them (Table 3). These findings can be used by health care providers to support patients in the hospital to survive with their illness by considering the religious approach and positive reframing in order the women can cope with their illness. Involvement of support system of the patients is also needed as the informants in this

study mentioned that support from family, neighbors, religious-group and other patient generated positive feeling to them (Table 3).

From the data gathered by 3CM method and additonal interview, the researcher has uncovered some relationships among categories. The way how the informants labeled breast cancer in their minds in the description of breast cancer category influenced the way they coped with breast cancer. For example, when the women perceived breast cancer was a test, a warning, or a punishment from God, they then tried to cope by using the religious approach. Perceived causes of breast cancer also seemed influence perceived coping and perceived cure/controllability. For example, when the women perceived the cause of breast cancer was germs, they tried to cope by doing self-care by maintaining hygienity of their breast to prevent recurrence of breast cancer, or when the women perceived the cause of breast cancer was not biomedically associated then they would look for non-medical treatment to control their illness.

Perceived consequences of disesase was associated with how the women labeled breast cancer in the description of breast cancer category. For example, when the women experienced lots of physical and psychological impacts from breast cancer, they labeled breast cancer as a serious disease. A perceived consequence of breast cancer also has relationship with cure/controllability category. When the women felt the progress of the disease was positive they thought their disease was controllable and might be cured and vice versa. Time-line category also has relationship with the description of breast cancer category. When the women perceived breast cancer is a chronic illness and take a long time to deal with, then they would perceive breast cancer as a serious illness. The last, support category has relationship with women's coping. Support was perceived by the informants could enhance their coping. For example, when the neighbors as one source of support gave information about treatment of breast cancer, the women then were supported to seek that treatment to deal with breast cancer. However, need further study to measure the significance correlations among these categories.

The contents of illness perception of Indonesian women with breast cancer

The description of breast cancer category in this study was defined by informants as the label and the signs or symptoms those appear to go with breast cancer. The findings showed the influence of culture in constructing informants' perception of illness. This is an accord with Angel and Thoits (1987) which suggested that culture constrains the perceptual, explanatory, and behavioral options in response to an individual's illness. As all informants were Muslim, they labeled breast cancer as test, a warning, and a punishment from God. This is in line with Rasool (2000) that mentioned Muslim patients understand that illness is a part of life and a test from Allah. Athar (1998) stated that Muslim patients consider an illness as atonement for their sins but they are strongly encouraged to seek medical treatment.

The informants were also influenced by stigma in their community regarding to breast cancer which was being sick with breast cancer was labeled as a bad woman. Therefore they perceived breast cancer as a shame which ought to be covered to maintain their social life. Previous research also found that cancer patients were sometimes felt stigmatized and this condition was perceived affected patients' relationship to family, friends, and doctors (Sarna et al., 2005).

Physical sign and symptom was a big issue as reflected by informants (75%) within description of breast cancer category. The informants tried to define their illness by relating symptoms experienced with the breast cancer diagnosis. As mentioned by Bishop (1991), when people process the illness information, they will do their best to relate symptoms to a given disease entity and, when successful, they make association to the overall set of symptoms.

The cause category was defined as all of informants' ideas about the possible causes of breast cancer. The informants tried hard to make sense of their illness by searching for explanation of the cause. They mentioned foods, stress, birth-control which refered to hormone, and petrified milk which was defined as having milk stored in breast because they did not breastfeed their babies, as the causes of their illness. These findings were in line with study from Kritpracha (2004) which was conducted on Thai women with breast cancer. One informant mentioned the cause of her illness was wearing bra during sleeping and another one perceived black magic as the cause of her illness. She tried to consult her illness with shaman for the treatment and being told the illness came from someone who did not like her. Since she believed

it then she followed followed the advice from the shaman to wipe her breast with her husband's black underwear everyday. These findings were in line with study from Oluwatosin (2006) about rural women's perception of breast cancer in Ibadan, Nigeria, which mentioned those two factors as breast-related factor and mystical-related factor. Other findings which were not found from previous study were being wicked to others, smoking behaviour, pulling out the armpit hairs, wearing tight dress, and wearing bra with sponge. Those findings supported Cameron and Moss-Morris (2004) study which proposed there is no difference between mind and body, self and others, human and environment, and science and spirituality particularly in Asian culture. The findings of causes of breast cancer category suggested the need of accurate information regarding to the causes of breast cancer from health care providers.

The consequences category was defined as physical and psychological impact or changes which happened as a result of being sick with breast cancer. It consisted of changes in life and progress of the disease. Positive changes in life in terms of personal life and family described the value of breast cancer to relieve the informants from their responsibility and also as a strategy to improve relationship in family. These ideas were in accord with the meaning illness from women with breast cancer in the study of Degner, Hack, O'Neil, & Kristjanson (2003). Being sick with breast cancer limited the informants' activity in social life. The problems came from the schedule of getting treatment from hospital and occurance of symptoms of breast cancer. In addition, psychological responses when the informants see the progress of their symptoms of breast cancer also brought positive consequences for them.

Financial problem regarding to high cost of breast cancer treatment was a big issue. Although 72.5% of informants used social insurance for poor citizen from government but they still had difficulty to prepare money for their children at home during hospitalization when they received treatment of breast cancer. They also needed money for transportation which was perceived expensive since most of them lived in rural area (57.5%) with low household income per month. One study of Kiatlaekakul (2005) among Thai population suggested lower cognitive status, where perception was presented as one domain of cognitive status in this study, is significantly associated with lower financial income. The facts that findings from this study described more than fifty-seven percent of informants were diagnosed with stage-III breast cancer and majority needed chemotherapy for the treatments of breast cancer and the trend of cancer

disease always increases every year suggested the need of breast cancer prevention and early detection program in Indonesian population so that the health curative expenses can be supresed.

Breast cancer was perceived by informants created negative impacts by making burden to others and generated family disruption. When the women were hospitalized for getting treatment, they felt like making burden to others because they had to leave their children to others to be taken care. They felt ashamed for this. They also worried about their children's future. According to Degner et al. (2003) this issue was described as "irreparable loss" where the women concerned about dying and worried about family future. Further, in this study the women thought that they could not fulfill their responsibility as a wife which caused family disruption. Some of the informants even mentioned about the presence of another woman in their marriage life as a result of this issue. Study from Holmberg, Scott, Alexy, and Fife (2001) revealed that male partners of women with breast cancer described the fear and anxiety associated with anticipated loss of their partners. Another thing which was not less important as mentioned by male partners was the changes in sexual functioning that occurred in the relationship. These problems might also arise because Muslim traditional culture places women roles as a mother and home-maker (Meleis & Hatter-Pollard, 1995 as cited in Rajaram & Rashidi, 1999). It also might happen because of the patriarchal marital beliefs in Muslim culture when some of men misinterpret Islam view women as their property (Rajaram & Rashidi, 1999), therefore the husbands used this issue as a reason of their reaction which generated family disharmony. In addition, breast cancer also made burden to the women themselves because by having breast cancer meant they had to maintain extra self-care like clean the wound every day and need to be careful when having bath. The findings suggested the need of spouse participation during health promotion of breast cancer with a religious and socio-cultural context.

Breast cancer gave physical impacts to women in terms of losing breasts by surgery and experiencing side effects of the treatment. The informants experienced hairloss (50%), pulling sensation on the area of their chest (50%), numbness on the chest wall or in the axillary area of the upper arm (47.5%), and numbness and tingling of fingers and toes (47.5%). As informed before that most of the women in this study were in the stage of III breast cancer diagnosis (57.5%) where the main treatment they got was chemotherapy (65%) after experiencing mastectomy previously, the findings of the symptom experiences were in accord to the previous

study which described that the women underwent surgical incision of primary lession and adjuvant chemotherapy mainly complained numbness in the chest wall, in the axillary area, or in the upper arm area, and also pulling sensation (Boehmke & Dickerson, 2005). Further they also revealed that women who underwent chemotherapy using Paclitaxel (Taxol), which was the same drug used for chemotherapy in the present study, experienced numbness and tingling of their fingers and toes. The researchers found the women in the present study used symptom experiences to monitor monitor the progress of the disease and to evaluate the treatment they got. This finding supported by Meyer, Leventhal and Gutmann (1985) as cited in Baumann & Keller (1991) who found that people will use symptoms they experience to to monitor the disease state and also used to evaluate the progress in controlling it.

Since breast was perceived by informants as a symbol of femininity, losing breast by surgery made the informants felt no more perfect and attractive as a woman. Hair loss (50%) as a side effect of treatment which was experienced by the informants also perceived as another source of losing women femininity for women with breast cancer. According to Degner et al. (2003) these ideas described the informants perceived breast cancer as an enemy where the illness had robbed their womenhood. These issues brought about feeling of ashamed of informants to physical appearance and influenced their social life. The findings are in accord with study from Landmark & Wahl (2002). The study revealed that losing breast can change the women's perception of her own body, changes in the way she experiences and understands herself, and changes in her experience and understanding of relationships with others. More than that the women felt ashamed to interact with other people because of the symptoms experienced such wound on their breasts which were wet and produced bad smell.

The exposure of body during the women were hospitalized in hospital was described as an embarrassing moment. In Muslim culture, after reaching puberty, women are required to cover their bodies except face and hands. To be exposed for medical purpose is allowed as long as privacy is maintained (Rajaram & Rashidi, 1999). Although it is allowed sometimes the women feel discomfort regarding to modesty requirement in Islam. Therefore, it is an important issue to provide privacy when dealing with Muslim women during medical examination or administering health care.

The findings revealed negative psychological responses as the most frequent negative consequences of breast cancer (46.53%). This issue might happen because majority of informants were diagnosed less than six months (65%) and between 6 – 12 months (22.5%). This finding is in line with study from Burgess, et al. (2005) which suggested the earlier time after diagnosis of breast cancer was reported the more psychological problem experienced namely depression and anxiety. Another factor which may generate high frequent of negative psychological responses, according to Millar et al. (2005), is perceived high impact of symptoms. The more informants perceived impact of symptoms, the more distress occurred. Similar findings from Kritpracha's (2004) which suggested the more symptoms experienced, the more overall mood disturbances experienced by informants. In this study the informants described side effects of treatment and losing breast as the physical impacts of breast cancer which counted more than forty percent of negative consequences category.

The time-line category was defined as the duration of breast cancer would last as expected by informants. All informants who mentioned time-line category perceived breast cancer was a long-term illness. This issue might appear because some informants had spent time trying non-medical treatment prior to medical treatment in hospital. They also had undergone surgery and several cycles of chemotherapy. Time-line category was the one with the least frequent content items. This might be because this category was not salient in the early time period in women with breast cancer since majority of women were diagnosed less than 6 months. This result is in accord with study from Kritpracha (2004) which found the women with breast cancer tended to perceive their illness would last a longer time which representing a more chronic time-line. The same study also reported the more women perceived their illness would last for a longer duration, the greater psychological problems they experienced. Hence, in this study the negative psychological responses as the consequences of breast cancer may be developed by informants' perception of breast cancer as a chronic illness.

The cure/controllability category indicated the extent to which the informants believe their condition was amenable to cure or control. This study found that informants perceived breast cancer was both curable and incurable. The contents suggested past experience particularly family history of breast cancer took roles to construct of negative perception of cure/controllability where the informants perceived breast cancer was incurable. Rees, et al. (2001) suggested the

experience of women with a family history of breast cancer were likely to have impact on perception of cure and controllability. Zakowski, et al. (1997) revealed women whose parents had died of cancer had the highest level of intrusive thoughts. Therefore, it is necessary for nurses to assess patients' family history of cancer and find out what kind of experience they have faced regarding to this issue to their family.

Coping was defined as behavioural and emotional processes to resolve the uncomfortable feeling associated with breast cancer. Majority of informants used religious practice (28.33%) to cope with breast cancer. As all informants were Muslim then they used Islamic teaching as their guidance. Praying, reciting God's names (dzikr), and being surrendered to God were perceived helped them to cope with breast cancer resulted in feeling of calm, increased spirit to get along with treatments of breast cancer, and increase the acceptance of illness. Carone, Jr. and Barone (2001) described that religious beliefs can provide order and understanding to a chaotic and unpredictable world by justifying control by powerful of God. Religious beliefs allow people to maintain hope and regulate negative emotions when no coping strategy seems possible. The informants also used positive reframing where they tried to think the positive side of being sick with breast cancer. The positive thinking was associated with the way they labeled breast cancer. For example when the informants labeled breast cancer as a punishment from God because of their sins in past, then they tried to cope by thinking that God would forgive their since when they were patient and sincere to accept the illness. The findings are in line with Taleghani, Yekta, & Nasrabadi (2006) who conducted study in 19 women with breast cancer in Iran (predominantly Muslim country). The study described that majority of the women used religious approach and think about the illness positively. Study from Chiu (2000) who conducted study with 15 Taiwanese women with breast cancer regarding their experience of spirituality also suppoerted the findings in present study. The women in that study mentioned they gained power from their relationship with God to deal with their sickness and difficulties because they believed God was a source of power. The findings regarding coping category suggested the importance of nurses to undestand role of religion for Indonesian women with breast cancer to cope with their illness. Religion coping strategy is recommended since majority of informants perceived this strategy created positive feeling to them.

Support seemed to be one of dominant category gathered from the 3CM method and additional interview. Family support was perceived by majority of informants (78.95%) created positive feeling to their minds. Family could lessen the suffering by providing material and spiritual support. This finding is consistent with study from Chiu (2000) which described relationship with others particularly family were described by informants as very important in supporting then through hard times of the disease. In general, Nosarti, Roberts, Crayford, McKenzie, & David (2002) revealed the presence of social support is associated with the adjustment in the first year following a breast cancer diagnosis. One interesting finding in this category was availability of one informant to be a source of support for other women who were sick with breast cancer. Study from Chiu (2000) also found the same issue. The women perceived showing compassion for those who were suffering and being willing to help meant helping their own selves.

The findings of this study also support the meaning of illness categories (Lipowski, 1970 as cited in Degner et al., 2003). Only one of eight categories of meaning of illness was not found in this study which was breast cancer perceived as a challenge, the rests (enemy, punishment, weakness, relief, strategy, irreparable loss, and value) were included in the content of seven categories of illness perception in present study. The women who perceived breast cancer is a challenge in the Degner and colleagues' study (2003) recalled female role models in their family who had influenced them to showing strength in the face of adversity. Comparing to Indonesian culture where in Indonesian female role models showing weakness in front of other people is allowed but for male role models, they must show their strength to face any hurdles in life and cannot present themselves as a weak person.

In summary, the findings from the present study support the components of illness perception in western country but the detail of each category which is called the contents of illness perceptions are different. Present study demonstrated the integration of illness perception, psychological responses or emotion and coping. The findings also described the uniqueness of culture which also includes religion, past experience, environment, and symptoms experienced take role in constructing Indonesian women's perceptions of breast cancer. The whole picture of findings of illness perceptions of Indonesian women with breast cancer can be seen in Figure 9.
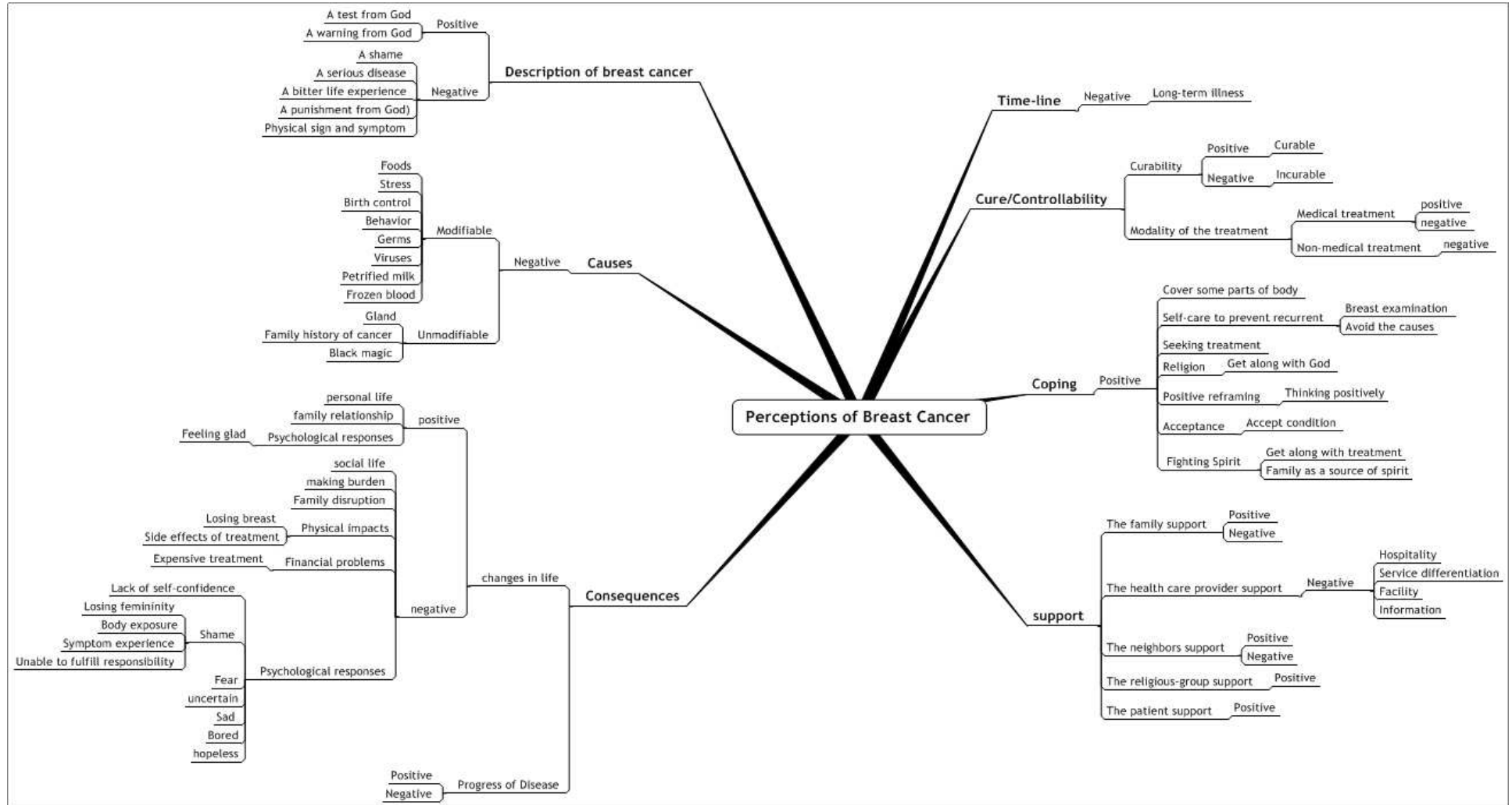
Figure 9 Structures and contents of perceptions of breast cancer

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

A descriptive study was designed to explore illness perceptions of Indonesian women with breast cancer in Indonesia. This study was conducted in regional government hospital of Palembang, Indonesia with forty informants' participation. Data were collected from November to December 2008. The informants were asked to complete the 3CM method and then they were interviewed to clarify the contents of informants' illness perceptions. The informants were asked questions based on their responses that were listed using the 3CM method. The 3CM method was translated into Indonesian language from English using back translation technique. The gathered data were analyzed by using content analysis technique. The results came up with the agreement of researcher with two nursing experts from Prince of Songkla University.

Summary of the Study Findings

Forty breast cancer survivors were involved in this study as informants; majority of them were of younger age and experienced education about 9.5 year; majority of them had junior high school level of education. Most of them were living in rural area with the household income per month less than or equal to Rp 750,000 (US$ 75) and being a homemaker. All informants were Muslim. Majority of them were in the third stage of breast cancer, were under chemotherapy, and were diagnosed with breast cancer less than 6 months before.

Illness perceptions of Indonesian women with breast cancer consisted of seven categories which are description of breast cancer, causes, consequences, time-line, cure/controllability, coping and support. Description of breast cancer consisted of a test from God, a warning from God, a shame, serious disease, a bitter life experience, a punishment from God, and physical sign and symptom of breast cancer. Causes of breast cancer consisted of modifiable and unmodifiable factors. Consequences of breast cancer consisted of changes in life and progress of disease. Time-line category described breast cancer was perceived as chronic illness. Cure/controllability was perceived in terms of curability and modality of breast cancer treatment. Coping of breast cancer consisted of cover some parts of body, self-care to prevent recurrent, seeking treatment, religious

practice, positive reframing, acceptance, and fighting spirit. Support was perceived in term of family, health care provider, neighbors, religious group, and support from other patient.

Strength and Limitation

The strengths of this study include:

1. The study used the 3CM method and additional interview to gather illness perceptions. The 3CM method was able to capture the structure and the contents of the informants' illness perceptions accurately while avoiding inadvertent biases that may be created by using a method that has not been normed in an Indonesian population, while additional interview is used to clarify and to find in depth the data gathered from the 3CM method.

2. The data gathered from 3CM and additional interviewe were translated by researcher and also by two bilingual translators separately. The best translations which had the closest meaning to original Indonesian language were used to the next step of data analysis.

The limitations of this study include:

1. The approach used in this study acquired quite long time to apply (20 – 30 minutes for the 3CM method) and made some informants burdensome to think the issues regarding to breast cancer but on the other hand the approach succeeded to find out detail information about perception of breast cancer in Indonesian women population and very useful for nurses in practice to help patients with breast cancer to survive with their illness by restructuring their perception to breast cancer.

2. The approach of this study may relate to the educational level of informants. Three informants in present study, who got formal education until the fourth year of Elementry School, were not able to make any groups of the contents gathered from the 3CM method although the researcher had given example how to make a group.

Implications and Recommendation

The findings from this study provide implications for clinical practice and nursing research.

1. Keeping patients' privacy while taking care of the patients in the hospital, hospitality of health care provider, fairness in service and health facility, and accurate information about

breast cancer are the needs which were not met as perceived by the informants in this study. Therefore, the health care provider must improve these issues in clinical practice.

2. While consequences of being diagnosed with breast cancer were perceived as the one which created the most negative feeling to the informants, the women perceived coping, mainly religious practice and positive reframing, as the most category which were labled positive by them. These findings can be used by health care providers to support patients in the hospital to survive with their illness by using the religious approach and positive reframing in order the women can cope with the negative consequences of their illness.

3. Involvement of patients' support system in clinical practice for improving patients' survival with breast cancer is necessary. The support system come from patients' family, health care provider, patients' neighbors, religious-group, and other patients with the same diagnosis.

4. The approach used in this study need to be simplified in order it can be applied in daily care of women with breast cancer in nursing practice and prolonged engagement while collecting data is recommended. Providing example how to label each group with word or phrase in the step 3 of the 3CM method is necessary to help informants understand the command.

5. Present study may be used as a baseline data for further research regarding perception of breast cancer, particularly in Indonesian culture. Further researches across ethnic are recommended.

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APPENDIX

APPENDIX A

INFORMED CONSENT FORM

Dear patient,

My name is Wenny Savitri. I am a master nursing student at Prince of Songkla University, Thailand. I am doing a master research to study illness perceptions of Indonesian women with breast cancer. I am asking patients with breast cancer, like you, to participate in this research.

The purpose of the research is to learn about personal thoughts that a person with a new diagnosis of breast cancer has, according to her illness. By taking part of this study, you will have an opportunity to think about important things that affect you and how you understand your illness. Your thoughts and concerns as a volunteer in this study can contribute to knowledge that may help improve understanding and care of future breast cancer survivors.

Participation in this study is entirely voluntary. You may drop out of the study at any time without penalty. If you agree to take part in this study, you will be asked to complete one test and then be interviewed. This will take time approximately one and a half hour.

There are minimal risks related to being in this study namely time spending, effort taken to answering the questions, it may make you think about some difficult things that may make you feel uneasy. The approach also may develop psychological effects because it will remind you about the issue of breast cancer diagnosis. But the investigator has been prepared to handle the possible risks.

All information collected for this study will be kept in a confidential file with the investigator's research records. This research records will not show your name, but will have a code number and will be destroyed after the report of this study finish.

Any questions or further information you may have about this study will be answered by Wenny Savitri, at the Faculty of Nursing, International Program, Prince of Songkla University, Phone: +66831837507 or +62711361813.

On the basis of information above, I (Ms……………………….) agree to participate in the study.

------------------------------   ---------------------------

Participant's signature   Date

------------------------------   ---------------------------

Researcher's signature   Date

APPENDIX B

DEMOGRAPHIC AND HEALTH RELATED DATA QUESTIONNAIRE

Code: ………………..

1. Age _____ years

2. Education level (choose one of the choices below):

> 1) None
>
> 2) Primary school
>
> 3) Junior high school
>
> 4) Senior high school
>
> 5) Undergraduate
>
> 6) Graduate

> Years of education _____ years

4. Marital status (choose one of the choices below):

> 1) Single
>
> 2) Married
>
> 3) Widowed/ Divorced/ Separates

5. Number of children _____

6. Number of family members in household _____

7. Residential area (choose one of the choices below):

> 1) Rural
>
> 2) Urban

> City _____ Province _____

8. Household income/ month (choose one of the choices below):

> 1) Less than or equal to Rp 750,000
>
> 2) Rp 751,000 – 1.5 million
>
> 3) Rp 1.51 million – 2.5 million
>
> 4) Rp 2.51 million – 3.5 million
>
> 5) More than Rp 3.51 million

9. Insurance status (choose one of the choices below):

    1) Government

    2) Private insurance

    3) Charity

4) Do not have any insurance

10. Employment status (choose one of the choices below):

    1) Employed outside home

    2) Housewife

    3) Retired

    4) Unemployed

11. Religion (choose one of the choices below):

    1) Islam

    2) Protestantism

    3) Catholicism

    4) Hinduism

    5) Buddhism

12. History of cancer in family _____

13. Stage of breast cancer (choose one of the choices below):

    1) Stage I

    2) Stage II

    3) Stage III

    4) Stage IV

   T ____N____M____

14. Current treatment _____

15. Time since diagnosis _____ days

16. Symptom experiences

Choose symptoms below that you have experienced since you have been diagnosed with breast cancer:

1) Fatigue

2) Headache

3) Difficulty sleeping

4) Feeling depressed or blue

5) Feeling anxious and nervous

6) Cognitive changes

7) Hot flushes or flashes

8) Aching muscle and joints

9) Backaches

10) Night sweats

11) Numbness in the chest wall or in the axillary area or the upper arm area

12) Feeling of disFigured and/ or lopsided

13) "Pulling sensation"

14) Nausea

15) Hair loss

16) Numbness and tingling of fingers and toes,

17) Taste changes

18) Other (mention) ……………………………………………………..

APPENDIX C

THE 3CM METHOD

Let's say you were going to explain someone what you think or understand about breast cancer. What things would you want to be mentioned? Please take a few minutes to write these things down. Write only one thing in each sticker.

After the above task is complete, the participants will be asked to:

1. Code each item with a positive (good feeling) or negative (bad feeling) sign according to how they feel about it.
2. Arrange or group the items in a way that makes sense in their minds.
3. Label each group with a word or phrase that describes the area of concern.
4. The participants will be free to add more items at any time.

APPENDIX D
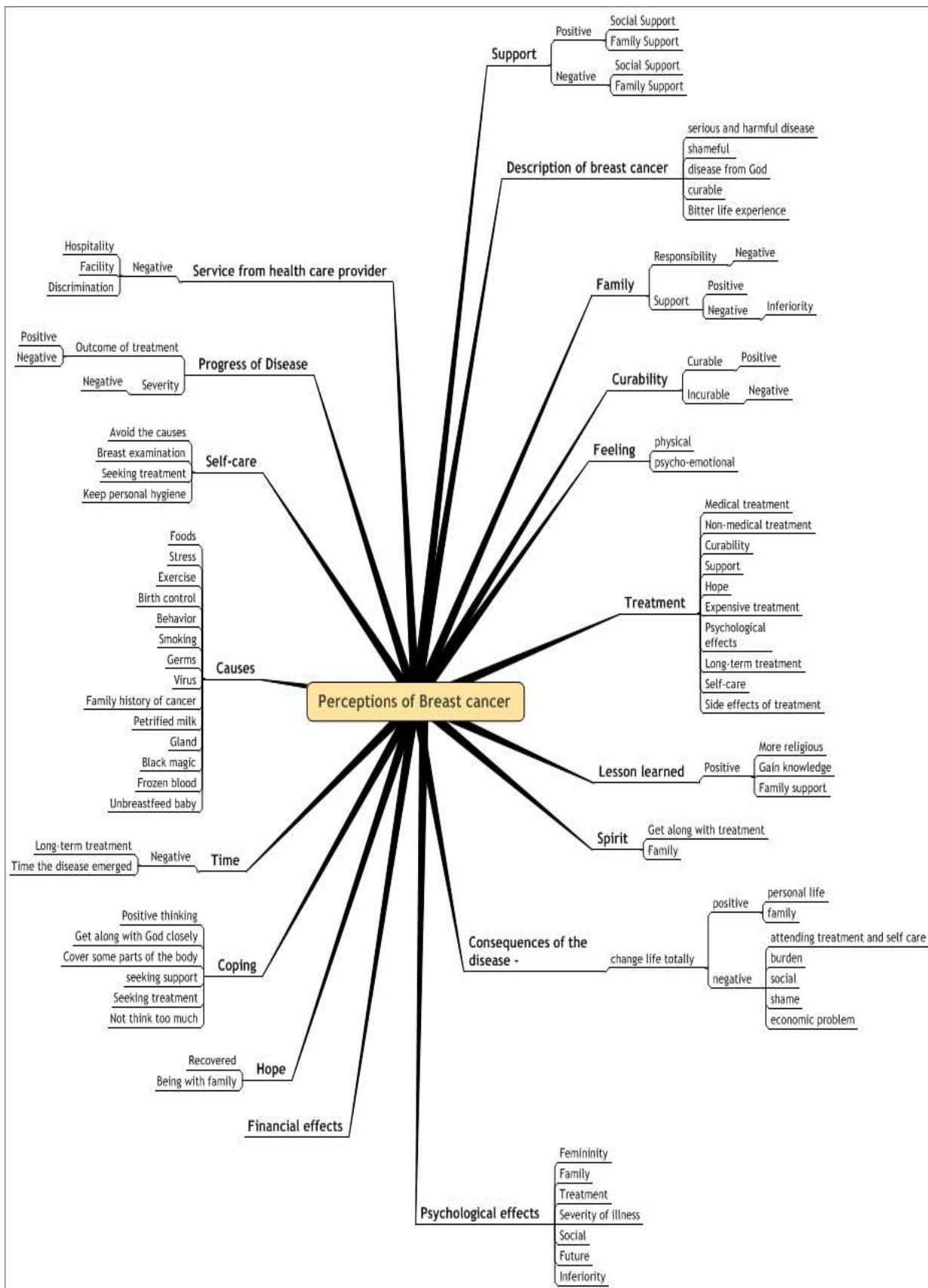
EXAMPLE OF STEPS OF CONTENT ANALYSIS
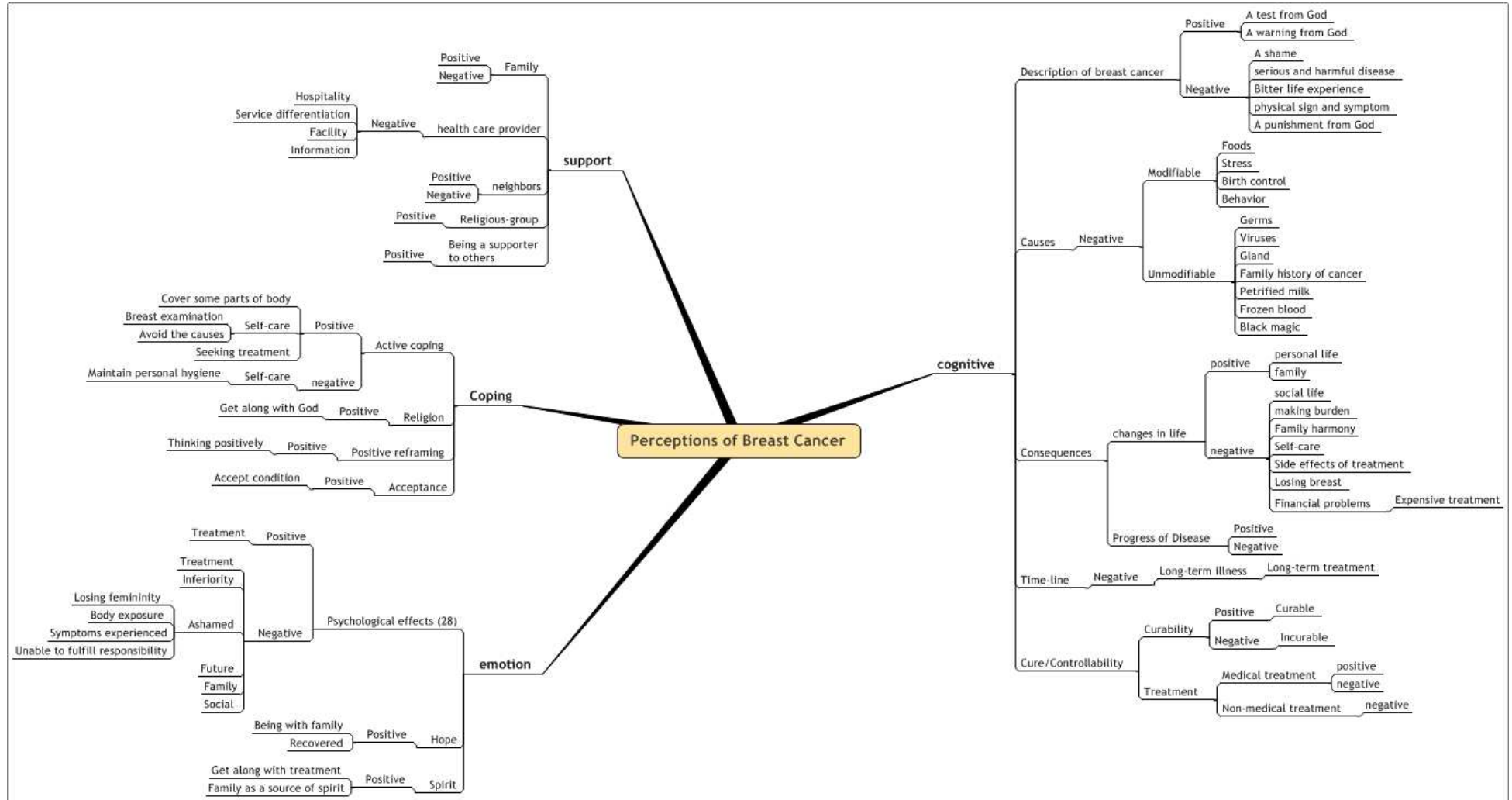
Figure 10 Perceptions of breast cancer (Step 1 of analysis)

Figure 11 Perceptions of breast cancer (step 2 of analysis)

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