NON-ADHERENCE IN INDONESIAN WOMEN WITH BREAST CANCER AND ITS DETERMINANTS

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NON-ADHERENCE IN INDONESIAN WOMEN WITH BREAST CANCER AND ITS DETERMINANTS

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CONTENTS

For my beloved wife and son
Lia and Reyhan

General Introduction

1.1 Breast cancer incidence and prevalence

Breast cancer is a disease in which malignant (cancer) cells form in the tissues of the breast. Usually, it starts off in the inner lining of the milk ducts or the lobules that supply them with milk. A malignant tumor can grow into surrounding tissues or spread to other parts of the body [1]. In 2008, at the start of our study, breast cancer was the most frequent cancer among women around the world with an estimated 1.38 million new cancer cases diagnosed (23% of all cancers) and accounting for 458,000 deaths a year [2]. In general, the incidence rate of breast cancer in economically developed countries is higher than in developing countries; however the case fatality rate is higher in developing countries, which indicates the more unfavorable survival [3]. In Indonesia, data from the 90s showed that breast cancer was the second most frequent cancer next to the cervical cancer among women, however, recent data shows that breast cancer has emerged as the most frequent cancer and the leading cause of death [4-5]. The breast cancer incidence rate per 100,000 people is 36.2 and the mortality rate is 18.6; both numbers are increasing [6]. A review study of cancer epidemiology in the South East Asian countries suggested that poorer survival among Indonesian breast cancer patients is largely due to late presentation of the disease [7]. This condition is compounded by lack of facilities for early detection and also poor access to primary treatment [8-9].

1.2 Detection and diagnosis of breast cancer

To detect and diagnose that a patient has breast cancer, the physicians may use the following procedures or tests: (1) Clinical breast exam (i.e. the physicians carefully examines the breasts and arm pits to check for signs of disease, such as lumps or anything else that seems unusual, (2) Mammogram (i.e. an x-ray of the breasts), (3) Ultrasound exam (i.e. a procedure in which high-energy sound waves (ultrasound) are used to make a picture of the breast tissues), (4) Magnetic Resonance Imaging (i.e. a procedure that uses magnet and radio waves to make a series of detailed pictures of the breast), (5) Blood chemistry exam (i.e. a procedure in which a blood sample is checked to detect possible abnormalities of certain substances released into the blood by organs and tissues in the body as a sign of disease), and (6) Biopsy (i.e. the removal of cells or tissues of the breast; these tissues are examined under a microscope by a pathologist to check for signs of cancer) [1].

1.3 Breast cancer treatment

In developed countries, most women come to the hospital with an early stage of breast cancer and they will have surgery as the main treatment [10]. However, as the majority of patients in Indonesia (60%-70%) are diagnosed at advanced stages (III and IV) and approximately 35% of them have metastasized [11-13], most patients receive combination treatment. Based on the protocol written by The Indonesian Society of Surgical Oncology, the treatment of breast cancer includes two types of therapy; the first is local therapy and the second is systemic therapy. Local therapy is intended to treat a tumor at the site without affecting the rest of the body; examples of local therapy are surgery and radiation therapy. Systemic therapy refers to drugs that spread throughout the body to eliminate or slow the growth of cancer cells. This type of therapy includes chemotherapy, hormonal therapy and molecular targeting therapy (biology therapy) [14]. The treatment plan is dependent on tumor size, degree of differentiation of the tumor and the presence of axillary metastases. Each type of therapy can be applied separately or in combination across time.

Survival rates are often used to indicate the outcome of the breast cancer treatment. According to the American Cancer Society's report, the 5-year survival rate (i.e. the percentage of patients who live at least 5 years after being diagnosed with breast cancer) for patients with stage I = 88%, stage IIA = 81%, stage IIB = 74%, stage IIIA = 67%, stage IIIB = 41%, stage IIIC = 49%, and stage IV = 15% [15]. In the USA, the mortality rate is gradually decreasing which has been attributed to the advancement of breast cancer treatment. Women's survival has improved by approximately 13% since the mid-1970s [16]. However, in Indonesia and also other developing countries the mortality is still increasing [3]. It has been suggested that besides the late presentation of the disease, patient's non-adherence to treatment is also an important factor attributed to ineffective breast cancer treatment in developing countries [17].

1.4 Psychosocial aspects of breast cancer

As cancer is a chronic and frequently terminal disease, receiving a breast cancer diagnosis can be one of the most threatening negative events women ever experience. Women who are diagnosed with breast cancer are faced with multiple stressors throughout their illness trajectory. Current cancer care has been improved a lot by the advancement in medical treatment programs. Women are generally provided with information about the details of their cancer diagnosis and prognosis and they are also involved in the decision-making process related to treatment. Still, women may experience several mental and behavioral

disturbances as an adverse effect of breast cancer diagnosis and treatment. A review study about behavioral symptoms in patients with breast cancer and survivors found that the most common mental and behavioral disturbances related to breast cancer were fatigue, sleep disturbance, depression, and cognitive impairment [18]. Previous literature reported that one third to 45% of cancer patients reported significant psychological distress [19]. In Western and Asian women with breast cancer, anxiety and depression are the most prevalent psychological problems. The prevalence of anxiety ranges from 21.1% to 29% [20-23], whereas the prevalence of depression ranges from 4.5% to 37% [24]. Previous studies have found that anxiety and depression are associated with several negative outcomes, namely: poor adherence to medical recommendation [25] and low quality of life [22, 26].

Besides psychological distress, women with breast cancer have also reported the following psychosocial issues: fear of recurrence, changes in body image and sexuality, intrusive thoughts about illness and existential concerns regarding mortality [27]. As these problems may lead to serious mental health issues, it is important to assess patient needs, distress, concerns, and the social context in which care is delivered.

1.5 Non-adherence to treatment

In general, the term adherence refers to the extent to which a patient's behavior coincides with medical advice [28], such as filling prescriptions, taking medication appropriately, attending follow-up appointments, and executing behavioral modifications. Many health providers prefer to use the term adherence instead of compliance because it is non-judgmental and describes a statement of fact rather than of blame of the patient, prescriber, or treatment [29]. In the context of chronic disease, which needs long-term therapy, the World Health Organization (WHO) defines non-adherence as the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider [30]. As the term non-adherence covers a broad range of behaviors, Levinsky & O'Donohue elaborated that non-adherence to treatment may appear in several forms, namely: (1) not initiating a recommended treatment, (2) not attending or coming late to appointments, (3) not completing behavioral recommendations, (4) not taking medication as prescribed, and (5) terminating the treatment prematurely [31].

A meta-analysis study of 569 published empirical studies about patient adherence to medical recommendations found that the rate of non-adherence ranged from 11.7% to 34.5%, with an overall average non-adherence rate of 24.8%. People with HIV disease,

arthritis, gastrointestinal disorders or cancer reported higher adherence rates, whereas people with pulmonary disease, diabetes or sleep disorders reported lower adherence rates. In cancer patients, the non-adherence rate is 20.9% [32]. Specifically, in the breast cancer population, a previous study among Malaysian breast cancer patients found that 29% of patients were non-adherent to chemotherapy and 13% of patients were non-adherent to radiotherapy [33], whereas a study among Canadian breast cancer patients found that 22% of patients discontinued adjuvant endocrine therapy within 2 years [34] . To the best of our knowledge, the adherence rate in the Indonesian breast cancer population is not known, however previous cancer studies found a considerable non-adherence rate. For example, a study in childhood leukemia found that 25% of patients refused or abandoned therapy [35]. Another study in retinoblastoma patients found that 31.5% of patients temporarily refused medical treatment, whereas 18.2% of patients refused treatment permanently [36].

Non-adherence to treatment has been found to have several serious consequences, including poor clinical outcomes, higher (re)hospitalization rates and increased health care costs [37]. A meta-analysis study found that patients with high adherence to the overall treatment regiment were 26% more likely to have a good clinical outcome than patients with low adherence [38]. A study among Indonesian retinoblastoma patients found that patients who had initially refused therapy but had later been readmitted to the hospital (temporary refusal) had significantly lower survival rates than patients who had not refused therapy. In addition, temporary-refusal was also found to be highly associated with progression of tumor stage [36]. While data about the direct and indirect health care costs related to non-adherence in Indonesia are not yet available, the U.S. health care system has reported that annual direct costs are approximately $100 billion and that annual indirect costs exceed $1.5 billion in lost patient earnings and $50 billion in lost productivity [39].

1.6 Factors related to non-adherence to treatment

Over the last several decades, experts of health, behavioral and social sciences have investigated the prevalence of non-adherence to medical recommendations and its underlying factors. Experts have suggested a comprehensive approach to the non-adherence phenomenon due to its multidimensionality and complexity. The ecological model suggests that poor adherence does not only concern patients, but also involves several other levels of factors, i.e. micro-level (health care provider and social support), meso-level (health care organization), and macro-level (health policy) [37]. Although health care systems, therapy-related problems, economic and logistic concerns are important factors in adherence, poor

adherence to medical recommendations is a behavioral problem at root [40]. Therefore, patients' psychosocial characteristics may influence their adherence in both direct and indirect ways [41]. A conceptual review and synthesis study about common psychosocial factors underlying adherence in breast cancer treatment differentiated potential factors into two groups, namely, cognitive variables and socio-emotional variables [40]. Both groups, which are studied in this thesis, are elaborated below:

1.6.1 Cognitive variables

Breast cancer knowledge. Commonly, cognitive aspects refer to women's knowledge about breast cancer which is assumed to have some influence on their adherence to treatment. Although there is only limited literature that examined the association between knowledge and treatment adherence, poor knowledge about risks for cancer, treatments and outcomes of treatments has been known to be associated with poor adherence to screening programs [42-45]. Breast cancer knowledge has been assumed to have a positive effect to patients' survival. In long-term survival patients, better knowledge about breast cancer may stimulate early consultation and may lead to early average stage of presentation which may result in a longer survival [46]. A study among breast cancer patients found that better knowledge was a predictor of greater adherence to lymphedema risk management recommendations [47].

Illness perceptions. The Common Sense Model of Illness Cognition assumes that patients respond to symptoms and signs of illness by forming cognitive and emotional representations of the illness on the basis of concrete and abstract sources of information available to them [48]. This model suggests that illness perceptions will have an effect on patients' coping behaviors and psychological outcomes, including adherence [49]. These perceptions consists of eight dimensions, namely, (1) consequences, the perceived consequences of the illness on the patient's life; (2) time line, the perceived duration of the illness; (3) personal control, the perceived personal control over the illness; (4) treatment control, how much the patient thinks treatment helps to control the illness (5) identity, symptoms that the patient attributes to the illness; (6) illness concern, how much the patient worries about his/her illness; (7) coherence, how well the patient understands his/her illness; and (8) emotional representation, how much the patient is emotionally affected by his/her illness [50]. A review study of patients' illness perceptions and medication adherence found that having more positive perceptions about the duration of the illness and consequences on the overall quality of life or functional capacity, having stronger beliefs in their personal and treatment control over their illness, having less worries about their condition and being

less emotionally affected by the illness were positively associated with better adherence, whereas having better or poor understanding of their illness was not associated with adherence to medication [51].

Health locus of control. Locus of control (LOC) has been suggested as a potential predictor of better adjustment to cancer [52-53]. The concept of LOC originally comes from Rotter's Social Learning Theory and is defined as a person's belief about the location of controlling forces in their life, either internal or external [54]. Wallston and colleagues [55] developed the Health Locus of Control (HLC) concept to examine an individual's generalized expectations about where the control over his or her health resides. Individuals with an internal HLC believe that what happens to their health condition results from their own actions, whereas individuals with an external HLC believe that their health condition is controlled by external forces, such as chance, doctors, powerful others. Later, Wallston and colleagues developed the God locus of health control concept which refers to individuals' beliefs about God's control over their health [56]. Associations between HLC, adherence and non-adherence behaviors have been investigated in chronically ill patients. Although internal HLC was assumed to be positively associated with better adherence, previous studies showed mixed results. For example, some studies among diabetes patients have found that internal HLC was associated with better adherence to medication [57-58], whereas others found no association between internal HLC and adherence to medication [59-60]. Conversely, a study that investigated breast cancer patients who were intentionally non-adherent (e.g. choosing not to take their medication) and who were not intentional non-adherent to medication (i.e. forgetting to take their medication) found no evidence that a high belief in external HLC (i.e. chance) was associated with poor adherence [61].

Satisfaction with cancer information. The provision of sufficient and adequate information is one of the main elements of supportive care in cancer treatment. A review study about information provision among cancer survivors found that patients who were satisfied with the information provided by health professionals had a better quality of life than dissatisfied patients [62]. However, previous studies on information provision among cancer patients found that the information supplied by health care providers frequently does not meet patients' individual informational needs [63-65], which may lead to patients' dissatisfaction. Previous studies that examined the association between satisfaction with information and adherence found that patients who were satisfied were more likely to comply with medical recommendations and treatments [66-67].

1.6.2 Socio-emotional variables

Psychological adjustment. Women with breast cancer may not only experience psychological distress at the time of diagnosis, but also years after disease diagnosis and treatment [68]. Previous studies have found that patients' psychological distress is associated with treatment non-adherence. For example, a study among adolescent cancer patients found that depression is positively associated with non-adherence [69]. A review study about risk factors for noncompliance with medical treatment found that the non-adherence rate in depressed cancer patients is had 3 times higher than in non-depressed patients [25].

Socio-demographic and economic status. Although previous literature showed inconsistent associations between socio-demographic and economic status and non-adherence to medical recommendations, low socioeconomic status may have a stronger influence on patients' health behaviors in developing countries. For example, financial problems may put patients in the dilemma between continuing cancer treatment and fulfilling other priorities, such as children's education expenses. Moreover, a review study about inequalities in health care use in developing countries showed significant differences in treatment provision by health-care providers and subsequent differences in treatment outcome between patients with different socio-economic status [70]. Sabaté [30] summarized several factors that have been reported to be associated with adherence, namely: poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from a treatment centre, high cost of transport, high cost of medication, changing environmental situations, culture, and misconceptions about illness and treatment.

1.7 This thesis

1.7.1 Aims and research questions

The main aim of this thesis was to identify possible psychosocial risk factors for non-adherence to treatment and for poor psychological adjustment in Indonesian women with breast cancer. When required, Indonesian versions of the measurement instruments concerned were developed and validated.

The research questions of this thesis are as follows:

Concerning non-adherence:

- What are the self-perceived reasons for delay in seeking help and non-adherence to treatment in Indonesian women with breast cancer? (Chapter 2)

- Which psychological factors are associated with non-adherence to treatment in Indonesian women with breast cancer? (Chapter 6)

   Concerning psychological adjustment:
- Is the Indonesian version of Distress Thermometer valid? (Chapter 3)
- Is the health locus of control of Indonesian women with breast cancer different than of healthy women? (Chapter 4)
- Is health locus of control associated with anxiety and depression in Indonesian women with breast cancer? (Chapter 4)
- How satisfied are Indonesian women with breast cancer with the information they received from health care professionals? (Chapter 5)
- What is the relation between illness perceptions and quality of life in Indonesian women with breast cancer? (Chapter 5)

1.7.2 Outline of the thesis

The thesis is structured as follows. Chapter 2 presents our qualitative study about psychosocial and cultural factors of non-adherence in Indonesian women with breast cancer. Chapter 3 explores psychological distress in women with breast cancer and presents the validation of the Indonesian version of the Distress Thermometer, as well as the cut-off score to be applied in the Indonesian cancer population. The study in chapter 4 investigates the difference in health locus of control between Indonesian women with breast cancer and healthy women, and assesses its associations with anxiety and depression. In chapter 5 women's satisfaction with cancer information is examined and its association with illness perceptions and quality of life is also discussed. Chapter 6 presents the quantitative study of psychological factors associated with non-adherence to treatment in Indonesian women with breast cancer. This thesis concludes with a general discussion of the findings in Chapter 7. Implications for clinical practice and future research are presented as well.

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Chapter 2

Psychosocial and Cultural Reasons for Delay in Seeking Help and Non-adherence to treatment in Indonesian Women with Breast Cancer: A Qualitative Study

Abstract

Objective: The aim of this study was to explore reasons for delay in seeking medical help and non-adherence to treatment in Indonesian women with breast cancer.

Methods: Semi-structured interviews were conducted by purposive sampling, using a consecutive sample of 50 breast cancer patients who were treated at the Outpatient Surgical Oncology Clinic of Hasan Sadikin Hospital in Bandung, Indonesia. Interviews were recorded, transcribed verbatim and coded using qualitative software. Codes were merged into main themes that were subsequently mapped onto the study's aim.

Results: Eight main themes concerning reasons for delay in seeking medical help and treatment non-adherence emerged, namely: lack of awareness and knowledge, cancer beliefs, treatment beliefs, financial problems, emotional burden, severe side effects, paternalistic style of communication and unmet information needs.

Conclusion: This study has identified several modifiable psychosocial and cultural factors related to delay in seeking help and non-adherence to treatment in breast cancer patients. We suggest that the provision of extensive information through media campaigns, treatment decision aids, and caregiver and patient education are needed to change the illness behaviors of Indonesian breast cancer patients.

Keywords: Breast cancer, psychosocial factor, non-adherence, Indonesia.

Introduction

Breast cancer is the most frequently occurring cancer and the leading cause of death among Indonesian women. The incidence rate per 100,000 people is 36.2 and the mortality rate is 18.6; both numbers are increasing [1-3]. Although the incidence of breast cancer in Indonesia is lower than in developed countries, the mortality rate is higher [4]. Similar to other low- and middle- income countries, poorer survival among breast cancer patients is largely due to late presentation of the disease. This condition is compounded by lack of resources for diagnosis and treatment [5-6]. Previous breast cancer studies in Indonesia found that about 60%-70% of patients had come to the hospital when the disease was already in advanced stages (III and IV) and 35% of them were metastasized [7-9].

In addition to a delay in seeking medical help, non-adherence to treatment has been recognized as a factor that leads to unfavorable outcomes among breast cancer patients. The World Health Organization (WHO) defines adherence as a multi-dimensional phenomenon which is determined by the interplay of five dimensions, namely: (a) social and economic factors (e.g. poor socioeconomic status, low level of education, cost of medications); (b) health care system-related and health care team-related factors (e.g. poorly developed health services, poor medication distribution systems); (c) condition-related factors (e.g. severity of symptoms, level of disability); (d) therapy-related factors (e.g. the immediacy of beneficial effects, side-effects, duration of treatment); and (e) patient-related factors (e.g. self-efficacy, knowledge, treatment beliefs and perceived barriers to adherence) [10]. Non-adherence to treatment may appear in the following forms: (1) not initiating a recommended treatment, (2) not attending or coming late to appointments, (3) not completing behavioral recommendations, (4) not taking medication as prescribed, and (5) terminating the treatment prematurely [11]. A study in the USA found that early discontinuation and non-adherence to adjuvant hormonal therapy was associated with increased mortality [12]. Up until now, the general adherence rate in Indonesian cancer population is not known. However, one study in childhood leukemia found that 25% of patients refused or abandoned therapy [13]. A study in retinoblastoma patients found that 31.5% of patients temporarily refused medical treatment, whereas 18.2% refused treatment permanently [14].

Factors that are allegedly associated with adherence have been investigated in several Western countries. Demographic factors such as higher income and education have been found to be associated with a higher level of adherence, whereas age and gender were not associated [15]. In addition to demographic factors, psychosocial and cultural factors have also been recognized as potential predictors of adherence in developing countries. The

lack of breast cancer awareness, social taboos of cancer, misconceptions about cancer treatment and strong beliefs in traditional treatment were identified as main barriers to achieve early diagnosis and effective treatment of breast cancer in developing countries [16].

Each culture has its own system of beliefs, perceptions and ideas about health and illness [17], which affect people's response to their illness. People's beliefs about their illness and medication have been found to be related to treatment adherence [18-19]. Marked by a high degree of religious, cultural and social diversity, Indonesia provides a unique socio-cultural environment which influences people's perceptions, attitudes and behaviors in daily life [20]. Previous studies about treatment refusal in retinoblastoma patients and childhood leukemia patients found that psychosocial factors such as beliefs about the incurability of cancer, belief in alternative treatments and dissatisfaction with health-care providers were frequently reported by patients as reasons for non-adherence [13-14]. To the best of our knowledge, qualitative research that systematically explores the psychosocial and cultural factors for non-adherence in Indonesian women with breast cancer patients has never been conducted.

The aim of this qualitative study was to explore reasons for delay in seeking help and non-adherence to treatment in Indonesian women with breast cancer. Identifying modifiable psychosocial and cultural factors influencing people's illness behavior is important to determine the focus of a future interventions to increase help-seeking and non-adherence to treatment in Indonesia.

Methods
Participants

This study was part of a larger quantitative study in which the potential determinants of non-adherence to treatment in Indonesian breast cancer patients were studied (in preparation). Due to the lack of prior knowledge about predictors of delay in seeking help and non-adherence to treatment in Indonesian patients, we decided to apply purposive sampling by recruiting consecutively 50 participants at the outpatient surgical oncology clinic of Hasan Sadikin Hospital (HSH) in Bandung, Indonesia between April-June 2010. This version of purposive sampling was chosen to obtain a sample with clear information concerning the criteria of seeking medical help and treatment non-adherence from their medical records. Inclusion criteria were (a) age ≥18 years, (b) diagnosis of breast cancer, (c) and adequate

command of the Indonesian language. Patients were ineligible if they had any major psychiatric disorder as assessed by their physician or if they were too ill.

Procedure

This study was approved by the Indonesian Medical Ethical Committee and the Board of Directors of HSH. A member of the administration staff of HSH identified eligible patients, explained the study purpose to them and asked for their initial consent to participate. One week later, the interviewers met with the patients who were willing to participate, asked them to sign a consent form and scheduled the interviews. The interviewers conducted semi-structured interviews in the clinic waiting room while participants waited for their appointment. We set a convenience place in the corner of the room outside hearing distance of other patients to provide privacy.

Data Collection and Analysis

This study followed the principles of the Grounded Theory which consists of systematic guidelines for gathering, synthesizing, analyzing and conceptualizing qualitative data to construct a theory grounded in the data from which it was developed [21]. This approach was chosen given the lack of prior knowledge about non-adherence in the Indonesian culture. To obtain good quality data we conducted semi-structured interviews to explore patients' experiences during their diagnosis and treatment. Interviews were conducted by seven master students in clinical psychology who first received a two-day interview training by two clinical psychologists. The training included instruction, demonstration, role-play and feedback. The trainees received information about the medical and psychological aspects of breast cancer, as well as information about the study and the semi-structured interview. Each interviewer was supervised by the first author during their first interview and received feedback afterwards.

Firstly, participants were asked about their demographic characteristics and back ground, including age, gender, marital status, education level, employment status, insurance status and family history of breast cancer. Afterwards, participants were interviewed on the following topics: knowledge of the disease, perceived disease severity, information provided by the patient's physician, use of health services and alternative treatment, attitudes towards western and traditional medicine particularly in relation to the patient's disease, the perceived benefits of, and barriers to, treatment and non-adherence to medical

recommendations. The semi-structured interviews took an average of 30-45 minutes and all interviews were transcribed verbatim by the master students.

To determine the delay in seeking help and uptake of treatment we adopted a three-month interval as our gold standard, since there is strong evidence that a delay in presentation of symptomatic breast cancer of three months or more is associated with lower survival [22-23]. We defined delay in seeking help if the period from the first breast symptom to the first medical consultation was >3 months; and delay in uptake of treatment if the period between the first diagnosis and the first admission at HSH was >3 months. Treatment non-adherence was defined if patients were absent from two or more consecutive treatment sessions at HSH [24].

We used a thematic analysis that refers to the principles of the Grounded Theory [25]. To achieve data analysis consistency, we used a qualitative software program ATLAS.ti version 5.2 [26]. The interview results were first typed in Word files and saved as plain text and subsequently the documents were assigned as a hermeneutic unit in the ATLAS.ti package. The first author coded the transcripts using open coding, after which codes obtained during the analysis were compiled into categories that covered all relevant information. Finally the categories were merged into main themes that were subsequently mapped onto the study's aim. The codes, categories and themes were discussed regularly with the second author until agreement on the themes was reached. Frequencies and percentages of patients mentioning a theme were calculated and typical citations were noted.

Results

A total number of 54 patients were approached. Fifty patients agreed to be interviewed and four patients declined to participate because they were too ill to be interviewed. As shown in table 1, the participants' ages ranged from 34 to 65 years. Thirty-nine participants had received junior high school or lower education. Forty-four participants were married and the rest were widows. The majority of the participants were housewives or unemployed. Thirty-two participants had advanced cancer (stages TNM III and IV) and 48 participants had undergone chemotherapy. Sixteen participants had a family history of breast cancer. Forty-six participants had health insurance provided by the government to poor people, whereas the other women financed their own medical expenses.

Table 1. Demographic and clinical characteristics of study participants

Variable	n (%)
Age range	
30-39	16 (32%)
40-49	18 (36%)
50-59	13 (26%)
60-69	3 (6%)
Marital Status	
Married	44 (88%)
Never married	0 (0%)
Divorced	0 (0%)
Widowed	6 (12%)
Education (yrs)	
None	3 (6%)
Elementary school (1-6)	23 (46%)
Junior high school (7-9)	13 (26%)
Senior high school (10-12)	11 (22%)
College ($\geq$ 13)	0 (0%)
Employment	
Housewife/unemployed	42 (84%)
Laborer/irregular job	7 (14%)
Private employee	1 (2%)
Stage of cancer	
1	0 (0%)
2	18 (36%)
3	29 (58%)
4	3 (6%)
Treatment	
Surgery	35 (70%)
Chemotherapy	48 (96%)
Radiotherapy	16 (32%)
Residency	
Bandung	10 (20%)
Outside Bandung	40 (80%)

Chapter 2

Place of the first diagnosis	
District Hospital	40 (80%)
Hasan Sadikin Hospital	10 (20%)
Health insurance	
Yes	46 (92%)
No	4 (8%)
Family history of breast cancer	
Yes	16 (32%)
No	34 (68%)

Delay in seeking help, treatment delay and treatment non-adherence

Thirty-five participants had delayed in seeking help, with the time of delay ranging from 4 to 24 months, except for the four participants (P.8, P.17, P.28 and P.49) who had delayed for 4 years, 10 years, 3 years and 15 years, respectively. The median duration of delay was 7 months. The majority had an advanced stage of cancer when they visited a doctor or a hospital. After receiving a cancer diagnosis, twenty-one participants had delayed treatment uptake at HSH with the time of delay ranging from 4 to 24 months, except for the two participants who had delayed for 4 years. The median time of treatment delay was 6 months. Ten participants reported that they had missed two or more consecutive treatment sessions during their treatment at HSH.

Factors related to treatment non-adherence

We constructed a theoretical model to describe factors related to delay in seeking medical help and non-adherence to treatment (Figure 1). Eight themes emerged from our data; these themes were categorized into 3 clusters, namely: (1) factors related to patients (lack of awareness and knowledge, cancer beliefs and treatment beliefs), (2) factors related to treatment (financial problems, emotional burden and severe side effects), and (3) factors related to patient-health provider relationships (paternalistic style of communication and unmet information needs). In the rest of this section we will elaborate the eight main themes.
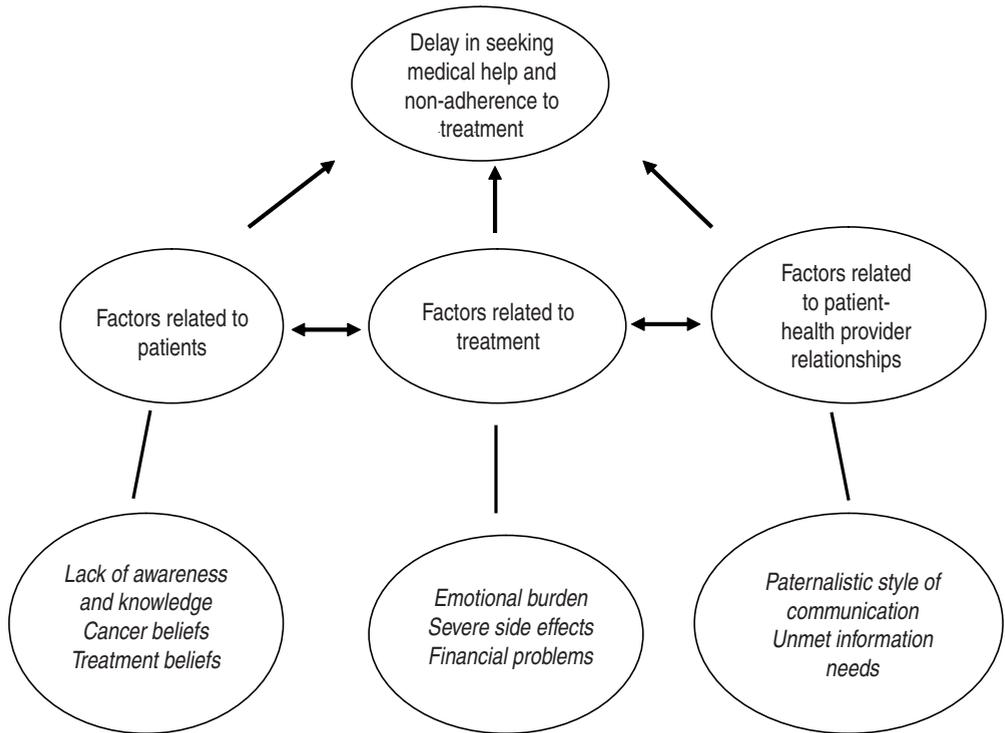
Figure 1. Generated theoretical model of factors related to delay in seeking medical help and non-adherence to treatment

Factors related to patients

Lack of awareness and knowledge

Most of the participants had not intentionally delayed seeking medical treatment. They had not been aware of the breast cancer risks due to limited knowledge. The majority of the participants had received only junior high school or lower education and also reported a lack of information provision about breast cancer in rural areas. Lack of breast cancer knowledge was the reason that many participants underestimated the severity of their disease, also because its symptoms had not hindered their daily activities. Even when the participants had already undergone the treatment program at HSH, some of them had poor knowledge about breast cancer. For example, one participant said "*I don't know what exactly the cause of my breast cancer is. I think it is because I wore my bra too tight. It may have irritated my breast skin and after a long period that developed into cancer*" (P.36).

Cancer beliefs

The majority of the participants described breast cancer as a dangerous, deadly and incurable disease. These cancer fatality beliefs were based on stories and breast cancer experiences of their relatives and neighbors or on media sources, such as magazines and newspapers. "*This disease is very dangerous; I have seen my relatives and my neighbor who had breast cancer. They did not recover and finally died*" (P.39). Some participants described breast cancer as a shameful disease because it threatened their womanhood and affected their identity as a wife or mother. They tended to hide and avoid discussing their illness with other family members. In addition, some participants believed that cancer could be passed down in the family. "*I heard from people that if the mother has cancer now, tomorrow the children will have it too*" (P.19). Moreover, some participants believed that their cancer was beyond their control because God determined their fate. They seemed to surrender and accepted their illness because they believed that an individual's faith cannot be changed and their illness is divine and aimed at testing their faith. "*This cancer is my destiny; I just have to be patient, accept my condition and try to seek a treatment, but only God can heal*" (P.13).

Treatment beliefs

The majority of participants perceived medical treatment of cancer involving frightening medical procedures, particularly surgery. Moreover, they perceived surgery as a painful treatment causing the loss of an essential organ. They described surgery as a process where a person is brought unconscious to an operating room with doctors wearing special clothes proceeded to use frightening operation tools. This fear of surgery was also a common reason to delay their treatment at HSH. "*When the doctor said that I got cancer and I had to be operated immediately in HSH, I was shocked because I was really afraid of surgery. I decided not to come to HSH until I was ready for it*" (P.40).

In addition to fear and misconceptions about medical treatment, we found that the majority of the participants had a strong belief in traditional healers. This belief seemingly influenced participants' treatment decisions; they perceived the traditional healer as an alternative solution for their health problem or as a complement to medical treatment. In the current study, many participants had consulted traditional healers, such as herbal therapists, acupuncturists and spiritual therapists. Most participants consulted a traditional healer after they had received a breast cancer diagnosis in a district hospital. Several reasons accounted for their decision to consult a traditional healer, namely: recommendation from their husband or relatives, healers provided treatment without surgery, affordable

consultation fee and transportation costs, and a holistic care approach. Some patients preferred traditional healers because they not only focus on patients' physical symptoms, but also on their feelings. "*I was really afraid of surgery, it was not wrong to try another treatment such as herbal medicine and another method of traditional treatment which were more comfortable for me*" (P.5).

Factors related to treatment

Financial problems

Most of the participants reported that the high cost of medical treatment was a main factor influencing their decision to undergo medical treatment at the referral hospital. In the current study, most people who had limited financial resources had been advised to apply for government health insurance to cover their medical expenses. Nevertheless they still had difficulty in paying their transportation, accommodation and logistical expenses. Moreover, a majority of participants reported that they came to the hospital accompanied by one to three family members which increased their financial burden. "*Although all medical treatment cost were covered by the government insurance, I had to wait until I had enough money to pay transportation, food and another expense for me and my family who accompanied me, because the distance from my home is quite far*" (P.30).

Emotional burden

The long duration of cancer treatment led to more psychological burden. Many participants worried about the uncertain outcome of the treatment and this influenced their cancer curability beliefs in the some extent. Some participants expressed their fear of death; they were worried that the treatment could not cure their cancer and that their body would only suffer more due to the disease and the side effects of treatment. "*Sometimes, I was really worried about my treatment effectiveness. I had to be optimistic that my cancer can be cured, however side effects often ruined my optimism. I am afraid that my body cannot handle this cancer anymore and I will die shortly*" (P.26). In addition, some participants felt despair and guilt towards their husband and children because their treatment was time and energy consuming and reduced their ability to function as a wife and mother.

Severe side effects

A large number of participants expressed that severe side effects were among the reasons they missed their treatment schedule. The majority of participants reported that the side effects of chemotherapy were the most burdensome for them. Of the side effects mentioned,

most included pain, fatigue, nausea, dizziness, loss of appetite, sleep disturbance and hair loss. "*I had to undergo chemotherapy and the side effects were very uncomfortable. I felt pain, fatigue, nausea and dizziness that limited my daily activities. Sometimes, I was thinking about not keeping to my chemotherapy schedule due to those side effects*" (P.3).

Factors related to patient-health provider relationships

Paternalistic style of doctor-patient communication

The majority of participants perceived that doctors have higher status than patients. They reported having a non-assertive style of communication during consultations with doctors to show respect and avoid conflict. Some of them felt inferior to the doctors because they came from a rural area and had low education. Many participants who wanted to know more about breast cancer causes and their treatment procedure never dared to ask the doctor for more information. "*I am a low educated person and come from a rural area; I just follow the doctor's advice for my health and I do not dare to ask anything*" (P.22)

Unmet information needs

Participants had obtained information about diagnosis and treatment from the doctors in the hospital. Most information had been delivered orally and written information was seldom provided. Some participants reported that information provided by doctors during consultations did not meet with their needs or expectation because the information was scant or unclear. The gap between needed and provided information appeared to have affected participants' understanding and treatment adherence. Almost all participants reported having received information about the tests they had to undergo for diagnosis and the side effects of the treatment, however only a few of them received clear information about the positive effects of the treatment. Moreover, some patients did not know the detrimental consequences of missing or postponing their treatment program. "*The doctor just asked me to follow the entire treatment program and explained its possible side effects, such as hair loss, blackened skin on fingers, nausea, fatigue, dizziness, eating and sleeping disturbance*" (P.21).

Discussion

This study is the first study exploring reasons for delay in seeking treatment and non-adherence to treatment in Indonesian women with breast cancer. The results of this qualitative study suggest eight main factors related to delay in seeking treatment and

non-adherence to treatment, namely: lack of awareness and knowledge, cancer beliefs, treatment beliefs, financial problems, emotional burden, severe side effects, paternalistic style of communication and unmet information needs.

Lack of breast cancer awareness and inadequate knowledge about signs and symptoms of breast cancer seem to influence women's ability to recognize breast cancer symptoms, disease severity and the necessity of seeking medical help. This finding is in accordance with previous studies in other developing countries which found that lack of awareness and knowledge is an essential predictor of delay in presentation of breast cancer [16, 27-29]. Several problems may contribute to this lack of knowledge, such as lack of health awareness and education, limited health education programs, particularly in rural or isolated areas and insufficient information provided by the health care providers [16, 30-31]. Currently, printed material (e.g. leaflets and brochures) and electronic sources (e.g. website) with breast cancer information are being provided by the Indonesian Cancer Foundation. However, these sources of information appear not to have achieved an optimal impact due to lack of dissemination and lack of Internet access, particularly in rural areas. Several programs could be introduced to improve breast cancer awareness and knowledge that may contribute to lowering the number of delay in seeking medical help. The use of media campaigns, such as public service announcements on television, radio and newspapers, have been found to be an effective way to improve breast health knowledge, to teach women how to conduct breast self-examination and to increase breast health practices [32].

Perceptions and beliefs about symptoms, disease and health determine how individuals understand and respond to their illness [33-34]. In the present study, some women believe that cancer is incurable, that cancer is a shameful disease and can be passed down to their family members. Similar perceptions have been found in South Asian women with breast cancer living in the UK and Canada [33, 35]. These beliefs seem to influence their perception of the necessity to seek medical help and to start their treatment in the referral hospital. Likewise, a study in Malaysian women found that negative perceptions of breast cancer were the main reason for delay in the presentation of breast cancer [29].

Indonesians are well-known for their religiosity [36]; religion and spiritual background also seem to influence women's perceptions and responses toward their illness. Women's faith in God influences their attitude toward their illness and either encouraged or discouraged them to seek medical help. A majority of women felt that their faith in God helped them to face their cancer. Peek, Sayad, & Markwardt [37] and Barton-Burke, Barreto, & Archibald [38] argued that religion and spirituality can be resources that help patients cope with their

illness and alleviate their fear about future health uncertainty and death. However, some women showed less motivation to fight their cancer and tended to resign themselves to their fate. This finding is in accordance with a breast cancer study in Iran [39] and supports another argumentation that reliance on God to cure cancer may discourage women from seeking medical care [40].

In regard to treatment beliefs, some women had negative perceptions of Western breast cancer treatment, resulting in medical mistrust. In contrast, many women had a great belief in traditional healers. Women used traditional therapy as an alternative solution for their health problem or as a complement to medical treatment. There is ample evidence from previous studies describing that a strong belief in a traditional healer influences patients' behavior and treatment decisions [16, 29, 41-42]. One explanation might be that traditional therapies are less expensive than 'Western-type' medical care, treatment without surgery and do not require expensive travel because traditional healers can be found locally. Furthermore, cultural and religious beliefs may persuade people to choose traditional therapies. For example, Moslem patients tend to consult traditional healers who offer Islamic consultation and treatment. Our study suggests that women may also prefer traditional healers because they are not only focused on patient's physical symptoms, but also on patient's feelings. Up till now, there has been no registration system for traditional healer practices in Indonesia. This condition limits the possibility for dissemination of breast cancer information to traditional healers. Such information could encourage them to refer their patients to the hospital immediately when they recognize breast cancer symptoms. Moreover, there is a fierce competition between traditional healers and evidence-based medicine, which is even fought in television-advertisements. We feel that advocating the integration of traditional healing into medical health care should be regulated by the government to prevent conflicts and rejection.

Previous studies in developing countries found that financial problems are the main barrier to achieving effective early diagnosis and breast cancer treatment [16, 29, 43], and this was also an important factor in the current study. Not only women from developing countries worry about the costs of cancer treatment, Western women also perceived that medical treatment for breast cancer as expensive [42]. Although medical costs were covered by the government health insurance, patient adherence to treatment was still influenced by financial difficulties in paying transportation costs to the hospital, accommodation and other logistical costs, which is similar to previous studies in child leukemia and retinoblastoma patients [13-14].

The long duration of treatment and its side effects lead to uncertainty about treatment effectiveness in women. Patients who reported having severe side effects were more likely to miss their treatment because they were too ill to come to the hospital or felt that the side effects were worse than cancer itself. A previous study in child leukemia patients also found that severe side effects were one of the main reasons for treatment abandonment [13]. In addition, women's uncertainty about the effectiveness of their treatment may lead to higher distress. High distress is known to be associated with high levels of non-adherence [44]. The majority of the participants were married and many reported that the severe side effects limited their role-functioning as a mother and wife. Inability to perform their role as mother and wife for a long period often elicited feelings of guilt towards husband and children.

Optimal doctor-patient communication is essential to achieve good medical services. However, in Indonesia several barriers to effective communication appear to exist. Women do not assert themselves in the presence of doctors; they feel inferior and do not dare to ask for further information about their disease and treatment. A study on doctor-patient communication in Southeast Asia found that a paternalistic style is common in Indonesia. Doctors and patients are not prepared for a participatory style of communication and the high patient load in health care centers might exacerbate this [45]. Moreover, having lower education and coming from rural area seem to amplify women's inferior attitude towards doctors during consultations. Similarly, a previous study about client communication behaviors in East Java and Lampung found that less educated patients experienced a greater social distance from the health service providers due to their limitation in understanding technical information [46].

Information provision by health professionals should ideally match patients' needs. In the present study, most information about cancer diagnosis and treatment was delivered orally. Some participants reported that they received too little or too complicated information. The gap between needed and provided information appeared to have affected participants' understanding and belief about treatment efficacy, which may decrease their treatment adherence. Llewellyn, Horne, McGurk, & Weinman [47] suggest that cancer patients who are not satisfied with the amount and content of the information received before treatment are more likely to be unsure about their treatment, suffer more symptoms and perceive the consequences of the illness to be greater.

Several limitations of the current study should be considered. Firstly, the majority of the participants were married, housewife/unemployed and had lower education level, because HSH is a referral hospital for patients with government insurance for poor people. These demographic characteristics seem to have substantially influenced women's perceptions

and beliefs about financial burden, motherhood role, and disease and/or treatment. As we used purposive sampling, limiting ourselves to patients in the HSH, our sample cannot be considered to be representative of the general population of breast cancer patients. We lack patients, for instance, who went for treatment abroad or those who never visited the hospital for treatment. However, it is probably a good representation of the patients at HSH because of the consecutive patient inclusion. Therefore, our findings need to be confirmed in women in the general breast cancer population. Secondly, delay time and adherence rate were obtained retrospectively through participants' self report which may have caused recall bias. Thus, a prospective study is needed to ascertain participants' delay and non-adherence rate.

In conclusion, this study has identified several modifiable psychosocial and culture-related barriers to seeking medical help and adherence in breast cancer patients. We argue that not only financial support is needed to reduce non-adherence in Indonesia, but also extensive information provision through media campaigns and the use of treatment decision aids. Women undergoing breast cancer treatment seem to be burdened by severe side effects of treatment suggesting that education for cancer professionals, such as in-hospital training about communication and symptom management for physicians and health professionals may be needed. The factors identified in this study present ample opportunities for future research, which may contribute to important understanding of illness behavior among cancer patients. Better understanding and knowledge of such factors is not only useful for physicians working in Asian countries, but also for physicians working with Asian populations in Western countries.

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Chapter 2

The Distress Thermometer and its validity: a first psychometric study in Indonesian women with breast cancer

Abstract

Purpose: This study aims to translate the Distress Thermometer (DT) into Indonesian, test its validity in Indonesian women with breast cancer and determine norm scores of the Indonesian DT for clinically relevant distress.

Methods: First, the original version of the DT was translated using a forward and backward translation procedure according to the guidelines. Next, a group of 120 breast cancer patients who were treated at the Outpatient Surgical Oncology Clinic in Hasan Sadikin Hospital in Indonesia completed a standard socio-demographic form, the DT and the Problem List, the Hospital Anxiety and Depression Scale (HADS) and the WHO Quality of Life (WHOQOL-BREF).

Results: Receiver operating characteristic (ROC) curve analyses identified an area under the curve = 0.81 when compared to the HADS cutoff score of 15. A cutoff score of 5 on the DT had the best sensitivity (0.81) and specificity (0.64). Patients who scored above this cutoff reported more problems in the practical, family, emotional, spiritual/religious and physical domains (30 out of 36 problems, p-value<0.05) than patients below the cutoff score. Patients at advanced stages of cancer experienced more emotional and physical problems. Patient's distress level was negatively correlated with overall quality of life, general health and all quality of life domains.

Conclusions: The DT was found to be a valid tool for screening distress in Indonesian breast cancer patients. We recommend using a cutoff score of 5 in this population.

Keywords: Distress Thermometer, validation, quality of life, breast cancer, Indonesia.

Introduction

In Indonesia, cancer incidence has an estimated number about 300,000 cases per year [1]. However, only 10% of these cases are treated in the health care system as the majority of these people do not seek medical help due to several factors, such as strong beliefs in traditional healers, fear and denial, and cultural taboos [2-3]. As one of the ten identifiable main diseases causing death in Indonesia [4], the diagnosis of cancer and its treatment often causes considerable psychological distress in patients. It has been recognized and reported in previous studies that 20-40% of cancer patients experience a significant level of distress [5-6]. Breast cancer is the primary cancer in Indonesia and its incidence and mortality rate is increasing [7]. Previous findings have shown that women with breast cancer experience psychological distress [8], even years after disease diagnosis and treatment [9]. Patients' distress is associated with a number of negative outcomes, including low adherence to treatment recommendation [10], poor satisfaction with care [11] and poor quality of life [12].

Similar to developed countries [13-14], distress among cancer patients often goes unrecognized by health care professionals in Indonesia. The ratio between the amount of health care professionals and cancer patients is still far from ideal in Indonesia. Data from 506 Government Hospitals in Indonesia showed that in average there are only 14 General Practitioners and 16 Specialists per hospital [4]. This condition may lead to several practical issues, including limited consultation time. In addition, a paternalistic style of doctor-patient communication and patients' unassertiveness are quite common in Indonesia [15]. These factors may also cause consultations to be focused primarily on physical aspects of cancer.

The National Comprehensive Cancer Network (NCCN) states that distress should be recognized, monitored, documented and treated promptly at all stages of the disease and in all settings [16]. Considering the high patients load and the unbalanced ratio between patients and health care professionals in Indonesia, there is an urgent need for a short and effective screening tool to detect distress among patients. Ideally, such a tool should be able to assess distress across the physical, psychological, social and spiritual domains [17]. As current screening tools are long and burdensome for patients to complete, there is a need for a brief, valid and easy to complete measure of distress in this population.

In order to meet this demand, the NCCN has developed the Distress Thermometer (DT) which is a single item that asks the patients to rate their distress using a visual analogue scale. It is accompanied by the Problem List (PL) that asks patients to identify

any of 36 issues that have been a problem for them in the past week. The DT is very brief, easy to administer and it uses a word for psychological problems with non stigmatizing connotations, namely distress [16]. This tool was initially developed by the NCCN and many studies have reported that the DT is an effective screening tool for detecting distress among various medical conditions, such as prostate carcinoma [18], bone marrow transplantation [19], lung cancer [20], breast cancer [8] and mixed site cancer [21]. The NCCN suggests that a score of 4 or higher on the DT indicates a clinically significant distress level [16]. Some validation studies using the Hospital Anxiety and Depression Scale (HADS) found the same cutoff score of 4 [22-24], whereas other authors found that a cut off score of 5 [25-28] best distinguished distressed patients from non-distressed ones. Most studies found that DT scores above the cutoff are correlated with emotional, family and physical problems as measured by the Problem List. However, results on spiritual and religious concerns are inconclusive [21-23].

The Distress Thermometer has been successfully translated from English into several languages, such as Arabic [29], Dutch [30], Japanese [25], Korean [23], Turkish [24] and Italian, Spanish and Portuguese [27], but it has not yet been used in Indonesian cancer patients. Therefore, this study aims to translate the DT into Indonesian, test its validity in Indonesian women with breast cancer by comparing it with a well-established distress measure, i.e. the HADS, and to determine norm scores of the Indonesian DT for clinically relevant distress. The other aim was to establish the validity of the DT by examined its associations with the Problem List scores, socio-demographic and clinical characteristics, and quality of life.

Methods

Participants

Consecutive sampling was used to recruit 120 women with breast cancer from the outpatient surgical oncology clinic at Hasan Sadikin Hospital (HSH) Bandung in two phases. The first group of 50 patients was recruited between April-June 2010; the second group of 70 patients was recruited between June-October 2011, due to logistical reasons. Inclusion criteria were age >18 years, first diagnosis of breast cancer and adequate command of the Indonesian language. Patients who had been treated by psychiatrists were excluded from the study.

Ethics statement

The study was approved by the Indonesian medical ethical committee and the Board of Directors of Hasan Sadikin Hospital. All samples were obtained with written informed consent reviewed by the ethical board.

Procedures

This validation study was part of a larger investigation in which the correlates of non-adherence behavior in Indonesian breast cancer patients were explored. After receiving written permission from the NCCN, we used the forward and back translation method to translate the DT, since this method is the most frequently recommended and used method in translation guidelines for cross-cultural studies [31]. One of the authors of this study (A.I) who is a clinical psychologist translated the DT from English into the Indonesian language; the back translation into English was carried out by an English language teacher (J.H) who is a Native American who speaks the Indonesian language fluently and who has been living in Indonesia for 6 years. Upon completing the translation, a linguist (A.C) examined the original English version and the back translation version of the DT to assess the significance of any discrepancies. After some discussions with A.C, we finalized the Indonesian version of the Distress Thermometer.

A member of the administration staff of HSH identified eligible patients, explained the study purpose to them and asked for their initial consent to participate. One week later, those who wanted to participate were approached by one of the research assistants before their next visit to their physician. Ten master´s students in clinical psychology were trained as research assistants and were supervised by S.S (clinical psychologist) and A.I. The research assistant provided further information about the study and instructions on how to fill in the questionnaires. After informed consent had been obtained, participants filled in the DT, the HADS, the World Health Organization Quality of Life (WHOQOL-BREF) and a demographic/background data form. Participants filled out the questionnaires in the waiting room before their consultations. Ten of the participants were illiterate, but they were able to speak and understand the Indonesian language. In these cases, the research assistants read both the informed consent form and the questionnaires out loud. After the participants signed the informed consent form, the research assistants helped them to fill in the questionnaires.

Measures

Socio-demographic and medical status.

A standard socio-demographic form was used to collect self-report data on age, marital status, education level, employment status, insurance status and family history of breast cancer. The patients' medical status, such as type and stage of cancer as defined by the TNM stadium classification system [32], type of treatment and time since diagnosis were obtained via a medical chart review.

Distress Thermometer (DT).

The DT is a 1-item, self-report measure of psychological distress developed by the NCCN [16]. Patients are asked to rate their distress in the past week on an 11-point visual analogue scale ranging from 0 (no distress) to 10 (extreme distress). Afterwards, patients are asked to fill in the Problem List (PL) that accompanies the visual image of the DT to check whether or not (yes/no) they experienced any of the problems listed during the previous 7 days. The PL version used in this study consisted of 36 problems that were grouped into five categories, namely practical problems, family problems, emotional problems, spiritual/ religious concerns and physical problems. The PL aims to better define the nature of the problems which possibly cause the reported distress. To assess its association with the DT scores, the total amount of problems checked was calculated (range 0-36).

Hospital Anxiety and Depression Scale (HADS).

The HADS is a 14-item self-report questionnaire that has been developed to assess psychological distress in people with medical illness [33]. It consists of 2 subscales; one subscale consists of 7 items to measure anxiety (HADS-A) and one subscale consists of 7 items to measure depressive symptoms (HADS-D). Respondents are asked to indicate which of 4 options (rated 3-0) best describes their feelings during the previous week, which results in a maximum score of 21 on each subscale. The sum scores of the two subscales can be added up to a total score (HADS-T). The HADS has been widely used to validate the DT because of the similarity in their conceptual background [18, 22-27, 30, 34-35]. The HADS is available in the Indonesian language, but has not yet been psychometrically validated in Indonesian patients and cut-off scores for clinically relevant symptoms are not yet available. Therefore, in the present study we used the global cutoff score of the HADS total ($\geq$15) that in studies elsewhere distinguished best between people with and without clinically significant emotional distress [36-37]. Factor analysis of the Indonesian version

of the HADS demonstrated a two factor solution in good accordance with the HADS-A and HADS-D subscales, except for item 3: I feel cheerful and item 4: I feel as if I am slowed down. The solution accounted for 45% of variance. Both subscales were found to be internally consistent, with values of Cronbach's coefficient (alpha) being 0.77 and 0.74, respectively.

World Health Organization Quality of Life (WHOQOL-BREF).

The WHOQOL-BREF was developed as an abbreviation of the WHOQOL-100 to provide a short form quality of life assessment [38] It was developed by the WHO through a multicentre field trial situated within 23 countries. This tool is a self-report questionnaire which consists of 26 items, each item representing one facet of life that is considered to have a contribution to a person's quality of life. Twenty-four items measure four broad domains, namely physical health (e.g. mobility, pain and discomfort; 7 items), psychological health (e.g. body image and appearance, negative feelings, self esteem; 6 items), social relationships (e.g. personal relationships, social support; 3 items) and environment (e.g. financial resources, health and social care, physical environment; 8 items). Two other items measure the overall perception of quality of life and general health. The WHOQOL-BREF employs a 5-points scale (1 to 5) with a higher score indicating a higher level of self-perceived quality of life. The WHOQOL-BREF is available in a validated Indonesian version [39].

Data Analysis

We used the Statistical Package for Social Science (SPSS 17.0) for data analysis. The mean score, the standard deviation, the median score and the frequency distribution of the DT were explored using descriptive statistical analysis. The concurrent and convergent validity of the DT with the HADS and the WHOQOL-BREF were examined by Pearson's correlation coefficient analyses. Receiver operating characteristic (ROC) analysis was used to identify the optimal DT cutoff score for distinguishing whether a patient experiences clinically significant distress as defined by the HADS. The Area Under the Curve (AUC) was used to estimate the overall discriminative accuracy of the DT cutoff score relative to the established cutoff score of the HADS $\geq$15. We used a qualitative guideline for interpreting AUC values by Hosmer and Lemeshow [40], namely AUC=0.50 as an indication that the test has no discrimination, AUC$\leq$0.70 as an acceptable discrimination, AUC$\leq$0.80 as a good discrimination and AUC$\leq$0.90 as an excellent discrimination. ROC curves were used to show the trade-off between the sensitivity (true-positive rate) and specificity (true-negative rate) for every possible cutoff score of the DT.

To explore the association between the DT cutoff score and the Problem List, the demographic variables and the clinical variables, Chi-square analyses were conducted for categorical variables and t-test analyses were conducted for continuous variables. The association between the DT and the total score in the PL was explored by Pearson's correlation coefficient; associations between the DT cutoff scores and individual items in the PL were explored by the Chi-square analyses.

Results

Demographic and clinical characteristics

A total of 120 patients participated in this study. The response rate was 91%. Twelve out of 132 women approached declined to participate because they were too ill to fill in the questionnaires. As shown in Table 1, the mean age of the women in this sample was approximately 45.5 years of age (range; 28-66). Most of the participants were married (84%). The majority of the participants had middle school or lower education (i.e. 49% had elementary school, 20% had junior high school and 8% had no education). Seventy-three percent of the participants (73%) were housewives or unemployed. The mean number of months since diagnosis was 21.5 (SD=20.3, range= 1-120 months). More than half of the study participants (52%) were in the disease stages III or IV. Fifty-six percent underwent mastectomy, 83% underwent chemotherapy and 23% underwent radiotherapy. Ninety-three percent of the participants had health insurance provided by the government to poor people (e.g. Jakesmas, ASKES, Gakin and Gakinda) and only 7% financed their own medical expenses. Twenty-five percent of the participants had a family history of breast cancer.

Table 1. Demographic and clinical characteristics of study participants

Variable	n (%)
Age (M±SD)	45.5 ± 8.04
Marital Status	
Married	101 (84%)
Single	2 (2%)
Divorced	0 (0%)
Widowed	17 (14%)
Education (highest)	
None	10 (8%)
Elementary school	59 (49%)
Junior high school	24 (20 %)
Senior high school	21 (18 %)
College or university	6 (5%)
Employment	
Housewife/unemployed	88 (73%)
Laborer/irregular job	25 (21%)
Private employee	2 (2%)
Government officer	5 (4%)
Months since diagnosis (M±SD)	21.5 ± 20.3
Range (months)	1-120
Current stage of cancer	
1	3 (3%)
2	54 (45%)
3	46 (38%)
4	17 (14%)
Treatment	
Mastectomy	67 (56%)
Chemotherapy	99 (83%)
Radiotherapy	28 (23%)
Health insurance	
Yes	112 (93%)
No	8 (7%)
Family history of breast cancer	
Yes	30 (25%)
No	90 (75%)

Average score on the DT and the Problem list

The average score of the patients on the DT was 4.7 (SD = 2.6). The most frequent problems checked in descending order in the practical domain were insurance/financial (60%), transportation (48%), housing (32%), work/school (24%) and child care (21%). The most frequently checked problems in the family problems category were: dealing with children (14%), the ability to have children (11%) and dealing with a partner (11%). In the emotional problems category, the most frequently checked problems were worry (81%), sadness (80%), fears (54%), depression (41%), nervousness (41%) and loss of interest in usual activities (33%). Eleven percent of the patients checked the item about spiritual/religious concerns. The ten most frequently checked problems in the physical problems category were pain (71%), fatigue (68%), nausea (55%), sleep (52%), getting around (51%), tingling in hands/feet (51%), eating (41%), appearance (36%), memory/concentration (36%) and skin dry/itchy (36%).

Establishment of a DT cutoff score

The Pearson's correlation coefficient between the DT scores and the HADS total was 0.58 (p<0.01); the correlation coefficients between the DT and the HADS-Anxiety and the HADS-Depression scales were 0.58 (p<0.01) and 0.48 (p<0.01), respectively. Using the HADS cutoff score of 15 as the criterion, sixty-two women (52%) were identified as experiencing clinically significant distress. The ROC analysis obtained the AUC of 0.81 (SE=0.04; 95%CI=0.73-0.88; p<0.001) (Figure1). This AUC value indicates an excellent discrimination. Table 2 lists the Sensitivity, Specificity, Positive predictive values and Negative predictive value on each the DT cut-off point. A cutoff score of 5 on the DT optimally identified 81% of the HADS cases (sensitivity) and 64% of the HADS non cases (specificity) with positive and negative predictive values of 70% and 76%, respectively. Of those screened positive by the DT, 30% would be false positives and of those screened negative by the DT 24% would be false negatives.
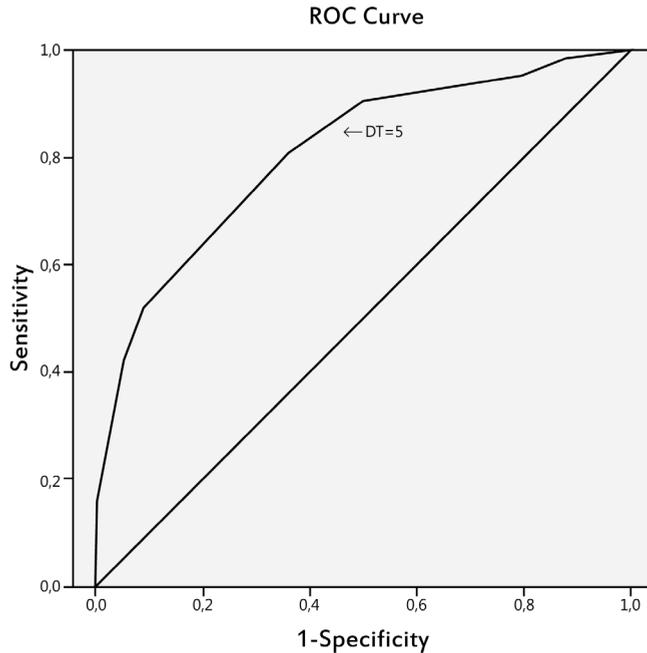
Figure 1. Receiving operation characteristic (ROC) curve of Distress Thermometer scores versus Hospital Anxiety and Depression Scale cutoff scores.

Table 2. Sensitivity, Specificity, Positive and Negative predictive values on each the Distress Thermometer cut-off point.

Cut-off point	Sensitivity	Specificity	Positive predictive value	Negative predictive value
0/1	0.98	0.11	0.51	0.88
1/2	0.95	0.21	0.56	0.80
2/3	0.92	0.40	0.62	0.82
3/4	0.90	0.50	0.66	0.83
4/5	0.81	0.64	0.70	0.76
5/6	0.52	0.91	0.86	0.64
6/7	0.42	0.95	0.90	0.60
7/8	0.24	0.98	0.94	0.54
8/9	0.15	1.00	1.00	0.52
9/10	0.10	1.00	1.00	0.51

Associations between the DT cutoff score and the Problem List items

The DT scores were statistically significantly correlated with the Problem List total score (r=0.47, p<0.01). In the practical problems category (p≤0.05), the DT cutoff score was significantly associated with four problems (i.e. child care, housing, insurance/financial and work/school), and was not associated with transportation. The DT cutoff score was significantly associated with each of the problems in the family problems category (p≤0.05). Patients who scored above the cutoff experienced more problems in dealing with children, dealing with their partner and the ability to have children. In the emotional problems category (p≤0.05), the DT cutoff score was significantly associated with five problems (i.e. depression, nervousness, sadness, worry and loss of interest in usual activities), and was not associated with fears. Patients who scored above the cutoff experienced more spiritual/religious concerns (p≤0.05). Finally, in the physical problems category (p≤0.05), the DT cutoff score was significantly associated with 17 out of 21 problems (i.e. appearance, bathing/dressing, breathing, changes in urination, constipation, diarrhea, eating, fatigue, feeling swollen, fever, indigestion, memory/concentration, mouth sores, nose dry/congested, pain, sexual and skin dry/itchy), and was not associated with four other problems (i.e. getting around, nausea, sleep and tingling in hand/feet).

Demographic and clinical characteristics associated with the DT cutoff score and the Problem List items

Marital status and insurance status were excluded in the Chi-square analyses, as some categories did not fulfill the minimum number of expected observations. We found that women with a score below the DT cutoff score of 5 did not differ significantly from women at or above the DT cutoff score of 5 on age, time since diagnosis, education, employment status and family history of cancer. However, we found a significantly difference in stage of cancer (X^2 = 3.90, df = 1, p= 0.048). Women with a score $\geq$ 5 were more likely to be at an advanced stage of cancer.

We found several significant associations between the PL-scores and the demographic and clinical characteristics. The advanced cancer patients (stage III or IV) had higher PL-total scores (t=-3.32, p<0.001), more emotional problems (t=-3.55, p<0.001) and more physical problems (t=-2.62, p<0.01) than the stage I or II cancer patients. Age was negatively correlated with physical problems (r=-0.21, p<0.05) and the PL-total scores (r=-0.182, p<0.05). PL scores were not associated with marital status, employment status, family history of cancer and time since diagnosis.

The DT and the HADS correlations with the WHOQOL-BREF scores

Table 3 shows the correlation coefficients of distress and quality of life. The DT, the HADS total, the HADS Anxiety and the HADS Depression scores were significantly negatively correlated with overall quality of life, general health and all quality of life domains.

Table 3. Association between distress and quality of life

	DT	HAD-A	HAD-D	HADS-T
Overall quality of life	-0.36**	-0.40**	-0.32**	-0.39**
General health	-0.43**	-0.44**	-0.31**	-0.41**
Physical health domain	-0.45**	-0.45**	-0.53**	-0.54**
Psychological domain	-0.55**	-0.55**	-0.53**	-0.59**
Social relationships domain	-0.22*	-0.29**	-0.38**	-0.35**
Environment domain	-0.31**	-0.30**	-0.36**	-0.36**

DT: Distress Thermometer; HAD-A: HAD Anxiety subscale score; HAD-D: HAD Depression subscale score; HADS-T: Hospital Anxiety and Depression Scale total score.
*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Discussion

In this study, we examined the validity of the DT and its screening efficacy in detecting distress in Indonesian cancer patients. Our results showed that the Indonesian version of the DT has concurrent validity with the HADS, which is a well-established screening tool for distress. A cutoff score of 5 on the DT yielded optimal sensitivity and specificity. Patients who had a score above the cutoff score of 5 experienced more problems in the practical, family, emotional, spiritual/religious and physical domains than women with DT scores below this cut off score. Also, they were more likely to be at an advanced stage of cancer. Finally, distress as measured with the DT was found to be negatively correlated with overall quality of life, general health and all quality of life domains which establish the convergent validity of the Indonesian version of the DT.

The ROC analysis comparing the DT scores with the well-established HADS cutoff score of 15 obtained an AUC which indicates a good discrimination. Using the DT cutoff score of 5, eighty-one percent patients were identified correctly as being distressed and 64% identified correctly as not being distressed which is comparable to the result of the meta-analysis study by Mitchell [41]. This evidence shows that the DT has a screening

efficacy for distress in Indonesian breast cancer patients. The current Distress Management Guidelines from the NCCN recommend that a DT score of 4 or higher indicates that a patient has a clinical significant level of distress and should be referred to a psychosocial care team [16]. However, we obtained a sensitivity of 90% and a specificity of 50% at a cutoff score of 4, resulting in a large proportion of patients incorrectly being identified as experiencing clinically significant distress. Considering the lack of health care professionals in Indonesia, we believe that it is more appropriate to use the cutoff score of 5 which yielded an optimal combination of sensitivity and specificity, to avoid a large number of false positive cases being diagnosed. Patients who may not require further intervention may feel burdened by further screening procedures. Moreover, false positive screening leads to higher health care costs and an increased need for health professionals. The DT cutoff score of 5 found in this study corresponds with the cutoff score found by other validation studies using the HADS [25-27, 34-35]

Patients who had significant distress were more likely to report more problems in the practical, family, emotional, spiritual/religious and physical domains. Interestingly, patients who had clinically significant distress were more likely to experience spiritual/religious concerns which is similar to the results of a study conducted in Korea [23]. In contrast, most studies conducted in Western countries found that clinically significant distress was not associated with spiritual/religious concerns [20, 22, 24], or only weakly related [34]. The significant correlation between high distress and spiritual/religious concerns is possibly due to the fact that Indonesian people are religious and have a strong belief in God. Many people rely on God to heal their disease. We hypothesize that people who do not feel any change in their illness will be more convinced their cancer as the will of God and they cannot change their destiny which in turn might trigger higher levels of distress.

Results of studies on associations between distress and socio-demographic and clinical characteristics in cancer patients are inconsistent [42]. In the present study, high distress was only found to be associated with stage of cancer, but not with other socio-demographic or clinical characteristics. This finding is in concordance with previous studies that were also unable to find significant associations between the DT and socio-demographic and clinical characteristics [18-19, 23-24, 27, 43]. Our finding that distress is associated with lower overall quality of life, general health and all quality of life domains is in line with the studies by Skarstein et al.[12] and Ozalp et al.[24], and further proves the validity of the Indonesian version of the DT.

The Problem List scores were associated with several demographic and clinical characteristics in the expected direction, suggesting that the Indonesian version of the

Problem List is also a valid tool. Advanced cancer patients experienced more emotional problems and physical problems than patients at an early stage of cancer, and younger patients experienced more physical problems. These results are in line with previous studies results [44-45].

Several limitations of this study should be noted. Firstly, we used only breast cancer patients as our sample. Furthermore, we conducted this study at HSH which is a referral hospital that provides health services to the poor people. Therefore, the majority of the study participants had middle to low socio-economic and educational level. However, demographic and clinical characteristics of the patients (e.g. mean age, education level, marital status and stage of cancer) were similar to previous studies in Indonesian breast cancer patients [46-47]. Multi-center studies with a larger sample of various patient groups are needed to be able to extrapolate these results of the present study to other patient groups. Secondly, all measures used were self-rating questionnaires. Nevertheless, we included ten illiterate participants and they were helped to fill out the questionnaires. This may have led to some bias. Thirdly, the HADS Indonesian version has only been linguistically validated by the MAPI Institute which may have lead to some cultural bias. However, the basic psychometric examination results indicated that the HADS Indonesian version can be considered as a good instrument in terms of factor structure and internal consistency. Since the Geriatric Depression Scale, which is an instrument that is similar to the HADS has been shown to have the same optimal cut off point in both Western and Asian countries [48], we used the general HADS cutoff score suggested for Western countries in our study. Finally, this study examined the validity of the DT, but further research is required involving oncologists and nurses to confirm the feasibility of its use in daily care practice.

Bearing these limitations in mind, our findings suggest that the Indonesian version of DT could be used as a screening tool in daily cancer care in Indonesia. As the DT is brief and easy to administer, it might be an acceptable tool for oncologists in Indonesia. The NCCN suggests that early detection and treatment of distress leads to better adherence to treatment, better communication and prevents severe anxiety and depression [6]. According to our findings, cancer patients who experience distress above the DT cutoff score of 5 should be referred to a psychologist or another health professional to manage their distress and get appropriate treatment of their main distress sources as indicated in the PL. The use of the DT in daily cancer care in Indonesia may help oncologists to prevent potential severe psychological problems in cancer patients and provide additional interventions to patients who need it. Our results suggest that patients in an advanced stage of cancer should be given priority for psychological intervention. Such interventions are often part of medical

psychology. Given that the field of medical psychology is new in Indonesia, we recommend its development by psychological faculties with academic hospitals in order to be able to provide adequate psychological resources to patients and doctors.

Our study did not only confirm the validity of the DT in Indonesian population, but also showed specific associations with several problems in the problem list. We found that women with breast cancer in Indonesia, most of whom are very religious, have different sources of distress than breast cancer patients in Western countries. In this respect, our study sheds light on cultural factors explaining cancer-related distress, thereby generating knowledge that is not only useful for physicians working in Asian countries, but also for physicians working with Asian populations in Western countries.

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Chapter 4

Health locus of control in Indonesian women with breast cancer:
A comparison with healthy women

Submitted:

Abstract

The aims of this study were to assess whether Indonesian women with breast cancer have higher external Health Locus of Control (HLC) than healthy women, and to explore the association between HLC and symptoms of anxiety and depression. In this study, 120 consecutive women with breast cancer were recruited at the outpatient surgical oncology clinic at the Hasan Sadikin Hospital in Bandung. One hundred and twenty two healthy women were recruited from the Bandung area. A standard demographic form, Form C of the Multidimensional Health Locus of Control, as well as the Hospital Anxiety and Depression Scale and patients' medical records were used. Data were analyzed using descriptive statistics, t-test, Pearson's correlation, MANOVA and multiple linear regressions. Women with breast cancer had higher scores on all external HLC subscales, i.e. chance, doctor, powerful others and God, and lower internal HLC compared to healthy women. High God LHC scores were associated with a high level of anxiety ($\beta=0.21$, $p<0.05$), whereas none of the HLC subscales were associated with depression. Our results suggest that women with breast cancer tend to have high external HLC, while healthy women tend to have high internal HLC. A strong belief in an external source of control, i.e. God, might be negatively associated with patients' emotional adjustment. Further research is needed to give an insight into the direction of this association.

Introduction

Breast cancer is a serious health condition among women worldwide. In 2008, approximately 1.38 million new cases were diagnosed and approximately 458,000 deaths were recorded both in developed and developing countries [1]. Receiving a breast cancer diagnosis is a life threatening negative event and potentially causes considerable psychological problems. Women who are diagnosed with breast cancer are faced with multiple stressors throughout their illness trajectory, such as having a biopsy, awaiting diagnosis, having surgery, experiencing treatment side effects, anticipating the possibility of cancer metastasizing, coping with financial, family and social problems and facing the risk of recurrence and/or death. The most prevalent psychological problems among women with breast cancer are anxiety and depression. The reported prevalence of anxiety ranges from 21.1% to 29% [2-5], whereas the prevalence of depression ranges from 4.5% to 37% [6].

Locus of control (LOC) has been suggested as a potential predictor of a better adjustment to cancer [7-8]. The concept of LOC derives from Rotter's social learning theory and is defined as a person's belief about the location of controlling forces in their life, either internal or external [9]. In particular, Wallston, Wallston, Kaplan, & Maides [10] developed the Health Locus of Control (HLC) concept to examine an individual's generalized expectations about where the control over his or her health resides. Individuals with an internal HLC believe that what happens to their health condition results from their own actions, whereas individuals with an external HLC believe that their health condition is controlled by external forces, such as chance, doctors, powerful others and God [11].

For several years, studies on HLC have focused on internal HLC, recognized as the most logical HLC dimension related to better health outcomes and emotional adjustment [12]. However, results have been mixed. For example, a study among cancer and chronic pain patients found that lower internal HLC predicted higher depression [13]. On the other hand, a study among breast cancer patients did not find any direct relationship between HLC and depression and anxiety [14]. Until now, studies in the Indonesian population have also produced mixed results [15-16].

Wallston and Wallston [17] have suggested that in medical situations where only a little personal control is possible, patients are more likely to be reliant on external sources of control, such as doctors or powerful others (e.g. family), than on internal sources. Evidence from previous studies found different HLC orientations between healthy persons and physically ill persons. Healthy college or adult samples tended to have a higher internal HLC and a lower external HLC, whereas chronically ill patients (e.g. chronic obstructive

pulmonary disease, hypertension and cancer) tended to have higher external HLC [18]. High external HLC among chronically ill patients may have advantages for their emotional adjustment, as patients who do not try to control their condition, may be able to minimize their level of frustration. For example, a study among cancer chemotherapy patients who received progressive muscle relaxation and/or biofeedback training to alleviate the side effects of treatment found that patients with a high external HLC showed greater improvement on measures such as pulse rate, blood pressure and depression than patients with a high internal HLC [19].

Luszczynska and Schwarzer [20] have suggested that culture and religion might affect the average level of HLC scores and that some dimensions might play a more prominent role in some cultures. They speculated for example, that internal HLC might be associated with better health behaviors in countries that are individualistic than in countries that are collectivistic [20-21]. A study about cultural variation in HLC among Caucasian, Asian and Afro-Caribbean women found that Asian women had higher scores on chance and powerful others HLC than other groups. Moreover among Asian women, being highly religious seemed to explain some of their higher scores [22]. Indonesian people are known to be highly influenced by their religion in relation to their health and illness behavior [23-24]. Thus, it is relevant to consider Indonesian patients' views in the context of their belief that God is a source of control over their health condition.

To the best of our knowledge, only a few systematic studies have been conducted in Indonesia evaluating HLC and its association with psychological problems, such as anxiety and depression. None of these studies included God as a perceived source of control over a person's health condition. Therefore, the aims of the present study were: (a) to assess whether Indonesian women with breast cancer have a higher external HLC than Indonesian healthy women, and (b) to explore the association of HLC and anxiety and depressive symptoms in Indonesian women with breast cancer.

Methods

Study design and participants

This study used a cross-sectional design. One hundred and twenty consecutive women with breast cancer were recruited at the outpatient surgical oncology clinic at Hasan Sadikin Hospital (HSH), Bandung in two phases. The first group of 50 patients was recruited between April-June 2010; the second group of 70 patients was recruited between June-October 2011, due to logistical reasons. Eligible patients were aged over 18 years, had a first diagnosis of breast cancer, were able to provide informed consent, had no psychiatric

treatment history, and had an adequate command of the Indonesian language. As HSH is a referral hospital for patients with government insurance for poor people, the majority of patients were middle to low socio-economic status. The healthy group was recruited from a selected area in Bandung (i.e. Maleer urban village). This area was chosen because the women's socio-demographic characteristics were similar to the patient group and also for pragmatic reasons. We consecutively included 122 healthy women between February and March 2012. Population registration records were used to select the healthy women sample. Women were eligible if they were aged over 18 years, were free of chronic disease, were able to provide informed consent, and had an adequate command of the Indonesian language.

Measurements

The study included a socio-demographic status form and measures of HLC, anxiety and depression symptoms. For this study, a self-report form was developed to obtain participants' socio-demographic data on age, marital status, insurance status, education level, employment status and religion. The patients' medical status, including type of cancer, time since diagnosis, stage of cancer and type of treatment was obtained via a medical chart review from HSH.

The C form of the Multidimensional Health Locus of Control (MHLC) scales [25] was used to assess participants' feelings of control over their illness or disease. It was designed as a generic medical-condition-specific measurement of locus of control that could easily be adapted for use with any medical condition. It consists of one Internal scale and three External scales: (1) chance, (2) doctors, and (3) powerful others. In this study, the word 'condition' was substituted with 'cancer' for the patients and 'health condition' for the healthy women. This instrument consists of 18 items using a 6-point Likert format, ranging from 1 = 'strongly disagree' to 6 = 'strongly agree'. A higher score is indicative of a stronger belief in that type of control. In conjunction with the MHLC scales, we used the God Locus of Health Control Scale (GLHC) [11] to assess individuals' beliefs about God's control over their health. The scale has the same format as the MHLC. After obtaining the written permission of the authors, we prepared the Indonesian version of the MHLC scales through the forward- and back-translation method. Firstly, the first author of this paper translated the questionnaire from English to Indonesian, and then a Native American who speaks the Indonesian language fluently translated it back into English. Secondly, a linguist compared the original English version and the back-translation of the questionnaire to assess the significance of any discrepancies. After discussing any possible discrepancies, consensus

was achieved and the Indonesian version of the MHLC scales was finalized. The Cronbach's alpha for each subscale of the Indonesian version of the MHLC in the current sample is as follows: internal HLC=0.62, doctors HLC=0.60, powerful others HLC=0.48, chance=0.56 and God HLC=0.77). For content validity, the items within both scales were scrutinized by three psychologists, who agreed that the items were valid.

In order to measure anxiety and depression symptoms, the Hospital Anxiety and Depression Scale (HADS) was included [26]. This scale has been known to be an effective screening measure for symptoms of anxiety and depression in a medical population [27-28]. It is a 14-item self-report measure that has two subscales; the HADS-A subscale consists of 7 items to measure anxiety, and the HADS-D subscale consists of 7 items to measure depressive symptoms. Respondents are asked to indicate which of 4 options (rated 3-0) best describe their feelings during the previous week. The scores range from 0 to 21 on each subscale, a higher score indicating higher anxiety and depression. The Indonesian version of the HADS has been linguistically validated by the MAPI Institute.

Procedures

The Indonesian Medical Ethical Committee and the Board of Directors of HSH approved the study material and procedure concerning patient participation for compliance with the ethical guidelines. This study was also approved by the Head of Maleer urban village. For women with breast cancer sample, a member of the administrative staff of the surgical oncology clinic identified and approached eligible patients during a regularly scheduled consultation and reported those who consented to a research assistant arranging an appointment during their next visit. Data collection was conducted by 10 Master's students in clinical psychology who had been trained as research assistants and who were supervised by two clinical psychologists. The research assistants provided the patients with further information about the study, instructions on how to fill in the questionnaires and a survey packet. The packet included a letter that described the study, an informed consent form, the socio-demographic form, the MHLC scales and the HADS. Participants completed the questionnaires in the waiting room while they were waiting for their consultation with the physicians for their treatment. There were seven illiterate participants in this study. In these cases, the research assistants read the questionnaires aloud and helped the participants to fill in the questionnaires.

For the healthy sample, data collection was conducted by two Community Association staff members. They identified eligible women, approached them personally to join the study, and arranged an appointment at their home. The Community Association staff provided the

participants with a survey packet consisting of written information about the study purpose, the socio-demographic form and the MHLC scales. First, participants were asked to read the information about the study and the questionnaire instructions. Afterwards they were asked to fill in the socio-demographic form and the MHLC scales. Each participant received a small gift for their participation.

Data Analysis

For data analysis, we used the IBM® SPSS® Statistics version 20. Descriptive statistics were used to describe participants' demographic and clinical characteristics. Differences in demographic characteristics between women with breast cancer and healthy women were analyzed by t-tests. To explore the association between demographic and clinical characteristics and MHLC scores, Pearson's correlation coefficients were performed for continuous variables and t-test analyses were performed for the categorical variables. Marital status (married vs. other), education level (junior high school or lower education vs. senior high school or higher), employment status (housewife/unemployed vs. other), health insurance status, stage of cancer (stage 1 or 2 vs. stage 3 or 4), treatment type (Mastectomy vs. no mastectomy, Radiotherapy vs. no radiotherapy and Chemotherapy vs. no chemotherapy), and family history of cancer were treated as dichotomous variables. Multivariate analysis of variance (MANOVA) was used to evaluate differences between women with breast cancer and healthy women on MHLC subscales scores. Multiple linear regression analyses were conducted to test the association between anxiety and depression and MHLC scores. We analyzed anxiety and depression as the dependent variables and Internal, Chance, Doctors, Powerful others and God subscale scores as the independent variables.

Results

Demographic and clinical characteristics

Women with breast cancer ranged in age from 28 to 66 years (M =45.52, SD = 8.04), and the healthy women ranged in age from 20 to 80 years (M =45.14, SD = 12.60). The difference in age between the two groups was not significant. The groups were also comparable regarding their marital status, education level and employment status. The groups were significantly different in relation to insurance status; the majority of women with breast cancer had health insurance whereas only a minority of healthy women did. A summary of the demographic and relevant clinical characteristics of the participants is presented in Table 1.

Table 1. Demographic and clinical characteristics of study participants

Variable	Breast Cancer Patients n (%)	Healthy Women n (%)
Age (M±SD)	45.52 ± 8.04	45.14 ± 12.60
Marital Status		
Married	101 (84%)	100 (82%)
Single	2 (2%)	3 (2%)
Widowed	17 (14%)	19 (16%)
Education		
None	10 (8%)	0 (0%)
Elementary school	59 (49%)	44 (36%)
Junior high school	24 (20 %)	31 (25%)
Senior high school	21 (18 %)	39 (32 %)
College or university	6 (5%)	8 (7%)
Employment		
Housewife/unemployed	88 (73%)	101 (83%)
Laborer/irregular job	25 (21%)	4 (3%)
Private employee	2 (2%)	14 (12%)
Government officer	5 (4%)	3 (2%)
Religion		
Islam	120 (100%)	122 (100%)
Others	0 (0%)	0 (0%)
Health insurance		
Yes	112 (93%)	23 (19%)
No	8 (7%)	99 (81%)
Months since diagnosis (M±SD)	21.5 ± 20.3	Na
Stage of cancer		
1	3 (3%)	Na
2	54 (45%)	Na
3	46 (38%)	Na
4	17 (14%)	Na
Treatment		
Mastectomy	67 (56%)	Na
Chemotherapy	99 (83%)	Na
Radiotherapy	28 (23%)	Na
Family history of breast cancer		
Yes	30 (25%)	Na
No	90 (75%)	Na

Association between demographic and clinical characteristics and health locus of control

Level of education was associated with internal and chance HLC in both sample groups, women with breast cancer who had junior high school or lower education had higher chance HLC scores (t=3.67, p=0.001), and healthy women who had junior high school or lower education had lower internal HLC (t=-3.02, p=0.003) and higher chance HLC (t=3.03, p=0.003). In women with breast cancer, time since diagnosis was significantly negatively correlated with God LHC scores (r=-0.23, p<0.05). No other demographic or clinical characteristic was significantly associated with HLC.

Health locus of control in breast cancer patients and healthy women

Table 2 shows the means, standard deviations, range and MANOVA results of women with breast cancer and healthy women on the MHLC scales and the HADS scores, whereas table 3 shows Pearson's coefficient correlations of the MHLC subscales. There were significant differences in HLC orientations between women with breast cancer and healthy women. Women with breast cancer had significantly lower scores on internal HLC (F=4.09, p<0.05), higher chance HLC (F=60.53, p<0.01), higher doctors HLC (F=42.80, p<0.01), higher powerful other HLC (F=61.49, p<0.01), and higher God LHC (F=72.59, p<0.01) than healthy women.

Table 2. Means, standard deviations, range and MANOVA results of breast cancer patients and healthy women on the MHLC scales and the HADS scores

Measure	Breast Cancer patients n=120			Healthy Women n=122					
	Mean	SD	Min-Max	Mean	SD	Min-Max	df	F	p-value
Internal	25.16	4.24	13-34	26.30	4.56	13-36	1	4.088	<0.05
Chance	25.03	3.91	15-31	20.28	5.46	8-30	1	60.532	<0.01
Doctor	15.08	1.93	4-18	13.07	2.75	6-18	1	42.798	<0.01
Powerful others	11.98	2.54	6-17	9.24	2.90	3-18	1	61.487	<0.01
God	27.76	4.13	12-36	21.60	6.78	9-35	1	72.593	<0.01
HAD-A	8.13	3.62	0-19	-	-	-			
HAD-D	6.59	3.69	0-15	-	-	-			

HAD-A: Hospital Anxiety and Depression-Anxiety subscale score;
HAD-D: Hospital Anxiety and Depression-Depression subscale score

Table 3. Correlations of the MHLC scales, Anxiety and Depression

Measure	Breast Cancer patients					Healthy Women				
	1	2	3	4	5	1	2	3	4	5
Internal (1)	-	0.34**	0.23*	0.18*	0.22*	-	0.09	0.37**	0.01	0.01
Chance (2)	0.34**	-	0.12	0.43**	0.39**	0.09	-	0.11	0.20*	0.43**
Doctor (3)	0.23*	0.12	-	-0.01	0.13	0.37**	0.11	-	0.05	0.08
Powerful others (4)	0.18*	0.43**	-0.01	-	0.25**	0.01	0.20*	0.05	-	0.35**
God (5)	0.22*	0.39**	0.13	0.25**	-	0.01	0.43**	0.08	0.35**	-
HAD-A	0.09	0.14	-0.014	0.19*	0.23*	-	-	-	-	-
HAD-D	0.02	0.15	-0.01	0.14	0.12	-	-	-	-	-

HAD-A: Hospital Anxiety and Depression-Anxiety subscale score; HAD-D: Hospital Anxiety and Depression-Depression subscale score
*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Association between health locus of control, anxiety and depression

Table 4 shows multivariate linear regression analyses results evaluating the association between HLC, anxiety and depression adjusted for patients' education level. God LHC was found to be the only HLC orientation associated with anxiety (β=0.21, p<0.05). No significant association between HLC orientations and depressive symptoms were found.

Table 4. Standardized betas of multivariate linear regression analyses evaluating HLC, anxiety and depression.

	HADS-A	HADS-D
Internal HLC	0.06	-0.05
Chance HLC	-0.01	0.04
Powerful others HLC	0.13	0.09
God HLC	0.21*	0.07

HAD-A: Hospital Anxiety and Depression-Anxiety subscale score;

HAD-D: Hospital Anxiety and Depression-Depression subscale score

*p< 0.05 corrected for educational level

Discussion

The present study is among the first to explore HLC among women with breast cancer and healthy women in the Indonesian population. Women with breast cancer had higher external HLC (chance, doctors, powerful others and God) and lower internal HLC than healthy women. God LHC was the only HLC belief that explained a significant amount of the variance of anxiety, whereas none of HLC orientations was related to depressive symptoms. Several associations between patients' characteristics and HLC were found. A strong belief that God has control over their cancer was more common in patients with shorter time since diagnosis. Education level was related to a high chance HLC in both women with breast cancer and healthy women.

The findings of the current study show that women with breast cancer tend to attribute their illness to external sources of control, namely: physicians, significant others, chance and God. On the other hand, healthy women tend to have high internal HLC which indicates that they believe their health condition resulted from their own behaviors and capabilities. This finding is in line with what has been found in the previous Western literature suggesting that high beliefs in external sources of control is common in chronically ill patients and breast cancer patients [17, 29-30], whereas healthy people are more likely to have an internal health locus control [18]. One possible explanation for this finding is related to the nature of cancer and its treatment process. The perceived uncontrollable nature of cancer and the uncertainty of treatment outcomes might reduce patients' beliefs in personal control over their illness. In addition, the majority of patients involved in the current study are in an advanced stage of cancer requiring long-term cancer treatment. This situation may lead to an increased belief in external forces among patients, i.e. the doctor, powerful others (e.g. family members), chance and God in the determination of their health condition.

In line with previous research [8, 14, 31], our results indicate that a HLC among women with breast cancer is not necessarily associated with emotional adjustment. Only high God HLC was related to higher level of anxiety. This result is in concordance with a previous study among Rheumatoid Arthritis and Systemic Sclerosis patients that found high God HLC was associated with poor emotional adjustment [11]. Levenson [32] interpreted chance HLC as a belief in an unordered and random nature of the world, whereas powerful others HLC was interpreted as a belief in the basic order and predictability of the world giving potential control over one's life outcomes. Although we did not find any significant relationship between a strong belief in doctors and powerful others HLC and patients' emotional adjustment, we did find that patients who attributed their health condition to God

(which could also be considered to be an unpredictable source of control), was associated with a higher anxiety level. Another explanation might be that high anxiety leads to a greater belief in God's control over one's health.

In the current study, several associations between HLC orientations and patients' demographic characteristics were found. The God HLC showed a modest negative association with time since diagnosis. This finding indicates that newly diagnosed patients are more likely to attribute control over their illness to God than other patients. A review study about religion and coping with serious medical illness suggested that when people become physically ill they tend to rely on religious belief and practice which may reduce the sense of helplessness and maintain hope [33]. In addition, we found a strong association between education and chance and internal HLC. Lower educated patients tended to have a stronger belief in chance than higher educated patients, whereas lower educated healthy women tended to have lower internal and higher chance HLC than higher educated healthy women. These findings are in concordance with previous studies from Western and Eastern countries [18, 34]. In contrast to a study by Wallston and colleagues [11] that found God HLC was negatively correlated with level of education, our results suggest that both women with breast cancer and healthy women have a high God LHC regardless of their level of education.

This current study has several limitations. First, the design is cross-sectional; therefore we could not evaluate the causality between HLC, anxiety and depression. Second, the Indonesian version of the MHLC scales used in the current study has not yet been validated in an Indonesian population. We found suboptimal Cronbach's alpha values in several subscales. Issues regarding to the reliability of the translation of the MHLC has not only occurred in the Indonesian version, but also in the Chinese version of the MHLC that found suboptimal Cronbach's alpha values in several subscales (internal HLC=0.52, doctors HLC=0.51, powerful others HLC=0.44 and chance HLC=0.66) [35]. Theoretically, Cronbach's alpha is related to the test length; therefore, the poor alpha value in the Powerful others subscales may be attributed to the small number of items in the subscales (n=3). The finding that the 6-item subscales have also suboptimal alpha value may be attributed to cultural factors. The research assistants reported that some patients interpreted Chance HLC items as statements about their destiny or fate. For example, the Indonesian term for fate is 'nasib', which refers to something that has been determined by God for each individual and no one else knows about it. Consequently, differences in understanding may have led to the variability of participants' responses. Schmitt [36] argues that there is no sacred level of acceptable level of alpha and in certain cases measures with low levels of alpha may

still useful for the interpretation. Nunnally [37] stated that in the early stages of research, the reliability coefficients of 0.60 or 0.50 may be considered sufficient. Nevertheless, we suggest that our results should be interpreted with caution and a full validation study of the Indonesian version of the MHLC scales is highly recommended before future research is undertaken.

In conclusion, Indonesian women with breast cancer tend to have high external HLC attributing control of their illness to their doctors, to powerful others, to chance, and to God. On the other hand, healthy women tend to have high internal HLC over their health condition. Our findings suggest that believing that an external source of control, i.e. God, controls the course of one's breast cancer may be associated with poorer emotional adjustment in Indonesian breast cancer patients. Interviews or longitudinal studies might give an insight into the direction of this association.

Clinical implications
The implication of the current study findings for clinical practice is that knowledge on patients' HLC can help cancer care professionals' to presume patients' emotional adjustment problem during their illness trajectory. Another implication is that assessing patient's HLC can help tailor psychological support to their specific needs.

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Satisfaction with information and its association with illness perception and quality of life in Indonesian breast cancer patients

Abstract

Purpose: The aims of this study were to assess the level of satisfaction with the information on illness and treatment among breast cancer patients, to explore its association with patients' illness perceptions and quality of life, and to provide recommendations for improvement of the information provided.

Methods: Seventy breast cancer patients at the Outpatient Surgical Oncology Clinic in Hasan Sadikin Hospital in Indonesia were recruited consecutively in a cross-sectional study design. They completed a demographic form, the Satisfaction with Cancer Information Profile, the Brief Illness Perception Questionnaire, and the World Health Organization Quality of Life

Results: A considerable number of breast cancer patients (41–86 %) were dissatisfied with the amount and content of the information they received, particularly on the information about access to patient support groups and the impact of their treatment on long-term quality of life. The majority of patients were dissatisfied with the amount of written information provided. Patients who were satisfied with the type and timing of information received had stronger beliefs in personal control ($\beta=-0.30$, $p<0.05$), lesser concerns about their health condition ($\beta=-0.47$, $p<0.01$), and better understanding of their illness ($\beta=-0.27$, $p<0.05$), and were less emotionally affected by their illness ($\beta=-0.27$, $p<0.05$). In addition, the satisfied patients had a more positive perception of their general health ($\beta=0.31$, $p<0.05$) and better psychological health condition ($\beta=0.33$, $p<0.05$).

Conclusions: Satisfaction with the information provided is associated with better health outcomes, including more positive illness perceptions. This study appears to highlight the importance of providing adequate and sufficient information that meets the needs of patients.

Keywords: Satisfaction with information, illness perceptions, quality of life, breast cancer, Indonesia

Introduction

Cancer is a chronic and frequently terminal disease. In 2008, approximately 12.7 million new cancer cases and 7.6 million cancer deaths were reported worldwide [1]. In Indonesia, breast cancer is the most prevalent cancer among women with an incidence rate of 36.2 and a mortality rate of 18.6 per 100,000 people [2]. Although advances in current breast cancer treatment have been found to improve women's survival by approximately 13% in Western countries [3], the female breast cancer mortality rate in Indonesia is still increasing [4].

In addition to the provision of appropriate medical treatment, cancer services should provide sufficient and adequate information about the disease and its treatment. The provision of information is one of the main elements of supportive care during their illness trajectory [5]. However, literature on the nature of the information provided to cancer patients suggests that the information supplied by health care providers frequently does not meet the needs of individual patients [6-9]. For example, a qualitative study among Indonesian women with breast cancer found that many patients reported having received too little or unclear information from their physicians, particularly the information about the chances of cure and treatment process [10]. Although most cancer patients want to obtain basic information about diagnosis and treatment, not all patients want extensive information at every stage of their illness [11]. Providing information that matches the needs of the patients will lead to higher satisfaction among patients as this information appears to be associated with better illness perception and better health-related quality of life [12-14].

The illness perception concept has been recognized as an important factor associated with psychological outcomes in persons with physical illness [15]. This concept is based on the Common Sense Self-Regulation Model by Leventhal et al. [16]. This model assumes that patients respond to symptoms and signs of illness by forming cognitive and emotional representations of the illness on the basis of concrete and abstract sources of information available to them. The patients' interpretation of that information is the first step in the process of coping with their illness and help seeking [15]. A recent study involving 4,446 cancer survivors in the Netherlands found that satisfaction with information obtained was associated with more positive illness perceptions, except for personal control [13].

Quality of life is another important endpoint of research and clinical practice among cancer patients that seems to be associated with satisfaction with information. The concept of quality of life comprises a broad range of aspects including the perceptions a person has about his/her physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to the salient features of the environment [17]. Information on the quality of life can make a substantial contribution

to the health care providers' understanding of the patients' experiences of their cancer treatment [18]. A review study among cancer survivors concluded that satisfaction with information was positively associated with quality of life [19].

To date, only a little information is known about patient satisfaction with information in the Southeast Asian population of cancer patients, such as that in Indonesia. Therefore, the aims of this study were to assess breast cancer patients' level of satisfaction with information on illness and treatment, to explore its associations with patients' illness perceptions and quality of life, and to provide recommendations for improvement of the information provision. We hypothesized that satisfied patients would report more positive illness perceptions and higher quality of life.

Methods

Participants

This study was part of a larger investigation in which psychosocial functioning of Indonesian breast cancer patients was explored. Seventy consecutive breast cancer patients were recruited from the outpatient surgical oncology clinic at Hasan Sadikin Hospital (HSH) Bandung from June until October 2011. The inclusion criteria were (a) age $\geq$18 years, (b) first diagnosis of breast cancer, and (c) an adequate command of the Indonesian language. Patients who had psychiatric treatment history were excluded from the study.

Procedures

This study was approved by the Indonesian Medical Ethical Committee and the Board of Directors of HSH. A staff member from the surgical oncology clinic who handled patient administration identified eligible patients, approached patients to participate in the study and asked for their initial consent. Patients who agreed to participate were approached by one of the research assistants to arrange an appointment before the next visit to their physician. Data collection was conducted by ten master´s students in clinical psychology who were trained as research assistants and were supervised by SS (clinical psychologist) and AI (first author). The research assistants obtained informed consent and provided detailed information about the study and instructions on how to fill in a demographic form and the questionnaires: the Satisfaction with Cancer Information Profile (SCIP), the Brief Illness Perception Questionnaire (BIPQ), and the World Health Organization Quality of Life (WHOQOL-BREF). Participants filled in the questionnaires while they waited for consultation with the physicians for their treatment in the waiting room. Seven of the participants were illiterate, but they were able to speak and understand the Indonesian language. In these cases, the research assistant helped the participants by reading items aloud and filling in their responses.

Measures

Socio-demographic and medical status

A standard socio-demographic form was used to collect self-report data on age, marital status, education level, employment status, insurance status, and family history of breast cancer. The patients' medical status, including type and stage of cancer, type of treatment, and time since diagnosis, were obtained via their medical records.

Satisfaction with Cancer Information Profile (SCIP)

The SCIP is designed to assess patient satisfaction with cancer information and comprises two subscales [14]. SCIP-A *Satisfaction with the amount and content of information consists of 14 items about unwanted effects* (items 1, 2, 3, 4 and 5), *long-term effects* (items 6, 9, 10, 11, 12 and 13) *and social/financial support* (items 7, 8 and 14). Patients are asked to rate each item using the following response scale: "too much", "about right", "too little" and "none wanted". Patients who rate the items with either 'about right' or 'none wanted' are given the score of 1, whereas patients who rate the items with either 'too much' or 'too little' are given score of 0. A subscale total score is obtained by summing the score for each item. The total score ranges from 0 to 14, with high scores indicating a high degree of satisfaction with the amount and content of the information received. SCIP-B *Satisfaction with type and timing of information received* consists of seven items about the format and timing of the information. Patients are asked to rate each item on a 5-response scale that ranged from "very satisfied"=5 to "very dissatisfied"=0. The total subscale score ranges from 7 to 35, with higher scores indicating higher levels of satisfaction with the type and timing of information. This instrument was translated to produce an Indonesian version using the forward and back translation method. Forward translation was conducted by the first author (AI) and backward translation was conducted by a bilingual native English speaker (JH). A linguist (AC) examined the original English version and the back translation version of the SCIP to assess the significance of any discrepancies and after some revisions, the Indonesian version of the SCIP was finalized. The reliability coefficient for the Indonesian version of the SCIP is good (SCIP-A α= 0.77 and SCIP-B α= 0.81).

Brief Illness Perception Questionnaire

The BIPQ is a shortened version of the Illness Perception Questionnaire-Revised which was developed to obtain a very short and simple measure of illness perception [20]. The

BIPQ consists of eight items using a linear 0-10 response scale and one causal scale. Five of the items assess cognitive illness representations, namely, item 1, consequences (the perceived consequences of the illness on the patient's life); item 2, timeline (the perceived duration of the illness); item 3, personal control (the perceived personal control over the illness); item 4, treatment control (how much the treatment can help to control the illness); and item 5, identity (symptoms that the patient attributes to the illness). Two of the items assess emotional representations, namely, item 6, concern (how much the patient worries about his/her illness) and item 8, emotions (how much the patient is emotionally affected by his/her illness); and one item (item 7) assesses how well the patient understands his/her illness (coherence). The causal representation is assessed by an open-ended response item, which asks patients to list the three most important causal factors in their illness (Item 9). In statistical analyses, response scales of items 3, 4, and 7 were reversed to obtain the same response directions with the other five items. A higher score indicates a more threatening view of illness. Item 9 was excluded from the analyses because of the variety of responses. This instrument was translated to produce an Indonesian version using the same procedure as the one used to translate the SCIP.

World Health Organization Quality of Life (WHOQOL-BREF)

The WHOQOL-BREF is a brief self-report quality of life assessment developed by the WHO group in 24 international field centers [21]. This instrument consists of 26 items, each item representing one aspect of life that is considered to contribute to a person's quality of life. Twenty-four items measure four broad domains: domain 1, physical health (7 items); domain 2, psychological health (6 items); domain 3, social relationships (3 items); and domain 4, environment (8 items). Two other items measure the overall perception of quality of life and general health. The WHOQOL-BREF employs a 5-point scale (1 to 5) with a higher score indicating a higher level of self-perceived quality of life. The Indonesian version of the WHOQOL-BREF is available and has been validated [22].

Statistical analysis

Descriptive statistics were used to describe demographic and clinical characteristics of the study participants, the SCIP, the BIPQ, and the WHOQOL-BREF scores. Associations between demographic and clinical variables and the SCIP, the BIPQ, and the WHOQOL-BREF scores were analyzed by the Pearson's correlation coefficients for continuous variables and t-tests for the categorical variables. The following demographic and clinical

variables were dichotomized: marital status (married vs. other), education level (junior high school or lower education vs. senior high school or higher), employment status (housewife/ unemployed vs. other), ethnic group (Sundanese vs. other), health insurance status (insured vs. not insured), stage of cancer (stage 1 or 2 vs. stage 3 or 4), treatment type (Mastectomy vs. no mastectomy, Radiotherapy vs. no radiotherapy, and Chemotherapy vs. no chemotherapy), and family history of cancer (yes vs. no). Associations among the SCIP, the BIPQ, and the WHOQOL-BREF scores were explored by Pearson's product moment correlation coefficient and Spearman's rank order correlation. Multiple regression analyses were performed to investigate the association between the two subscales of the SCIP, with the BIPQ and the WHOQOL-BREF scores controlled for demographics and clinical characteristics which were correlated with dependent variables. In the multivariate regression analyses, employment status, educational level, and time since diagnosis were entered in the first block and the two SCIP subscales were entered in the second block, whereas the eight domains of illness perception, overall quality of life, general health, and the four domains of quality of life scores were the dependent variables. We applied an alpha value of 0.05 on the 14 regression analyses. A Bonferroni correction for 14 tests would require a nominal alpha of 0.004. However, with our sample size of 70, this conservative value would unduly raise the type II error. Therefore, and also given the pioneer character of the present study in this population, we decided to maintain an alpha value of 0.05. All analyses were conducted using the IBM® SPSS® Statistics version 20.

Results

Demographic and clinical characteristics

The response rate was 91%. Seven out of 77 patients approached declined to participate because they were too ill to fill in the questionnaires. The mean age of participants was 45.6 years (SD=7.88, range=28-66). Fifty-eight (81%) participants were married and forty-six (66%) participants were unemployed/housewife. The majority of the participants had a lower level of education (Junior high school=16% and Elementary school=51%) and seven (10%) had no education. Fifty-five (79%) of participants had Sundanese ethnic origin and fifteen (21%) participants had others ethnic origin (i.e. Javanese and Minang Kabau). Almost half of participants had advanced stages of cancer (stage III=23% and stage IV=20%). The mean number of months since diagnosis was 22.6 (SD=19.7; range= 1-84 months). Ninety-four percent of the participants had health insurance provided by the government to poor people. Demographic and clinical variables are summarized in Table 1.

Table 1. Demographic and clinical characteristics of study participants.

Variable	n (%)
Age (M±SD)	45.60 ± 7.88a
Marital Status	
Married	57 (81%)
Single	2 (3%)
Widowed	11 (16%)
Education (highest)	
None	7 (10%)
Elementary school	36 (51%)
Junior high school	11 (16 %)
Senior high school	10 (14 %)
College or university	6 (9%)
Employment	
Housewife/unemployed	46 (66%)
Laborer/irregular job	18 (26%)
Private employee	1 (2%)
Government officer	5 (7%)
Ethnicity	
Sundanese	55 (79%)
Other	15 (21%)
Months since diagnosis (M±SD)	22.6 ± 19.7a
Range (months)	1-84b
Current stage of cancer	
1	3 (4%)
2	37 (53%)
3	16 (23%)
4	14 (20%)
Treatment modality	
Mastectomy	32 (46%)
Chemotherapy	51 (73%)
Radiotherapy	12 (17%)
Health insurance	
Yes	66 (94%)
No	56 (80%)

a Values are presented as M±SD
b Number of months

Patients' satisfaction with information

Table 2 shows means, standard deviations, and ranges of the SCIP, the BIPQ and the WHOQOL-BREF scores. Satisfaction with the amount and content of information scores were positively skewed with scores ranging from 0 to 13 (mean=5.24, median=5, SD=3.33), whereas satisfaction with the type and timing of information scores were normally distributed with scores ranging from 14 to 33 (mean=22.80; SD=4.12).

Table 2. Means, standard deviations and range of the SCIP, the BIPQ and the WHOQOL-BREF scores.

Measure	Breast Cancer patients n=70		
	Mean	SD	Min-Max
Satisfaction with the amount and content of information	5.24	3.33	0-13
Satisfaction with the type and timing of information	22.80	4.12	14-33
Illness perception			
Consequences	6.19	2.49	0-10
Timeline	5.43	2.12	0-10
Personal control	3.46	2.16	0-8
Treatment control	1.69	1.94	0-7
Identity	5.29	2.43	0-10
Illness concern	6.93	2.34	1-10
Coherence	4.37	2.64	0-10
Emotional representation	5.51	2.56	0-10
Overall quality of life	3.06	0.66	1-5
General health	2.93	0.94	1-5
Physical health	11.77	2.13	7-16
Psychological health	12.69	2.17	8-17
Social relationships	13.11	1.63	9-18
Environment	11.45	1.66	8-15

In regard to the amount and content of information, we found that a considerable number of patients (41%-86%) reported that they received insufficient information regarding several aspects related to their illness and treatment. Table 3 shows the information aspects and proportion of patients who reported that they received too little information, based on the SCIP-A items. Most patients were dissatisfied with the information about social/

financial support, namely, access to patient support groups, how treatment may influence their ability to work and how to ask for possible financial support.

Table 3. Proportion of patients who reported to have received 'too little' information on the SCIP-A.

SCIP-A item	Number of patients (%)
Subscale 1 : Unwanted effects	
Whether your treatment interferes with other medicines you may be taking	**54 (77%)**
What the risks of your experiencing complications are	43 (61%)
What you should do if you experience unwanted side effects	39 (56%)
What the risks of your experiencing side effects are	31 (44%)
Whether the treatment has any unwanted side effects	29 (41%)
Subscale 2: Long-term effects	
How your treatment may impact on your quality of life over the next year	54 (77%)
How long you expect recovery to take	46 (66%)
How you may expect to feel immediately after treatment	45 (64%)
The long term impact of treatment on functioning (daily activities)	42 (60%)
The effect of treatment on your appearance	37 (52%)
Whether you may need further treatment in the future	35 (50%)
Subscale 3: Social/financial support	
Patient support groups for you and your partner	60 (86%)
The effects of treatment on your ability to work	50 (71%)
Who to ask/where to go for possible financial support	48 (69%)

Table 4 shows means and standard deviations of the SCIP-B items, i.e. satisfaction with the type and timing of information. We found that participants were satisfied (SCIP-B item score > 3) with the usefulness of the information provided (mean=3.60), the amount of verbal information (mean=3.46), the usefulness of information for their partner/family

(mean=3.40), the understandability of the information given to them (mean=3.32), the timing at which they received the information (mean=3.13) and the detail of information provided (mean=3.13). However, participants were dissatisfied with the amount of written information provided (mean=2.77).

Table 4. Means and standard deviations of the SCIP-B items scores.

SCIP-B item	Mean (SD)
The usefulness of the information to you	3.60 (0.87)
The usefulness of the information to your partner/family	3.40 (0.87)
The amount of written information supplied	2.77 (0.76)
The amount of verbal information supplied	3.46 (0.81)
The timing at which you received information	3.13 (0.88)
The detail of the information given to you	3.13 (0.93)
How understandable the information was to you	3.31 (0.84)

Demographic variables related to the SCIP, the BIPQ, and the WHOQOL-BREF scores

None of demographic and clinical characteristic was significantly associated with the SCIP scores; however several associations were found with the BIPQ and the WHOQOL-BREF scores. The time since the diagnosis was negatively correlated with the illness concern aspect of illness perception ($r= -0.24$, $p<0.05$), and positively correlated with physical health ($r= 0.25$, $p<0.05$), psychological health ($r= 0.27$, $p<0.05$) and environmental ($r= 0.26$, $p<0.05$) domains of quality of life. Participants who were housewives/unemployed had higher scores on identity ($t=2.568$, $p=0.01$) and the illness concern ($t=2.159$, $p=0.04$) aspect of illness perception, and had lower scores on physical health domain of quality of life ($t=-2.116$, $p=0.04$) compared to participants who worked irregularly or had a permanent job. Participants with middle school or lower education had higher scores on coherence aspect of illness perception ($t=2.452$, $p=0.02$) and had lower scores on the environment domain of quality of life ($t=-2.854$, $p=0.01$) than participants with higher education.

Association between satisfaction with cancer information, illness perception, and quality of life

Table 5 shows the Pearson's product moment correlation coefficients and Spearman's rank order correlation coefficients that describe the magnitude and directions of the bivariate associations between patients' satisfaction with information, illness perceptions, and quality of life. Satisfaction with the amount and content of information scores was only negatively correlated with the emotional representation aspect of illness perception (r=-0.25, p<0.05). Patients who felt less emotionally affected by the illness were more likely to have higher levels of satisfaction with the amount and content of information received. Satisfaction with the type and timing of information scores was negatively correlated with personal control (r=-0.24, p<0.05), illness concern (r=-0.36, p<0.01), coherence (r=-0.25, p<0.05) and the emotional representation aspect of illness perception (r=-0.33, p<0.01). Patients who perceived that they had a high personal control over their illness, less worries about their illness, and better understanding about the illness, and felt less emotionally affected by the illness were more likely to have higher levels of satisfaction with the type and timing of information received. Satisfaction with the type and timing of information scores was also positively correlated with the psychological health domain of quality of life (r=0.26, p<0.05), which means that patients who had higher levels of satisfaction with information were more likely to have better psychological health.

Table 5. Pearson's correlations between the SCIP, the BIPQ and the WHOQOL-BREF scores.

Measure	SCIP-A	SCIP-B
SCIP-A (Satisfaction with the amount and content of information)	-	0.45**
SCIP-B (Satisfaction with the form and timing of information)	0.45**	-
Illness perception		
Consequences	-0.08	-0.05
Timeline	-0.12	-0.02
Personal control	-0.01	-0.24*
Treatment control	-0.08	-0.21
Identity	-0.08	-0.10
Illness concern	-0.09	-0.36**
Coherence	-0.09	-0.25*
Emotional representation	-0.25*	-0.33**

Overall quality of life	0.20 [a]	0.18 [a]
General health	0.15 [a]	0.23 [a]
Physical health	-0.04	-0.03
Psychological health	0.12	0.26*
Social relationships	0.22	0.16
Environment	0.15	0.07

*Correlation is significant at the 0.05 level (two-tailed); **Correlation is significant at the 0.01 level (two-tailed).

a Spearman's rank order correlation coefficient

Table 6 shows multivariate regression analyses results in evaluating the SCIP scales with the BIPQ and the WHOQOL-BREF scales. Satisfaction with the type and timing of information explained a significant amount of the variance of personal control (β=-0.30, $p<0.05$), illness concern (β=-0.47, $p<0.01$), coherence (β=-0.27, $p<0.05$) and emotional representation (β=-0.27, $p<0.05$) of illness perception, the general health (β=0.31, $p<0.05$) and psychological health aspect (β=0.33, $p<0.05$) of quality of life. On the other hand, satisfaction with the amount and content of information did not significantly explain the variance of illness perception and quality of life.

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Table 6. Standardized betas of multivariate linear regression analyses evaluating the SCIP scales with the BIPQ and the WHOQOL-BREF scales.

	BIPQ1 Consequences	BIPQ2 Timeline	BIPQ3 Personal control	BIPQ4 Treatment control	BIPQ5 Identity	BIPQ6 Illness concern	BIPQ7 Coherence	BIPQ8 Emotional representation	Overall QoL	General health	Physical health	Psychological health	Social relationships	Environment
SCIP-A	-0.08	-0.14	0.14	0.02	-0.07	0.13	0.01	-0.12	0.20	0.04	-0.05	-0.06	0.19	0.12
SCIP-B	-0.01	0.05	-0.30*	-0.21	-0.08	-0.47**a	-0.27*b	-0.27*	0.11	0.31*	0.04	0.33*c	0.07	0.07

SCIP-A: Satisfaction with the amount and content of information, SCIP-B: Satisfaction with the form and timing of information, BIPQ: Brief Illness Perception Questionnaire.
*p< 0.05; **p< 0.01
a Corrected for employment status and time since diagnosis
b Corrected for educational level
c Corrected for time since diagnosis

Discussion

Our results show that a considerable number of patients were dissatisfied with the information that was provided. In regard to the amount and content of the information, many patients were dissatisfied with the information about social/financial support, namely; access to a patient support group, how treatment may influence the ability to work and how to ask for possible financial support. In regard to the type and timing, the majority of patients were dissatisfied with the amount of written information provided. None of the demographic and clinical characteristics were associated with patient satisfaction with cancer information. Patients who were satisfied with the type and timing of information had stronger beliefs in their personal control over their illness, less worries about their condition, and a better understanding of their illness and were less emotionally affected by the illness. Patients who were satisfied with the type and timing of information had also a more positive perception of their general health and psychological health condition. However, satisfaction with the amount and content was not associated with any illness perception or quality of life aspects.

Although the importance of sufficient information provision has been recognized, the current sample seems to be less satisfied with the information provided by their physicians compared to a Western sample. In the Western sample, more than half of the participants reported are satisfied, with only two out of fourteen aspects being dissatisfied of the information provided, namely, where to go for financial advice (64 out of 82 patients; 78%) and information about patient support groups (43 out of 82 patients; 52%) [7], whereas in the current sample there were 11 out of 14 aspects of information that patients reported being dissatisfied with by more than half of participants. The majority of Indonesian patients were dissatisfied with the information about social/financial support either because it was not provided or they received too little information. This finding is similar to the previous studies among head and neck cancer, colorectal cancer and endometrial cancer patients in Western countries that found a considerable number of patients who were dissatisfied with the information about access to patient support groups and other services [7, 23-24]. One possible explanation for this finding might be the busy setting and the unbalanced ratio between doctors and patients in the Indonesian health care services which results in a short consultation time [25]. Doctors seemed to focus their information on the physical aspect of illness and treatment. Therefore, although several patient support groups exist (e.g. the Indonesian Palliative Community/Masyarakat Paliatif Indonesia), the information about patient support groups is rarely provided. The improvement of information provision about

access to patient support groups is obviously needed, as social support has been known to be associated with better adjustment to cancer, better quality of life, less treatment side effects, less sense of isolation and alienation, and less psychological distress [26-28].

In the social/financial support aspect, the study showed that many patients were also dissatisfied with the information about long-term effects, in particular, how the treatment may impact on their long-term quality of life. Previous studies in Eastern countries found that doctors were more likely to limit their information about cancer diagnoses and prognoses because they assumed that full disclosure may have negative effects on the outcome of treatment or evoke serious psychological problems [29-31]. We assume that the same applies in Indonesia.

With regard to the type and timing of information, most of the patients were dissatisfied with the amount of written information. This finding corroborates the results of our qualitative study in which patients reported that most of the information was delivered orally by the physicians, whereas written information was seldom provided [10]. Although the need for written information may vary among patients, written information seems to be the most cost effective and fruitful information source in complementing verbal information. The provision of written information will be helpful to increase patient's knowledge, to empower patients, and to help patients to be able to "ask the right questions" during a consultation session [32]. We suggest that the lack of written information provision in the current Indonesian oncology setting can be improved by the provision of clear, concise, easy to understand, and attractive leaflets.

In general, our findings show that patients who are satisfied with the received information had more positive illness perceptions than people who were less satisfied, which is in concordance with the previous studies among cancer patients in the Netherlands and UK [13-14]. The present study found that people who were satisfied with the information provided had stronger beliefs in personal control over their illness, less worries about their condition, and a better understanding of their illness, and were less emotionally affected by the illness. According to the Common Sense Self-Regulatory Model, patients form cognitive and emotional representations of the illness by comparing their own ideas and information received [15]. Therefore, misconceptions about their illness and inappropriate information provision can lead to a maladaptive response to the illness. The provision of appropriate and adequate information for the patients prior to treatment can help patients to reformulate their illness perceptions which will enable them to have a better adjustment during and after treatment [33]. In regard to the quality of life, patient satisfaction with the type and timing of information was associated with better perceptions about their general

health and psychological health condition. These findings show that patient satisfaction with information is associated with illness perceptions; however, it may have only a minor effect on the patients' quality of life.

This study has several limitations. First, the cross-sectional design used in this study limits the possibility to establish a causal association between satisfaction with cancer information, illness perceptions and quality of life. The reverse causal relationship (i.e. negative illness perceptions which lead to lower levels of satisfaction with information) may be possible too. For example, a randomized controlled follow-up study found that patients' illness perception before consultation predicted patient satisfaction with the consultation [34]. In contrast, a prospective study showed that satisfaction with information before treatment was predictive of health related-quality of life 6–8 months after the end of treatment [23]. Second, the number of tests related to the small sample size (n=70) may lead to a limited statistical power. Post-hoc power analyses based on the number of tests yielded powers in the range of 0.47 and 0.83 for the significant analyses. One outcome (i.e., the negative correlation between satisfaction with the form and timing of information received and illness concern) had a power over 0.80 which is generally accepted as sufficient. Lastly, we conducted this study at HSH which is a referral hospital that provides health services to patients who have middle to low socio-economic status. Therefore, larger samples of various patient groups are needed to extrapolate the findings of the present study to other Indonesian patient groups.

Our findings suggest that many Indonesian breast cancer patients are dissatisfied with the information they receive, particularly the information on access to patient support groups and written information. Satisfaction with the type and timing of information is associated with more positive illness perceptions, better perception of general health, and psychological health. However, longitudinal studies are needed to determine whether there is a support for these findings.

Practice implications

Although the Indonesian version of the SCIP used in the present study is the first adaptation based on a single sample of breast cancer patients, it shows a good reliability and is easy to be administered. Therefore, this measure could be used as a screening tool in daily cancer care and helpful in designing tailored information provision for breast cancer patients in Indonesia. Nevertheless, further research is needed to evaluate the psychometric properties of the SCIP which include a larger sample of various cancer patient groups.

Provision of concise and clear information about illness and treatment for the patients is a fundamental principle of care. However, many breast cancer patients reported dissatisfaction with the provision of information, which suggests an alarming gap between the provision of information and the needs of individuals. This situation leaves room for improvement and intervention. Provision of clear, concise, and easy to understand written information (e.g. leaflets) prior to treatment can be a cost-effective and efficient source of information, supplementing the verbal information provided in the busy setting of the oncology clinic in Indonesia.

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Chapter 5

Psychological factors associated with non-adherence to treatment in Indonesian women with breast cancer

Submitted:

Abstract

Objective: The aim of the present study was to test the association between potential psychosocial factors and non-adherence to treatment in Indonesian women with breast cancer.

Methods: Seventy consecutive breast cancer patients who were treated at the Outpatient Surgical Oncology Clinic in Hasan Sadikin Hospital in Indonesia were recruited. They completed a demographic form, the non-adherence questionnaire, the Breast Cancer Knowledge Test, the Brief Illness Perception Questionnaire, the Multidimensional Health Locus of Control Scales, the Satisfaction with Cancer Information Profile and the Distress Thermometer.

Results: Seventeen (24%) out of seventy patients reported that they had delayed initiating treatment at the hospital, and nine (13%) out of seventy patients had missed two or more consecutive treatment sessions. In the bivariate analyses, we found no significant differences on any of the psychological variables between patients who delayed initiating treatment and those patients who did not, whereas patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided and more negative illness perceptions than patients who had not missed their sessions. In multivariate regression analyses, consulting a traditional healer before diagnosis was associated with treatment delay ($\beta=1.27$, $p=0.04$). Poorer perceptions of illness ($\beta=0.10$, $p=0.02$) and whether a traditional healer had been consulted after diagnosis ($\beta=1.67$, $p=0.03$) were associated with missing treatment sessions.

Conclusions: Having negative illness perceptions was associated with missing treatment sessions, whereas consulting a traditional healer was a risk factor for treatment delay and missed treatment sessions.

Keywords: Breast cancer, psychosocial factor, non-adherence, Indonesia.

Introduction

Breast cancer is the most frequently diagnosed cancer among women both in developed and developing countries [1]. However, the mortality rate in developing countries is higher than developed countries due to the more favorable survival rate in developed countries [2]. A review study of cancer epidemiology in South East Asian countries found that late presentation at the hospital for treatment was the major problem related to lower survival rates among women with breast cancer in Indonesia [3]. In addition, poor adherence to treatment is considered to be an important factor contributing to higher mortality rates in developing countries [4].

In general, the term adherence refers to the extent to which patients follow the instructions they are given for prescribed treatments [5]. More specifically, Levinsky & O'Donohue elaborated that non-adherence to treatment may appear in several forms, namely: (a) not attending or coming late to appointments, (b) delay or not initiating a recommended treatment, (c) not completing behavioral recommendations, (d) not taking medication as prescribed, and (e) terminating the treatment prematurely [6]. A recent meta-analysis study about patient adherence which involved 569 published studies found an average non-adherence rate of 25% and a non-adherence rate of 21% for cancer patients [7]. Specifically among breast cancer population, previous studies found about 16%-32% of patients delayed initiating treatment [8-9], and approximately 30% of patients discontinued therapy early [10]. In Indonesia, the general non-adherence rate among the cancer population is not yet known. However, previous studies reported a considerable non-adherence rate. For example, we found in a retrospective study in fifty breast cancer patients that 42% had delayed the uptake of treatment at the hospital and 20% had missed two or more consecutive sessions during their treatment [11]. In a study among childhood leukemia patients, approximately 25% of patients refused or abandoned therapy (12), and another study in retinoblastoma patients found that 31.5% of patients temporarily refused medical treatment, whereas 18.2% of patients refused treatment permanently (13).

A conceptual review study about psychosocial factors underlying breast screening and breast cancer treatment adherence by Magai et al.,[12] suggested that in principle, non-adherence to treatment recommendation is a behavioral problem. They argued that there are at least two reasons to focus on psychological factors in the study of patients' adherence; First, psychosocial factors have been known to play significant roles in health protective and health maintenance behaviors, and second, psychosocial factors are relatively modifiable and can potentially be targeted by an intervention program compared to demographic and structural factors.

In general, psychosocial factors of non-adherence to treatment can be differentiated into two groups, namely: cognitive variables and socio-emotional variables. Cognitive variables include patients' knowledge, risk perception, beliefs and attitude to breast cancer treatment, whereas socio-emotional variables include social networks and social support, and patients' emotions [12]. Previous studies among breast cancer patients found that greater knowledge of the disease and treatment are associated with better adherence [13-15]. How patients' perceive and respond to their illness (i.e. illness perceptions) and the degree to which a person believes that he/she controls the events in his/her life have also been assumed to be predictors of non-adherence. A review study of patients' illness perceptions and medication adherence found that negative illness perceptions were directly or indirectly associated with poor adherence to medication [16]. A review study about adherence to therapy with oral anti-neoplastic agents suggested that people with a strong belief that their behavior played a large role in determining their circumstances (internal locus of control) are more likely to adhere to a prescribed treatment regimen [17]. With regard to socio-emotional variables, a meta-analysis study about social support and patient adherence to medical treatment found that better social support was associated with better adherence [18]. Another meta-analysis found that high levels of psychological distress was associated with poor adherence [19].

Our previous qualitative study in Indonesian breast cancer patients identified several potential psychosocial factors underlying patients' adherence to treatment, including: lack of awareness and knowledge, cancer beliefs, treatment beliefs, emotional burden and unmet information needs [11]. The aim of the present study was to test the association between these potential psychosocial factors (i.e. knowledge, illness perception, health locus of control, satisfaction with information and distress) and non-adherence to treatment in Indonesian breast cancer patients in a quantitative way.

Methods

Participants

This study was part of a larger investigation in which the psychosocial aspects of Indonesian breast cancer patients undergoing medical treatment (i.e. surgery, chemotherapy and radiotherapy) were explored. Seventy consecutive patients were recruited between June-October 2011 at the outpatient surgical oncology clinic at Hasan Sadikin Hospital (HSH) Bandung. The study included: patients aged eighteen years or older; patients who had

received a first diagnosis of breast cancer; patients who had no psychiatric treatment history, and patients who had an adequate command of the Indonesian language.

Measures

Socio-demographic characteristics

A standard socio-demographic form was used to collect self-report data on age, marital status, education, employment status, family income, insurance status, travel time to hospital, time since diagnosis, family history of cancer and use of traditional healer. The patients' medical records were also reviewed to obtain data on type and stage of cancer and type of treatment.

Adherence to Treatment

Patients' adherence to treatment was assessed using a self report. We evaluated 2 forms of non-adherence; (1) treatment delay, and (2) not attending treatment appointments. As there is a strong association between delaying breast cancer treatment by three months or more and lower survival [20], we adopted a three-month interval as our gold standard for treatment delay. A patient was categorized as a non-adherer according to the first definition if the period between the first diagnosis and the first admission at HSH was >3 months. A patient was categorized as a non-adherer according to the second definition if they were absent from two or more consecutive treatment sessions at HSH [21].

Breast Cancer Knowledge

Patient knowledge was assessed using the Breast Cancer Knowledge Test (BCKT) [22]. This instrument comprises 2 sections; the first section consists of 12 items to assess individual breast cancer general knowledge, and the second section consists of 8 items to assess individual knowledge about the curability of breast cancer. For each item, patients are asked to mark whether the statement is 'true' or 'false'. Items correctly answered are given a score of 1, and items answered incorrectly are given a score of 0. The BCKT was translated to the Indonesian language using the forward- and back-translation method. In the first section, item number 3 about the breast cancer prevalence was adjusted with the actual Indonesian prevalence rate. The total score ranged from 0 to 20, with higher scores indicating higher breast cancer knowledge. The BCKT has an acceptable reliability coefficient (α=0.69).

Illness Perceptions

Patient's cognitive and emotional representation of illness was assessed using the Brief Illness Perception Questionnaire (BIPQ) [23]. This instrument was constructed based on the Common Sense Model of Illness Cognition which assumes that illness perceptions will have an effect on patients' coping behaviors and psychological outcomes [24]. Illness perceptions consists of 8 dimensions, namely: (1) *consequences* which reflect the expected effects and outcome of the illness; (2) *time line* which refers to the perceived duration of the illness; 3) *personal control* which reflects the beliefs about personal abilities to control the illness; (4) *treatment control* which reflects the beliefs about the efficacy of the treatment to cure or manage the illness; (5) *identity* which refers to the label the person uses to describe the illness and the symptoms; (6) *illness concern* which refers to how much the person worries about his/her illness; (7) *coherence* which refers to how well the person understands his/her illness; and (8) *emotional representation* which reflects a person's evaluation of the potential emotional impact of the illness [23]. Each dimension is measured by a single item using a continuous linear 0-10 point scale. Answer scales of items about personal control, treatment control and coherence were reversed to elicit the same response directions with the other five items. The overall score was obtained by summing the eight item scores where a higher score indicates a more threatening view of the illness. This instrument was translated into the Indonesian language using the forward- and back-translation method.

Internal Health Locus of Control

The Internal Health Locus of Control (HLC) was assessed using the Internal HLC subscale of the Multidimensional Health Locus of Control (MHLC) Scales [25]. The MHLC was developed as a generic medical condition-specific measurement of locus of control that assesses individuals' feelings of control over their illness or disease, including the internal, chance, doctors and powerful others subscales. This measure is an 18-item scale using a 6-point Likert format, ranging from 1 = 'strongly disagree' to 6 = 'strongly agree'. A higher score on each subscale is indicative of a stronger influence of the dimension in health behaviors. The MHLC scales were translated into Indonesian through the forward- and back-translation method. Cronbach's alpha coefficients were ranged from 0.48 to 0.77. For content validity, the scales were assessed by three psychologists.

Satisfaction with Cancer Information

Patient satisfaction with the information provided was assessed using the Satisfaction with Cancer Information Profile (SCIP) [26]. This measure comprises 2 subscales: Subscale 1 consists of 14 items which measures patient satisfaction with the amount and content of information. Patients are asked to rate each item using the following response scale: 'too much', 'about right', 'too little' and 'none wanted'. Patients who rate the items with either 'about right' or 'none wanted' are given score of 1, whereas patients who rate the items with either 'too much' or 'too little' are given score of 0. A subscale total score is obtained by summing the score for each item, which ranged from 0 to 14. High scores indicating a high degree of satisfaction with the amount and content of information received. Subscale 2 consists of 7 items which measure patient satisfaction with the type and timing of information received. Patients are asked to rate each item on a 5-response scale ranged from 'very satisfied'=5 to 'very dissatisfied'=0. The total subscale score ranged from 7 to 35, with higher scores indicating higher levels of satisfaction with the form and timing of information. The SCIP was translated to the Indonesian version using the forward- and back-translation method. The reliability coefficient for the Indonesian version of the SCIP was good (subscale 1 α= 0.77 and subscale 2 α= 0.81).

Psychological Distress

Psychological distress was assessed using the Distress Thermometer (DT) [27]. The DT was developed by the NCCN and is a 1-item self-report measure of psychological distress in patients with cancer. Patients are asked to report their distress in the past week on a thermometer-like 11-point visual analogue scale, with scores ranging from 0 (no distress) to 10 (extreme distress). We prepared an Indonesian version of the Distress Thermometer using the forward- and back-translation method.

Procedures

This study was approved by the Indonesian medical ethical committee and the Board of Directors of HSH. Eligible patients were approached by a member of the administration staff from the surgical oncology clinic. They asked patients for initial consent and referred patients who were willing to participate in the study to the research assistants. One of the research assistants followed up and arranged an appointment with the patients on their next visit. All data collections were conducted by 10 master´s students in clinical psychology who were trained as research assistants and were supervised by AI (first author) and SS

(fifth author). After signing the informed consent, patients were asked to complete a socio-demographic form, the non-adherence questionnaire, the BCKT, the BIPQ, the MHLC, the SCIP, and the DT. For those who were unable to complete the questionnaires unassisted (i.e. seven patients were illiterate), the research assistants read the questionnaires aloud and recorded the patients' answers on the questionnaires. Patients filled in the questionnaires in the waiting room of the clinic before their consultation with the physicians.

Data Analysis

All data analyses were performed using the IBM® SPSS® Statistics version 20. Descriptive statistics were used to describe the demographic and clinical information, the mean scores of the questionnaires (i.e. the BCKT, the BIPQ, the MHLC, the SCIP and the DT), and the non-adherence status. To explore the association between non-adherence and the demographic, clinical and psychological variables, Chi-square analyses were conducted for categorical variables and t-test analyses were conducted for continuous variables. Backward stepwise logistic regression analyses were performed to analyze the association between psychosocial variables and non-adherence. The BCKT, the BIPQ, the Internal HLC, the SCIP and the DT scores were the predictors whereas treatment delay and not attending treatment appointment were the outcomes. In addition, backward stepwise logistic regression analyses were performed to explore the association between demographic and clinical characteristics and non-adherence. Age, marital status, education level, employment status, family incomes, travel time to hospital, consult a traditional healer before and after diagnosis were the predictors whereas treatment delay and not attending treatment appointment were the outcomes. For the logistic regression of not attending treatment appointments, current stage of cancer was also included as a predictor. A power calculation for 70 cases with 6 predictors in a linear regression analysis turns out that a medium effect (f^2=0.21) should exist in the population to find a significant effect [28].

Results

Demographic and clinical characteristics

The mean age of participants was 45.6 years (SD=7.88, range=28-66). Fifty-seven (81%) participants were married and forty-six (66%) participants were unemployed/housewives. The majority of participants had a lower education level (junior high school=16% and elementary school=51%) and seven (10%) had no education. Fifty-three (76%) participants had a low monthly income (<USD$200) and twenty-eight (40%) had a travel time from

home to the hospital >3 hours. Almost half of participants had an advanced stage of cancer (stage III=23% and stage IV=20). The mean number of months since diagnosis was 22.6 (SD=19.7; range=1-84 months, median=15 months). Ninety-four percent of the participants had health insurance provided by the government to poor people. Demographic and clinical variables are summarized in Table 1.

Table 1. Demographic and clinical characteristics of study participants

Variable	n (%)
Age (M±SD)	45.60 ± 7.88
Marital Status	
Married	57 (81%)
Single	2 (3%)
Widowed	11 (16%)
Education (highest)	
None	7 (10%)
Elementary school	36 (51%)
Junior high school	11 (16 %)
Senior high school	10 (14 %)
College or university	6 (9%)
Employment	
Housewife/unemployed	46 (66%)
Laborer/irregular job	18 (26%)
Private employee	1 (2%)
Government officer	5 (7%)
Family income (monthly)	
< USD$ 200	53 (76%)
USD$200 - USD$300	13 (18%)
> USD$300	4 (6%)
Travel time to hospital	
< 1 hour	22 (31%)
2-3 hours	20 (29%)
> 3 hours	28 (40%)
Months since diagnosis (M±SD)	22.6 ± 19.7
Range (months)	1-84
Current stage of cancer	
1	3 (4%)

2	37 (53%)
3	16 (23%)
4	14 (20%)
Treatment modality	
Mastectomy	32 (46%)
Chemotherapy	51 (73%)
Radiotherapy	12 (17%)
Health insurance	
Yes	66 (94%)
No	4 (6%)
Family history of breast cancer	
Yes	14 (20%)
No	56 (80%)
Consult a traditional healer	
Before diagnosis	33 (47%)
After diagnosis	12 (17%)

Non-adherence to treatment

(1)   Treatment delay

Seventeen (24%) out of seventy patients had delayed initiating treatment at HSH with a time delay ranging from 3 to 27 months, except for the two participants who had delayed treatment for four years. The median time of treatment delay was seven months. In regard to demographic and clinical characteristics, we found that the stage of cancer and consulting a traditional healer before diagnosis was associated with treatment delay. Patients who delayed initiating treatment were more likely to be at an advanced cancer stage (stage III and IV) (χ^2 = 9.244, df = 3, p= 0.03) and had more frequently consulted a traditional healer before their diagnoses (χ^2 = 4.953, df = 1, p= 0.03). Means, standard deviations and range of the psychological variable scores are detailed in Table 2. T-test results showed no significant differences on any of the psychological variables between patients who delayed initiating treatment and who did not. Backward stepwise logistic regression analyses found that consulting a traditional healer before diagnosis was the only significant predictor of treatment delay (χ=1.27, p=0.04).

(2)   Not attending treatment appointments

Nine (13%) out of seventy patients reported that they had missed two or more consecutive treatment sessions. In regard to demographic and clinical characteristics, we found that

only consulting a traditional healer after diagnosis was associated with missing two or more consecutive treatment sessions (χ^2 = 5.420, df = 1, p= 0.02). Means, standard deviations and range of the psychological variable scores are detailed in Table 2. T-test results showed that patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided (t=2.247, p= 0.03) and higher illness perceptions scores (t=-2.520, p= 0.01) than patients who had not missed two or more consecutive sessions. Backward stepwise logistic regression analyses found that illness perception (β=0.10, p=0.02) was the only significant psychological predictor of missing two or more consecutive treatment sessions. In addition, consulting a traditional healer after diagnosis (β=1.67, p=0.03) was a significant demographic predictor of missing two or more consecutive treatment sessions.

Table 2. Means, standard deviations and t-test results of the psychological variables of the non-adherers and the adherers group

Measure	Initiating a recommended treatment				Attending appointments			
	Adherers (n=53)	Non-adherers (n=17)			Adherers n=61	Non-adherers n=9		
	Mean (SD)	Mean (SD)	t-test	p-value	Mean (SD)	Mean (SD)	t-test	p-value
Distress	4.58 (2.76)	4.82 (2.60)	-0.315	0.75	4.46 (2.66)	5.89 (2.80)	-1.495	0.14
Internal Health locus of control	24.57 (4.18)	23.59 (4.53)	0.823	0.41	23.97 (4.08)	26.78 (4.84)	-1.885	0.06
Satisfaction with the amount and content of information	5.40 (3.50)	4.76 (2.75)	0.679	0.50	5.34 (3.28)	4.56 (3.75)	0.662	0.51
Satisfaction with the form and timing of information	23.23 (4.07)	21.47 (4.11)	1.544	0.13	23.21 (3.89)	20 (4.72)	2.247	0.03
Illness perception	38.51 (9.35)	39.94 (13.25)	-0.414	0.68	37.70 (10.26)	46.67 (7.35)	-2.520	0.01
Breast cancer knowledge	9.42 (4.16)	8.82 (4.16)	0.582	0.56	9.18 (3.63)	9.89 (3.79)	-0.544	0.59

Chapter 6

Discussion

Findings from the present study showed that 24% of breast cancer patients reported that they had delayed initiating treatment at the hospital and 13% of breast cancer patients had missed two or more consecutive treatment sessions. In the bivariate analyses, we found no significant differences on any of the psychological variables between patients who delayed initiating treatment and those who did not. Patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided and more negative illness perceptions than patients who had not. In multivariate regression analyses, consulting a traditional healer before diagnosis was associated with treatment delay. Having negative illness perceptions and consulting a traditional healer after diagnosis were associated with missing two or more consecutive treatment sessions.

Of the seventy patients who were currently receiving treatment for their breast cancer, 24% reported that they delayed initiating treatment after their diagnosis which is lower than our previous study that found 40% delayed initiating treatment [11]. One possible explanation for this difference may be related to the clinical characteristics of the patients. We found that the majority of patients (57%) in the current study were at stage I and II and, therefore probably had more positive expectations, whereas in the previous study the majority of patients (64%) were at stage III and IV. This difference indicates also that patients in the current study came earlier to the hospital compared with patients in the previous study. Nevertheless, the non-adherence rate in this study was higher than a recent study in South-East Asian breast cancer patients which adopted a similar gold standard (i.e. 3 months delay) that found 7% of patients delayed initiating treatment at the hospital [29]. Thirteen percent of patients were non-adherent to treatment by missing two or more consecutive treatment sessions. This percentage is lower than previous studies in Asian and Western breast cancer patients. For example, a study among Malaysian breast cancer patients found that 29% of patients were non-adherent to chemotherapy and 13% of patients were non-adherent to radiotherapy [30]. A study among American breast cancer patients found that 31% of patients discontinued therapy and 28% were non-adherence to adjuvant hormone therapy [10], and a study among Canadian breast cancer patients found that 22% of patients discontinued adjuvant endocrine therapy within 2 years [31]. This difference may be attributed to the operational definition of non-adherence. In the current study, the non-adherence rate refers to the percentage of breast cancer patients who had missed two or more consecutive treatment sessions, whereas the non-adherence rate in the previous literature refers to several outcomes, such as non-adherence to adjuvant endocrine therapy

or other medical regiments. In addition, non-adherence was measured by patients' self report in a retrospective way; therefore patients' responses were vulnerable to recall and social desirability bias which may have resulted in an underestimation of non-adherence.

Having negative illness perceptions was associated with missing two or more consecutive treatment sessions in both bivariate and multivariate analyses. These results are in concordance with the result of a recent review study that found a negative association between illness perception and adherence to medication [16]. According to the Common Sense Model (CSM) of illness, patients create cognitive and emotional representations of the illness as responses to symptoms and signs of illness, and those perceptions will lead to their coping responses [23]. For example, previous studies among diabetes and hypertension patients found that patients who felt treatment could control their illness were more likely to take their medication as prescribed [32-33]. This finding identifies a potential target for intervention to improve patients' adherence to treatment. Provision of appropriate and adequate information about illness and treatment may eliminate patients' misunderstanding and negative conceptualization of the illness and may lead to better adherence [34].

In bivariate analyses, lower satisfaction with information provided was found to be associated with missing two or more consecutive treatment sessions. This finding is in line with previous literature which found that greater satisfaction with information was associated with higher adherence to medical recommendations and treatments [35-36]. However, this association was not significant in multivariate analyses. One possible explanation for this result is a high collinearity between illness perception and satisfaction with information (r=-0.35, p=0.01), therefore multivariate analyses showed only the strongest predictor (i.e. illness perception) of missing two or more consecutive treatment sessions.

We found that consulting a traditional healer before diagnosis was a risk factor for treatment delay and consulting a traditional healer after diagnosis was a risk factor for missing treatment sessions. This finding supports the results of our previous study that identified a strong belief in traditional healers as one of the main barriers of non-adherence to treatment [11]. As a strong belief in traditional healers has been confirmed as a factor influencing patients' adherence to treatment, it implies that it is important to understand patients' attitudes towards, and perceptions of, traditional healers. Better knowledge about this topic may assist health professionals to give more appropriate information about cancer and its treatment. Improving patient knowledge may help to reduce the unrealistic reliance of patients on traditional healers.

Contrary to our expectations, none of psychological variables was associated with treatment delay, and illness perception was the only psychological factor that significantly associated with missing two or more consecutive treatment sessions. Our finding that patients' level of knowledge was not associated with non-adherence is in contrast with previous breast cancer studies that found greater knowledge was associated with greater adherence [13-15]. A possible explanation for this divergence is that patients' knowledge was measured after the time period of non-adherence in our study; therefore patients' knowledge may have changed. According to a review study about common factors underlying breast cancer treatment adherence by Magai et al., [12] literature on the impact of knowledge on breast cancer treatment adherence is still limited, therefore the role of patients' knowledge on adherence to treatment is still indecisive and more research is required. As internal HLC has been known to be positively associated with health behavior [37], we expect that patients with a high internal HLC will be more likely to adhere to treatment. This was not supported by our results which were similar to a previous study in breast cancer patients [38]. As cancer is chronic and has an uncontrollable nature, it leaves only a little personal control. Therefore, having an internal HLC is not necessarily associated with better adjustment in cancer patients. In regard to the emotional variables, the current study found that distress was not associated with non-adherence which is in contrast with previous literature that found that a higher level of distress was associated with poor adherence to medical recommendations [19]. This non-significant association might be explained by the possible changes in patients' distress between the time of non-adherence and the psychological measurements.

Several methodological limitations should be noted. First, this study is based on consecutive patients where the majority has low socio-economic status because HSH is a referral hospital for the poor people. The relatively small sample size and homogeneity of the current sample could have some influence on the results. For example, a review study of 50 years of research about adherence to medical recommendations found that studies with smaller sample sizes reported higher adherence than larger samples [7]. Therefore, the adherence rate obtained in this study should be interpreted with caution and may not represent the general Indonesian cancer patient population. Lastly, the cross-sectional design of the study limits the causal association between psychological factors and non-adherence to treatment. Moreover, the psychological variables were measured after the occurrence of non-adherence, thus further prospective studies are needed to ascertain the current study findings. In conclusion, we found that an alarming number of breast cancer patients delayed initiating treatment at the hospital. We found indications for a difference

among non-adherence and adherence groups on illness perceptions and satisfaction with information provided, and having negative illness perceptions was associated with missing treatment sessions. Finally, as consulting a traditional healer was associated with treatment delay and also missing treatment sessions, health professionals' awareness about this issue is important and the provision of sufficient information about illness and its treatment is urgently needed from the first medical consultation in order to reduce patients' unrealistic beliefs in traditional healers and improve their adherence to medical recommendations.

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General discussion

The case fatality of women with breast cancer in Indonesia is increasing [1]. It is therefore important for health care professionals, including oncologists, nurses and medical psychologists to understand psychological adjustment and potential psychosocial factors that relate to non-adherence to medical recommendations in women with breast cancer.

The main aim of this thesis was to identify possible psychosocial risk factors for non-adherence to treatment and for psychological adjustment in Indonesian women with breast cancer. Considering the pioneering character of the present study in this population, we also developed and validated an Indonesian version of the measurement instruments to be used in daily cancer care in Indonesia. This chapter consists of 3 sub-sections; the first section presents the summary of the main findings and a synthesis of the evidence from our studies. The second section discusses the strengths and limitations of the current study and also presents recommendations for future research directions. The final section describes potential implications of the findings for clinical practice.

7.1 Main findings

7.1.1 Psychological adjustment to breast cancer

In Indonesia, breast cancer is the most prevalent cancer among women and has a relatively high mortality rate [1]. Therefore, women who receive a breast cancer diagnosis are facing multiple stressors throughout their illness trajectory, including experiencing treatment side effects, coping with financial, family and social problems, and facing the risk of recurrence and/or death. Understanding the psychological adjustment and its related factors in women with breast cancer seems to be an important aspect in cancer care, as poor psychological adjustment to cancer has been reported to be associated with several negative outcomes. For example, patients with a high level of distress were more likely to have a low adherence to treatment recommendations, poor satisfaction with care and poor quality of life [2-4].

In our study described in **Chapter 3**, we investigated the Indonesian version of the 'Distress Thermometer' (DT) in order to know its psychometric properties. It showed a good concurrent validity with the Hospital Anxiety and Depression Scales (HADS), which is a well-established screening tool for distress. A cutoff score of 5 on the DT yielded optimal sensitivity and specificity for the current population, which is in concordance with the results of a meta-analysis study looking at the accuracy of the DT to detect possible distress, anxiety and depression in cancer settings [5]. Using a HADS cutoff score of 15, more than a half of the Indonesian women with breast cancer in our population were identified as experiencing clinically significant distress. The proportion of women who experienced

significant levels of distress in the current sample is higher than results of previous studies which found that 20-40% of cancer patients experience a significant level of distress. These studies were mainly performed in Western countries [6-7]. We found that patients who had significant distress were more likely to report more problems in the practical, family, emotional, spiritual/religious and physical domains. Interestingly, patients who had clinically significant distress were more likely to experience spiritual/religious concerns which included concerns about the meaning of life and trust in God. This finding is similar to the result of a study in Korean cancer patients [8], however it is in contrast with the results of studies in Western cancer patients that found that clinically significant distress was not or only weakly associated with spiritual/religious concerns [9-12]. The positive association between high distress and spiritual/religious concerns is possibly due to cultural factors. Indonesian people are generally religious[1] and have a strong belief in God to heal their disease. We assume that women who do not experience progress in their illness, will be more convinced that their cancer is the will of God and they therefore cannot change their destiny which might trigger higher levels of distress. We also found that distress, as measured with the DT, was negatively correlated with patients' quality of life, which is in concordance with previous studies among Turkish, Norwegian, Germany and Spanish cancer patients [11, 13-15].

With regard to psychological adjustment, Health Locus of Control (HLC) has been recognized as a potential predictor of a better adjustment to cancer. Theoretically, internal HLC (i.e. an individual's belief that what happens to his/her health condition is a result of his/her own actions) is considered to be associated with better health outcomes and emotional adjustment [16]. Our study presented in **Chapter 4** revealed that Indonesian women with breast cancer had higher external HLC (i.e. chance, doctors, powerful others and God) and lower internal HLC than healthy women which is concordance with the previous studies in chronically ill patients and breast cancer patients in other countries [17-20]. One possible explanation for this finding may involve the uncontrollable nature of cancer and the uncertainty of treatment outcomes which could reduce patients' beliefs in personal control over their illness. In addition, many patients in our study had an advanced stage of cancer which required a long-term cancer treatment. Such a condition may increase patients' belief that external sources are determining their health condition, such as physicians, powerful others (e.g. family members), chance and God. In this study, only God LHC explained

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1. It is obliged to have a religion in Indonesia, which is also registered in each identification card.

a significant amount of the variance of anxiety, other HLC dimensions did not show any association with anxiety and depression symptoms, This seems in concordance with a previous study among Rheumatoid Arthritis and Systemic Sclerosis patients [21], whereas none of the HLC orientations was related to depressive symptoms. Our results on God HLC suggest that a strong belief in an external source of control, i.e. God, might be negatively associated with patients' emotional adjustment. However, another explanation might be possible too; patients who experienced higher anxiety level may get a greater belief in God's control over their health conditions. For example, a previous study in the UK cancer patients found that religious control was positively associated with the hospital anxiety and depression scale scores and expression of a fatalistic attitude to cancer, therefore it suggests a link that anxiety and depression feelings coupled with fatalistic perception of cancer may increase patient's belief that religious control (i.e. God and religion) has an influence on the course of their disease [22].

Improving patients' quality of life is considered the ultimate goal of cancer care service in both clinical practice and research. Satisfaction with information and positive illness perception were factors that have been found to be associated with patients' quality of life [23]. The study presented in **Chapter 5** showed that a considerable number of patients who were treated at the outpatient surgical oncology clinic, were dissatisfied with the information provided by the health care professionals (i.e. oncologist and nurses). With regard to the amount and content of the information many patients were dissatisfied with information about social/financial support, namely; access to a patient support group, how treatment may influence the ability to work and how to ask for possible financial support. The lack of information about social/financial support may be attributed to a high number of patients and limited practice hours, and the unbalanced ratio between doctors and patients in the Indonesian health care services which results in a short consultation time [24]. Doctors seem to focus their information primarily on the physical aspects of illness and treatment. Although several patient support groups (e.g. the Indonesian Palliative Community) as well as government financial support for the poor people are available (e.g. ASKESKIN and JAMKESDA), this information is rarely provided during consultation time. In regard to the type and timing of information provided, the majority of patients were dissatisfied with the amount of written information provided. Patients reported that most of the information was delivered orally by the physicians, whereas written information was seldom provided. As the provision of written information has been considered to be beneficial to increase patient's knowledge and to empower patients during a consultation session [25], providing clear, concise, easy to understand and attractive leaflets may be beneficial. The current study

also found that higher satisfaction with the received information was associated with more positive illness perceptions, i.e. stronger beliefs in personal control, less concerns about their health condition, better understanding of the illness, and less emotionally affected by the illness, which is in concordance with previous studies among cancer patients in the Netherlands and the UK [23, 26]. According to the Common Sense Self-Regulatory Model, patients form cognitive and emotional representations of the illness by comparing their own ideas and information received [27]. Misconceptions about cancer and inappropriate information provision prior to and during treatment may lead to incorrect patients' perceptions toward their illness, which might lead to a maladaptive response to the illness.

In regard to quality of life, we found that only patient satisfaction with the type and timing of provided information was associated with more positive perceptions about their general health and psychological health condition, whereas satisfaction with the amount and content of provided information was not associated with quality of life. Overall, these results show that patient satisfaction with information is associated with illness perceptions, whereas only the aspects of type and timing seem to have an effect on patients' quality of life.

7.1.2 Psychological factors associated with non-adherence to treatment

In **Chapter 2** we explored psychosocial factors related to delay in seeking medical help and non-adherence to treatment in Indonesian women with breast cancer qualitatively. Our results showed that a considerable number of patients had delayed in seeking medical help and initiating their treatment at Hasan Sadikin Hospital (HSH). We found 8 themes related to delay in seeking medical help and non-adherence to treatment which can be categorized into 3 clusters, namely: (1) factors related to patients (i.e. lack of awareness and knowledge, cancer beliefs and treatment beliefs), (2) factors related to treatment (i.e. financial problems, emotional burden and severe side effects), and (3) factors related to patient-health provider relationships (i.e. paternalistic style of communication and unmet information needs). Our findings indicated that lack of breast cancer awareness and inadequate knowledge about signs and symptoms of breast cancer influenced patients' delay in seeking medical help negatively, which is similar to the results of previous studies that found lack of breast cancer knowledge was associated with women's ability to recognize breast cancer symptoms and the perceived necessity of seeking medical help [28-31]. Several programs could be introduced to improve breast cancer awareness and knowledge that may contribute to lowering the number of delay in seeking medical help. Considering the demographic and

infrastructure factors in Indonesia, we suggest the use of media campaigns, including public service announcements on television, radio and newspapers. The use of media campaigns have been found to be an effective way to improve breast health knowledge, to teach women how to conduct breast self-examination and to increase breast health practices in Chinese population [32]. Besides the lack of knowledge, incorrect cancer beliefs (e.g. cancer is incurable and a shameful disease) and negative treatment beliefs influenced women's perception of the necessity to seek medical help and to start their treatment in the referral hospital. In the same way, a previous study in Malaysian women found that negative perceptions of breast cancer were the main reason for delay in the presentation of breast cancer [31]. Many women had negative perceptions of medical treatment of breast cancer; in contrast, they had a great belief in traditional healers. They believed that traditional therapy was an alternative solution for their health problem or a complement to medical treatment, which influenced patients' behaviors and treatment decisions.

Although most patients in our study had government insurance for poor people, which covers all medical expenses, financial problems (e.g. financial difficulties in paying transportation costs to the hospital, accommodation and other logistical costs) were the most reported reason to skip two or more consecutive treatment session. This result is similar to previous studies in Indonesian child leukemia and retinoblastoma patients [33-34]. Furthermore, we found that patients who experienced severe side effects were more likely to miss their treatment because they were too ill to come to the hospital or felt that the side effects of the treatment were worse than cancer itself. This finding is in concordance with the results of a review study about adherence rates in long-term hormonal therapy, which included European, African and Asian breast cancer patients [35]. In addition, dissatisfaction with the information provided at consultations was also a factor related to patients' non-adherence to treatment. Some participants reported that they received either too little or too complicated and incomprehensive information, leaving their informational needs unmet. This condition seems to influence patients' understanding and belief about treatment efficacy, which may decrease their treatment adherence.

To confirm the findings from our qualitative study, we conducted a quantitative study aimed to evaluate the association between potential psychosocial factors (i.e. knowledge, illness perception, health locus of control, satisfaction with information and distress) and non-adherence to treatment in Indonesian women with breast cancer, which was presented in **Chapter 6**. Our results showed that a lower percentage of breast cancer patients delayed initiating treatment at the hospital (24%) than we found in our previous study in which 40% of patients had delayed initiating treatment. Differences in clinical characteristics of both

sample groups were associated with this difference; the majority of patients (57%) in the latter study were in the early stages (stage I and II), whereas in the former study the majority of patients (64%) were in an advanced stage (stage III and IV). Therefore, the sample in the quantitative may have had more positive expectations about the medical treatment of breast cancer. Notwithstanding, the percentage of non-adherence in this study was higher than in a recent study in South-East Asian breast cancer patients which adopted a similar gold standard (i.e. 3 months delay) and found that only 7% of the patients delayed initiating treatment at the hospital [36]. The authors of a comparison study between breast cancer patients in Indonesia and Malaysia that found that patients in Indonesia were more likely to present at advance stages and metastatic breast cancer suggested several barriers of early presentation of breast cancer in Indonesia, namely: (1) the referral hospital in Indonesia is situated in the capital city, whereas a large percentage of Indonesian population resides in the rural area; therefore, some women who reside in the rural area may not present to the referral hospital, (2) the lack of a population-based breast cancer screening program, (3) financial problems, and (4) cancer and treatment beliefs (e.g. fatalism, shame, belief in traditional medicine) [37].

In regard to treatment non-adherence, we found that 13% of the patients were non-adherent to treatment by missing two or more consecutive treatment sessions, which is lower than results of previous studies in Asian and Western breast cancer patients. In a study among Malaysian breast cancer patients, 29% of the patients were non-adherent to chemotherapy and 13% of the patients were non-adherent to radiotherapy [38]. Similarly, a study among American breast cancer patients found that 31% of the patients discontinued therapy and 28% were non-adherent to adjuvant hormone therapy [39]. We assume that the operational definition of non-adherence which we used (i.e. had missed two or more consecutive treatment sessions) may have led to different results compared to previous literature which adopted various outcomes, such as non-adherence to adjuvant endocrine therapy or other medical regiments. In addition, the use of patients' self report in a retrospective way may have caused recall and social desirability bias which may have resulted in an underestimation of non-adherence. Our results showed a difference among non-adherence and adherence groups in illness perceptions and satisfaction with information provided, and having negative illness perceptions was associated with missing treatment sessions. We again found that consulting a traditional healer was associated with treatment delay and also with missing treatment sessions. In contrast, knowledge, health locus of control, and distress were not associated with treatment delay and non-adherence to treatment.

In comparison with the results of our qualitative study, we found an inconsistency concerning the association between breast cancer knowledge and non-adherence to treatment. One possible explanation for this difference may be related to the measurement that was used to assess women's knowledge about breast cancer. In the first study, we determined that patients had a lack of awareness and knowledge based on qualitative judgment of their answers during the interview (e.g. named the diagnosis wrongly, didn't know the symptoms of breast cancer, didn't know the cause of breast cancer), whereas in the second study, patients' general knowledge about breast cancer and their knowledge of breast cancer curability was measured objectively by the Breast Cancer Knowledge Test.

7.2 Methodological considerations

7.2.1 Strengths of the current study

The studies presented in this thesis have several strengths as well as limitations. The strengths of the studies were: Firstly, the studies formed a series of investigations that explored the factors associated with non-adherence to treatment in Indonesian women with breast cancer, and the use of both qualitative and quantitative methods were likely to obtain richer and deeper information about potential psychological factors of non-adherence. Secondly, the relatively high response rate (91%) in all studies promotes confidence in the accuracy of our study results. Thirdly, the use of healthy women as a comparison group for the health locus of control study provided a more comprehensive knowledge about health locus of control of Indonesian women with breast cancer (and of healthy women (**Chapter 4**)).

7.2.2 Limitations of the current study

Particular limitations of the studies were the cross-sectional design, the specificity (i.e. the referral area of the Hasan Sadikin Hospital) and the size of the sample, and the availability of validated Indonesian version of some measurements. Firstly, the cross-sectional design used in these studies limits the possibility to establish a causal association among variables that were investigated. Further prospective studies are needed to give an insight into the direction of these associations.

Concerning the specificity, the studies that were presented in this thesis were conducted in Hasan Sadikin Hospital (HSH) which is a referral hospital that provides health services to patients who have middle to low socio-economic and educational level. Therefore, multi-center studies with a larger sample of various patient groups are needed to be able to extrapolate these results of the present study to other groups. The relatively

small sample size in the study about satisfaction with information (**Chapter 5**) and the study about psychological factors associated with non-adherence to treatment (**Chapter 6**) may have led to a limited statistical power. In the latter study, the problem with sample size was due to the low non-adherence rate. Our post-hoc power analyses based on the number of tests yielded power rates in the range of 0.47 and 0.83 for the significant analyses which implies that the findings should be interpreted with caution. However, several associations that were found in these studies also appear in other studies. For example, the finding that negative illness perceptions are associated with non-adherence to treatment was similar with the results of a review study about patients' illness perceptions and medication adherence [40].

Thirdly, some measurement instruments were not available in the Indonesian language and were translated by our research group. The unavailability of their psychometric properties, population norms and the cutoff scores may raise some issues. For example, the use of the general cut-off score of the HADS, which has been obtained from Western populations, may have led to an overestimation or underestimation of the depression and anxiety levels of our Indonesian samples. We addressed these issues by using the forward and back translation method as suggested by the experts [41] to translate the Distress Thermometer (**Chapter 3**), the C form of the Multidimensional Health Locus of Control Scales (**Chapter 4**), the Satisfaction with Cancer Information Profile and the Brief Illness Perception Questionnaire (**Chapter 5**), and the Breast Cancer Knowledge Test (**Chapter 6**). We used the general cutoff score suggested by the HADS authors for the determination of distress and explored its psychometric properties (**Chapter 3**). Factor analysis of the Indonesian version of the HADS demonstrated a two factor solution in good accordance with the HADS-A and HADS-D subscales. A final limitation is that we used patients' self report to measure treatment delay and non-adherence to treatment in a retrospective way which may have been susceptible to recall and social desirability bias. Therefore, the non-adherence rates reported in our studies should be interpreted with caution, and future prospective research using standardized medical record information is required to confirm and extend the current findings.

7.3 Implications for clinical practice and future research

Information about patients' psychological problems and psychological adjustment during their treatment (e.g. depressive symptoms and anxiety), risk perceptions, beliefs and attitudes is important to provide to health care professionals. They could use this knowledge

to develop appropriate psychosocial care and symptom management, and to provide information that matches with patients' individual needs.

As suggested by The National Comprehensive Cancer Network, distress among cancer patients should be screened, monitored and treated promptly at all stages of the disease [42]. Our findings suggest that the Indonesian version of Distress Thermometer is a brief, easy to administer and valid screening tool for distress that can be used in daily cancer care in Indonesia (Chapter 3). Considering the high number of patients at the Outpatient Surgical Oncology Clinic, nurses and/or administration staffs could administer the DT while patients are waiting for their appointment in the waiting room. Findings of our study showed that more than half of the patients reported a significant level of distress. The use of the DT in daily cancer care may help oncologists and other health professionals to do a quick distress screening, which may help them to prevent potential severe psychological problems in cancer patients and to provide additional interventions to patients who need it. For example, patients who have higher distress levels could receive cognitive behavioral stress management training which aims to help patients to manage their stress effectively. In particular, and given the scarcity in psycho-medical help in Indonesia, we suggest that patients in an advanced stage of cancer with a high level of distress should be given priority for psychological intervention. Accordingly, monitoring patients' distress and investigating the efficacy of a particular intervention for patients' distress is also a required topic for future research.

People's perceptions of factors controlling their health (i.e. Health Locus of Control) may lead to an understanding of health or illness-related behaviors. In comparison to healthy women, women with breast cancer had higher external HLC (i.e. chance, doctors, powerful others and God) and lower internal HLC, and God LHC was associated with a higher level of anxiety (Chapter 4). Knowledge about the tendency of patients' health locus of control may help health care professionals to identify patients' emotional adjustment problems during their illness trajectory. The high external HLC among women with breast cancer indicates the importance to assess women's feelings of the lack of self control over their illness, and provide interventions to help women gain a sense of control over their illness.

In cancer care services, the provision of sufficient and adequate information about the disease and its treatment is important to add to appropriate medical treatment. A significant gap between individual informational needs and information provided by the health care professionals may not only influence patients' satisfaction with information but also influences patients' illness perceptions by not receiving the correct information about disease and its treatment. We found that a considerable number of patients were dissatisfied with several

aspects of information provided by the health care professionals, especially with information about social/financial support and the provision of written information. In addition, having negative illness perceptions was associated with missing treatment sessions (**Chapter 5**). Therefore, the provision of appropriate and adequate information about disease and its treatment is urgently needed to help patients reformulate their illness perceptions which in turn enables them to cope more adequately during and after treatment [43]. Considering the imbalance ratio between health care professionals and cancer patients in the oncology clinic in Indonesia, some practical issues emerged, such as limited consultation time and the fact that consultation focuses primarily on physical aspects of cancer. Therefore, the provision of clear, concise and easy to understand written information about illness and its treatment (e.g. leaflets) can be a cost-effective and efficient source of information supplementing the vis-à-vis information. In addition, the improvement of verbal information provided by the physicians is needed, too. Future research to investigate physicians' perceptions about the provision of verbal and written information for breast cancer patients will be fruitful to confirm the current study results.

Our qualitative and quantitative studies identified several psychosocial factors that were associated with non-adherence (**Chapter 2** and **Chapter 6**). Having negative illness perceptions was associated with missing treatment sessions, whereas a strong belief in traditional healers was associated with treatment delay and missing treatment sessions. This also emphasizes the relevance of provision of clear information to the patients about their illness and its treatment, taking into account what traditional healers tell and do. At this moment, we are developing a psycho-education intervention program that aims to diminish delay in seeking help and treatment delay, and increase treatment adherence in Indonesian women with breast cancer. However, poor adherence might not only be related to patients' behavior, but also to health care providers' behavior. Further investigation of health care providers' health beliefs and adherence with breast cancer protocols in Hasan Sadikin Hospital in Bandung is needed. In addition, a retrospective medical records study to investigate the rates of treatment refusal and abandonment, the most severe types of non-adherence among Indonesian women with breast cancer is necessary to ascertain the current study findings.

In conclusion, our results show several important issues related to the psychological adjustment of Indonesian patients with breast cancer, namely: more than half of women with breast cancer reported a significant level of distress, had a high external HLC and low internal HLC, and were dissatisfied with several aspects of information provided by the health care professionals (e.g. information about social/financial support and the

provision of written information). God LHC was associated with a higher level of anxiety. We also found that non-adherence to treatment was associated with a lack of awareness and knowledge, negative illness perceptions and a strong belief in traditional healers, and was not associated with Health Locus of Control, satisfaction with information provided and distress. Future research should be focuses on the development and evaluation of an information package, based on these outcomes.

Chapter 7

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Summary

Chapter 1 provides the background, aims and outline of this thesis. It presents changes in the prevalence and the unfavorable direction of the case fatality rate among Indonesian women with breast cancer. The recent data showed that breast cancer has emerged as the most frequent cancer and the leading cause of death among Indonesian women. Although the incidence rate is lower than in developed countries, the case fatality rate from breast cancer is remarkably high. Similar with others South East Asian countries, the poorer survival among Indonesian breast cancer patients is largely due to late presentation of the disease. This is caused by many factors, such as a lack of facilities for early detection and a poor access to primary treatment. As cancer is a chronic and frequently terminal disease, women who are diagnosed with breast cancer are confronted with multiple stressors throughout their illness trajectory. Therefore, understanding psychological adjustment and potential psychosocial factors that related to non-adherence to medical recommendation in women with breast cancer is urgently needed.

The objective of this thesis was to identify possible psychosocial risk factors for non-adherence to treatment and psychological distress in Indonesian women with breast cancer. To answer the objective of this thesis, first we explored potential determinants of non-adherence qualitatively, subsequently we conducted several validations and exploratory studies to better comprehend the nature of psychological problems and adjustment related to breast cancer, and finally we explored the psychological factors that might be associated with non-adherence to treatment quantitatively.

Chapter 2 presents the results of a qualitative study about psychosocial and cultural reasons for delay in seeking help and non-adherence to treatment in Indonesian women with breast cancer. Consecutive fifty breast cancer patients who were treated at the Outpatient Surgical Oncology Clinic were interviewed. The interview included participants' demographic characteristics and the following topics: knowledge of the disease, perceived disease severity, information provided by the patient's physician, use of health services and alternative treatment, attitudes towards western and traditional medicine particularly in relation to the patient's disease, the perceived benefits of, and barriers to, treatment and non-adherence to medical recommendations. Interviews were recorded, transcribed verbatim and coded using qualitative software program ATLAS.ti version 5.2. Eight main themes concerning reasons for delay in seeking medical help and treatment non-adherence emerged, namely: lack of awareness and knowledge, cancer beliefs, treatment beliefs, financial problems, emotional burden, severe side effects, paternalistic style

of communication and unmet information needs. This study found several modifiable psychosocial and cultural factors that may be used to develop interventions to reduce non-adherence behavior in this population. These findings suggest that the provision of extensive information through media campaigns, treatment decision aids, and caregiver and patient education are needed to change the illness behaviors of Indonesian breast cancer patients.

In *Chapter 3*, we aimed to translate the Distress Thermometer (DT) into Indonesian, test its validity in Indonesian women with breast cancer and determine norm scores of the Indonesian DT for clinically relevant distress. We translated the original version of the DT into Indonesian version using a forward and backward translation procedure according to the guidelines. Therefore, one-hundred and twenty breast cancer patients at the Outpatient Surgical Oncology Clinic completed a standard socio-demographic form, the DT and the Problem List, the Hospital Anxiety and Depression Scale (HADS) and the WHO Quality of Life (WHOQOL-Bref). The receiver operating characteristic curve analysis identified a good discrimination (AUC=0.81) of the DT cutoff score relative to the established cutoff score of the HADS $\geq$15, and a cutoff score of 5 on the DT had the best sensitivity and specificity. Patients who reported distress above this cutoff experienced more problems in the practical, family, emotional, spiritual/religious and physical domains than patients below the cutoff score. In addition, patients at advanced stages of cancer experienced more emotional and physical problems. Patient's distress level was negatively correlated with overall quality of life, general health and all quality of life domains. We conclude that the DT was a valid tool for screening distress in Indonesian breast cancer patients, and we recommend using a cutoff score of 5 in this population. A particular finding of this study was the positive association between clinically significant distress and spiritual/religious concerns, which is similar to the results of a study conducted in Korea, but in contrast to most studies conducted in Western countries that found no association or only weak association. We conclude that patients in an advanced stage of cancer should be given priority for psychological intervention.

Chapter 4 investigates whether Indonesian women with breast cancer have higher external Health Locus of Control (HLC) than healthy women, and explores the association between HLC and symptoms of anxiety and depression. In this study, one-hundred and twenty consecutive women with breast cancer who were recruited at the outpatient surgical oncology clinic completed a standard demographic form, Form C of the Multidimensional Health Locus of Control, as well as the Hospital Anxiety and Depression Scale. As a comparison group, one hundred and twenty two healthy women who were recruited

from the Bandung area completed a standard demographic form and the Form C of the Multidimensional Health Locus of Control. Women with breast cancer had higher scores on all external HLC subscales, i.e. chance, doctor, powerful others and God, and lower internal HLC compared to healthy women. Lower education level was associated with higher chance HLC scores in women with breast cancer, and was associated with lower internal HLC and higher chance HLC in healthy women. Time since diagnosis was significantly negatively correlated with God LHC scores. High God LHC scores were associated with a high level of anxiety, whereas none of the HLC subscales were associated with depression. Our results suggest that a strong belief in an external source of control, i.e. God, might be negatively associated with patients' emotional adjustment. Further research is needed to give an insight into the direction of this association.

In *Chapter 5*, breast cancer patients' level of satisfaction with information on illness and treatment and its association with illness perceptions and quality of life were studied. Seventy consecutive breast cancer patients at the Outpatient Surgical Oncology Clinic completed a demographic form, the Satisfaction with Cancer Information Profile, the Brief Illness Perception Questionnaire and the World Health Organization Quality of Life. A considerable number of patients (41%-86%) reported that they received insufficient information regarding several aspects related to their illness and treatment, particularly information about access to patient support groups and the impact of their treatment on long-term quality of life. In regard to the type and timing of information, the majority of patients were dissatisfied with the amount of written information provided. Patients' satisfaction with the type and timing of information was positively associated with stronger beliefs in personal control, less concerns about their health condition, better understanding of their illness, and satisfied patients were less emotionally affected by their illness. Satisfaction with the type and timing of information was also associated with a more positive perception of their general health and a better psychological health condition. On the other hand, satisfaction with the amount and content of information was not associated with illness perception and quality of life. Our study results suggest that satisfaction with information provided is associated with better health outcomes, including more positive illness perceptions; therefore it highlights the importance of providing adequate and sufficient information that meets the needs of patients. Even though, longitudinal studies are needed to determine whether there is support for this interpretation.

The study in *Chapter 6* evaluates the association between psychosocial factors (i.e. knowledge, illness perceptions, health locus of control, satisfaction with information and distress) and non-adherence to treatment in Indonesian women with breast cancer.

Seventy consecutive breast cancer patients participated in this study. They completed a demographic form, the non-adherence questionnaire, the Breast Cancer Knowledge Test, the Brief Illness Perception Questionnaire, the Multidimensional Health Locus of Control Scales, the Satisfaction with Cancer Information Profile and the Distress Thermometer. Seventeen (24%) out of seventy patients reported that they had delayed initiating treatment at the hospital, and nine (13%) out of seventy patients had missed two or more consecutive treatment sessions. The multivariate regression analyses showed that having a negative view of cancer (i.e. a view with the emphasis on its threatening character) was associated with missing treatment sessions, whereas having consulted a traditional healer was associated with both treatment delay and missed treatment sessions. Contrary to our expectations, patients' knowledge, health locus of control and satisfaction with information was not associated with treatment delay and missed treatment sessions. We suggest that health professionals need to be aware of patients' negative illness perceptions and unrealistic beliefs in traditional healers, and provide them with clear information about their illness and its treatment. However, the relative importance of these factors should be studied in future prospective studies, also considering the exploratory character of this study.

Finally, *Chapter 7* provides a general discussion of the findings, discusses the accumulated results which related to our research aims, and presents implications for clinical practice and future research. The studies presented in this thesis identified several cultural differences in psychological factors associated with non-adherence to treatment and psychological adjustment compared to the Western cancer population, namely: Indonesian women with breast cancer had higher belief that God determines their health conditions, were more dissatisfied with several aspects of information provided by the health care professionals (e.g. information about social/financial support and the provision of written information) and had a stronger belief in traditional healers.

Screening for psychological distress among women with breast cancer is needed in daily cancer care services to prevent potential severe psychological problems and provide additional psychological interventions to patients who need it. Health professionals need to be aware of patients' negative illness perceptions and a strong belief in traditional healers, factors which were associated with treatment delay and non-adherence to treatment. Provision of clear, concise and easy to understand written information about illness and its treatment (e.g. leaflets) can be a cost-effective and efficient source of information supplementing the verbal information in the busy setting of the oncology clinic in Indonesia. At this moment, we develop a psycho-education intervention program that aims to diminish delay in seeking help and treatment delay, and increase treatment adherence in Indonesian women with breast cancer.

Determinanten van therapie-ontrouw bij Indonesische vrouwen met borstkanker

Samenvatting

Hoofdstuk 1 bevat de achtergrond, doelstellingen en de grote lijnen van dit proefschrift. Veranderingen in de prevalentie en de ongunstige trend in het letaliteitspercentage bij Indonesische vrouwen met borstkanker worden erin gepresenteerd. Recente gegevens tonen aan dat borstkanker zich heeft ontpopt tot de meest voorkomende soort kanker en de voornaamste doodsoorzaak onder Indonesische vrouwen. Hoewel de incidentie lager ligt dan in ontwikkelde landen is het letaliteitspercentage bij borstkanker opmerkelijk hoog. Zoals ook in andere Zuidoost-Aziatische landen het geval is, is de kleinere overlevingskans bij Indonesische borstkankerpatiënten voornamelijk te wijten aan late onderkenning van de ziekte. Dit wordt veroorzaakt door verschillende factoren, waaronder een gebrek aan faciliteiten voor vroege detectie en slechte toegang tot primaire zorg. Aangezien kanker een chronische en vaak terminale ziekte is, hebben vrouwen bij wie borstkanker is vastgesteld met meerdere stressoren te kampen tijdens hun ziektetraject. Om deze reden is het dringend nodig een beter inzicht te krijgen in de psychologische adaptatie en de psychosociale factoren die verband kunnen houden met falende therapietrouw bij vrouwen met borstkanker.

Het doel van dit proefschrift was om mogelijke psychosociale risicofactoren voor therapieontrouw en distress bij Indonesische vrouwen met borstkanker op te sporen. Ten behoeve van dit doel hebben wij ten eerste de potentiële bepalende factoren voor therapieontrouw kwalitatief verkend; vervolgens hebben wij verschillende validaties en verkennende studies uitgevoerd om beter te begrijpen wat de aard is van de psychische problemen en psychologische adaptatie in relatie tot borstkanker; tenslotte hebben wij de psychische factoren die mogelijk verband houden met therapietrouw/-ontrouw kwantitatief verkend.

In hoofdstuk 2 worden de resultaten besproken van een kwalitatieve studie naar de psychosociale and culturele redenen voor uitstel bij het zoeken van hulp en voor therapietrouw/-ontrouw bij Indonesische vrouwen met borstkanker. Vijftig opeenvolgende borstkankerpatiënten die behandeld werden bij de polikliniek oncologie en chirurgie zijn ondervraagd. Het gesprek betrof, naast de demografische kenmerken van de deelnemers, de volgende onderwerpen: kennis van de ziekte, ernst van de ziekte in de beleving van de patiënt, door de behandelend arts verstrekte informatie, het gebruik van de gezondheidszorg

en alternatieve behandelingen, attitude ten opzichte van westerse en traditionele geneeskunde met name in relatie tot de ziekte van de patiënt, door de patiënt ervaren voordelen van, en drempels voor, de behandeling en ten slotte therapietrouw/-ontrouw. De interviews zijn opgenomen, woordelijk uitgeschreven en gecodeerd middels het kwalitatieve softwareprogramma ATLAS.ti, versie 5.2. Bij de redenen voor het uitstellen van het zoeken van medische hulp en voor therapieontrouw, zijn acht overkoepelende thema's aan het licht gekomen, te weten: gebrek aan kennis en inzicht, opvattingen over kanker, opvattingen over behandelingen, financiële beperkingen, emotionele belasting, zware bijwerkingen, een paternalistische communicatiestijl en het niet voorzien in de informatiebehoefte. Deze studie heeft een aantal veranderbare psychosociale en culturele factoren aan het licht gebracht, waarvan gebruik gemaakt kan worden voor het ontwikkelen van interventies om therapieontrouw in deze populatie terug te dringen. Uit de resultaten komt naar voren dat er om het ziektegedrag van Indonesische borstkankerpatiënten te veranderen behoefte is aan uitgebreide voorlichtingscampagnes in de media, hulpmiddelen ten behoeve van beslissingen over de behandeling, evenals voorlichting voor zorgverleners en patiënten.

Hoofdstuk 3 betreft de vertaling van de Distressbarometer (DB) in het Indonesisch, toetsing van de validiteit ervan bij Indonesische vrouwen met borstkanker en vaststelling van de normscores van de Indonesische DB voor klinisch relevante distress. De oorspronkelijke versie van de DB werd naar het Indonesisch vertaald met behulp van een terugvertaalprocedure, zoals voorgeschreven in de richtlijnen. In dit verband vulden honderdtwintig borstkankerpatiënten bij de polikliniek chirurgie en oncologie een standaard sociaaldemografisch formulier in, evenals de DB en de klachtenlijst, de Hospital Anxiety and Depression Scale (HADS) en de WHO Quality of Life (WHOQOL-Bref). Analyse van de ROC-curve toonde een goede discriminatie aan (AUC=0.81) van de DB-drempelwaarde in relatie tot de drempelwaarde van de HADS $\geq$15; een drempelwaarde van 5 op de DB leverde de beste sensitiviteit en specificiteit op. Patiënten die aangaven dat hun distress boven deze drempelwaarde lag, ervoeren meer praktische, emotionele, levensbeschouwelijke en fysieke problemen en meer gezinsproblematiek dan patiënten die onder deze waarde uitkwamen. Bovendien hadden patiënten met kanker in vergevorderde stadia meer emotionele en fysieke problemen. Er was een negatieve correlatie tussen de mate van distress van de patiënt en de algehele kwaliteit van leven, de algemene gezondheidstoestand en alle domeinen van de kwaliteit van leven. Hieruit concluderen wij dat de DB een valide middel was voor het signaleren van distress bij Indonesische borstkankerpatiënten, en wij bevelen aan dat er een drempelwaarde van 5 wordt gehanteerd bij deze populatie. Een opvallend resultaat van dit onderzoek was het positieve verband tussen klinisch significante distress

en levensbeschouwelijke problemen, een resultaat dat vergelijkbaar is met de resultaten van een onderzoek in Korea, maar niet overeenkomt met de meeste onderzoeken in Westerse landen, waarbij geen of slechts een zwak verband werd vastgesteld. Wij concluderen hieruit dat patiënten in een vergevorderd stadium van kanker met voorrang psychologische hulp zouden moeten krijgen.

Hoofdstuk 4 onderzoekt of Indonesische vrouwen met borstkanker een meer externe Health Locus of Control (HLC) hebben dan gezonde vrouwen, en verkent het verband tussen HLC en symptomen van angst en depressie. Voor dit onderzoek vulden honderdtwintig vrouwen met borstkanker, opeenvolgend geworven bij de polikliniek chirurgie en oncologie, een standaard demografisch formulier, Formulier C van de Multidimensional Health Locus of Control en tevens de Hospital Anxiety and Depression Scale in. Ter vergelijking vulde een groep van honderdtweeëntwintig gezonde vrouwen, geworven in Bandoeng en omstreken, een standaard demografisch formulier en Formulier C van de Multidimensional Health Locus of Control in. Vrouwen met borstkanker hebben op alle subschalen voor externe HLC hogere waarden, d.w.z. voor toeval, dokter, invloedrijke derden en God, en lagere interne HLC-waarden dan gezonde vrouwen. Een lager opleidingsniveau hield bij vrouwen met borstkanker verband met hogere waarden op de toeval-schaal, en bij gezonde vrouwen met een lagere interne HLC en hogere waarden op de toeval-schaal. De tijd die sinds de diagnose was verstreken, vertoonde een significant negatieve correlatie met de waarden op de God-schaal. Hogere waarden op de God-schaal hielden verband met een hoger angstniveau; geen van de HLC-subschalen hield echter verband met depressie. Onze resultaten lijken uit te wijzen dat een sterk geloof in een externe bron van beheersing, d.w.z. God, mogelijk negatief verband houdt met de emotionele adaptatie van de patiënten. Er is verder onderzoek nodig om inzicht te krijgen in de richting van dit verband.

In *hoofdstuk 5* komt aan de orde hoe tevreden borstkankerpatiënten waren met de informatie over de ziekte en de behandeling, evenals het verband tussen tevredenheid en percepties van ziekte en kwaliteit van leven. Zeventig opeenvolgende borstkankerpatiënten bij de polikliniek chirurgie en oncologie vulden een demografisch formulier in, evenals het Satisfaction with Cancer Information Profile, de Brief Illness Perception Questionnaire en de World Health Organization Quality of Life. Een aanzienlijk deel van de patiënten (41%-86%) liet weten onvoldoende informatie te hebben ontvangen over verschillende aspecten van hun ziekte en behandeling, met name informatie over toegang tot steungroepen voor patiënten en de impact van de behandeling op de kwaliteit van leven op de lange termijn. Wat betreft de aard en de timing van de informatie was een meerderheid van de patiënten ontevreden met de hoeveelheid schriftelijke informatie die was aangeboden.

De tevredenheid van patiënten met de aard en de timing van informatie hield positief verband met een sterker gevoel van persoonlijke beheersing, minder zorgen over hun gezondheidstoestand en een beter begrip van de ziekte. Tevreden patiënten waren minder emotioneel geraakt door hun ziekte. Tevredenheid met de aard en de timing van de informatie hield ook verband met een positievere perceptie van hun algehele gezondheidstoestand en een betere psychische gezondheid. Tevredenheid met de hoeveelheid en de inhoud van de informatie hield daarentegen geen verband met de perceptie van de ziekte en van de kwaliteit van leven. Onze onderzoeksresultaten suggereren dat tevredenheid met de informatie die aangeboden wordt verband houdt met betere gezondheidsresultaten, waaronder een positievere perceptie van de ziekte; zij onderstrepen dus het belang van adequate en voldoende informatieverstrekking die voorziet in de behoefte van de patiënt. Toch is er longitudinaal onderzoek nodig om vast te stellen of deze interpretatie wordt ondersteund.

Het onderzoek in *hoofdstuk 6* evalueert het verband tussen psychosociale factoren (bijv. kennis, perceptie van de ziekte, health locus of control, tevredenheid met informatie en distress) en therapietrouw bij Indonesische vrouwen met borstkanker. Zeventig opeenvolgende patiënten met borstkanker namen deel aan het onderzoek. Zij vulden een demografisch formulier in, de therapieontrouw-enquête, de Breast Cancer Knowledge Test, de Brief Illness Perception Questionnaire, de Multidimensional Health Locus of Control Scales, het Satisfaction with Cancer Information Profile en de Distressbarometer. Zeventien (24%) van de zeventig patiënten meldden dat zij het begin van de behandeling in het ziekenhuis hadden uitgesteld, en negen (13%) van de zeventig patiënten hadden twee of meer opeenvolgende behandelsessies gemist. De multivariate regressieanalyses toonden aan dat een negatief beeld van kanker (een beeld waarbij de nadruk ligt op het bedreigende karakter) verband hield met het missen van behandelsessies, terwijl voorafgaande raadpleging van een traditionele genezer verband hield met zowel uitstel van de behandeling als het missen van behandelsessies. Tegen de verwachting in werd er geen verband gevonden tussen de kennis van de patiënten, de health locus of control en tevredenheid met de informatie enerzijds, en het uitstellen van de behandeling en het missen van behandelsessies anderzijds. Naar onze mening moeten zorgprofessionals zich bewust worden van de negatieve ziektepercepties onder de patiënten en hun onrealistische geloof in traditionele genezers, en moeten zij patiënten duidelijke informatie over hun ziekte en hun behandeling verschaffen. Het relatieve belang van deze factoren moet echter in toekomstig prospectief onderzoek worden getoetst, ook gezien het verkennende karakter van het onderhavige onderzoek.

Hoofdstuk 7 bevat ten slotte een algemene discussie van de resultaten, bespreekt het totaal van de resultaten in relatie tot onze onderzoeksdoelen en beschrijft enkele implicaties voor de klinische praktijk en toekomstig onderzoek. De onderzoeken die in dit proefschrift zijn besproken leggen een aantal culturele verschillen bloot in de psychologische factoren die verband houden met therapietrouw/-ontrouw en psychologische adaptatie vergeleken met de Westerse kankerpopulatie, te weten: Indonesische vrouwen met borstkanker hadden een vastere overtuiging dat God hun gezondheidstoestand bepaalt; zij waren minder tevreden met verschillende aspecten van de informatieverstrekking door zorgprofessionals (bijv. informatie over sociale/financiële ondersteuning en schriftelijke informatie) en hadden een sterker geloof in traditionele genezers.

Distress onder vrouwen met borstkanker moet in de reguliere kankerzorg worden gesignaleerd om eventuele ernstige psychische problemen te voorkomen en aanvullende psychische hulp te bieden aan patiënten die daar behoefte aan hebben. Zorgprofessionals dienen zich bewust te zijn van negatieve ziekteperceptie bij patiënten en een sterk geloof in traditionele genezers, factoren die verband hielden met uitstel van de behandeling en therapieontrouw. Het bieden van heldere, bondige en makkelijk te begrijpen schriftelijke informatie over ziekte en behandeling (bijv. folders) kan een kosteneffectieve en efficiënte bron van informatie zijn die de mondelinge informatieverstrekking aanvult in de drukke setting van een oncologiekliniek in Indonesië. Op het moment zijn wij bezig een psychologisch-educatief interventieprogramma te ontwikkelen om waar mogelijk te voorkomen dat Indonesische vrouwen met borstkanker het zoeken van hulp en de behandeling uitstellen en om de therapietrouw te vergroten.

Faktor yang menentukan ketidakpatuhan terhadap pengobatan pada wanita Indonesia yang menderita Kanker Payudara

Ringkasan

Bab 1 memberikan gambaran tentang latar belakang, tujuan dan kerangka dari disertasi ini. Bab ini menunjukkan adanya perubahan dalam prevalensi dan semakin memburuknya angka kematian pada wanita Indonesia yang menderita kanker payudara. Data terbaru menunjukkan bahwa kanker payudara tampil sebagai jenis kanker yang paling sering terjadi dan penyebab kematian utama pada wanita Indonesia. Meskipun angka kejadian masih lebih rendah daripada negara-negara maju, angka kematian dari kanker payudara tergolong cukup tinggi. Seperti halnya negara-negara Asia Tenggara lainnya, buruknya angka harapan hidup pada pasien kanker payudara di Indonesia sebagian besar disebabkan oleh keterlambatan presentasi dari penyakit. Hal ini disebabakan oleh berbagai faktor, diantaranya kurangnya fasilitas untuk deteksi dini dan keterbatasan akses kepada sarana pengobatan primer. Oleh karena kanker adalah suatu penyakit kronis dan seringkali menyebabkan kematian, wanita yang didiagnosa kanker payudara akan dihadapkan dengan berbagai stresor selama pengalaman sakitnya. Maka dari itu, memahami penyesuaian psikologis dan faktor-faktor psikososial potensial yang berhubungan dengan ketidakpatuhan terhadap rekomendasi medis pada wanita yang menderita kanker payudara sangatlah dibutuhkan.

Tujuan dari disertasi ini adalah untuk mengidentifikasi faktor-faktor psikososial yang mungkin menjadi faktor risiko untuk ketidakpatuhan terhadap pengobatan dan distress psikologis pada wanita Indonesia yang menderita kanker payudara. Untuk menjawab tujuan dari disertasi ini, pertama kami melakukan ekplorasi secara kualitatif terhadap determinan-determinan yang potensial dari ketidakpatuhan, selanjutnya kami melakukan beberapa studi validasi dan ekplorasi untuk bisa memahami secara lebih baik jenis masalah psikologis dan penyesuaian diri yang berhubungan dengan kanker payudara, dan akhirnya kami melakukan eklorasi secara kuantitatif terhadap faktor-faktor psikologis yang mungkin berhubungan dengan ketidakpatuhan terhadap pengobatan.

Bab 2 menyajikan hasil dari studi kualitatatif tentang faktor-faktor psikososial dan kultural untuk penundaan dalam mencari pertolongan dan ketidakpatuhan terhadap pengobatan pada wanita Indonesia yang menderita kanker payudara. Secara berurutan limapuluh pasien kanker payudara yang sedang menjalani pengobatan di klinik rawat jalan bagian bedah onkologi diwawancara. Wawancara meliputi karakteristik demografis dari partisipan dan topik-topik sebagai berikut: pengetahuan akan penyakit, persepsi tentang tingkat keparahan penyakit, informasi yang disediakan oleh dokter, penggunaan layanan

kesehatan dan pengobatan alternatif, sikap terhadap pengobatan barat dan pengobatan tradisional khususnya berkaitan dengan penyakit pasien, persepsi mengenai keuntungan-keuntungan dan hambatan-hambatan terhadap pengobatan dan ketidakpatuhan terhadap rekomendasi medis. Wawancara direkam, dicatat secara verbatim dan dikode dengan menggunakan program perangkat lunak kualitatif ATLAS.ti versi 5.2. Diperoleh delapan tema utama yang berkaitan dengan alasan menunda untuk mencari pertolongan medis dan ketidakpatuhan terhadap pengobatan, yaitu: kurangnya kesadaran dan pengetahuan, kepercayaan mengenai kanker, kepercayaan mengenai pengobatan, masalah keuangan, beban emosional, efek samping yang parah, gaya komunikasi paternalistik dan kebutuhan akan informasi yang tidak terpenuhi. Studi ini menemukan beberapa faktor-faktor psikososial dan kultural yang dapat diubah untuk bisa digunakan dalam mengembangkan intervensi untuk mengurangi perilaku tidakpatuh dalam populasi ini. Temuan-temuan ini memberi kesan bahwa penyediaan informasi yang ekstensif melalui media kampanye, bantuan untuk memutuskan pengobatan, dan pendidikan terhadap pemberi bantuan dan pasien sangatlah dibutuhkan untuk merubah perilaku sakit dari pasien kanker payudara di Indonesia.

Pada *Bab 3*, kami bertujuan untuk menterjemahkan *Distress Thermometer* (DT) ke dalam bahasa Indonesia, menguji validitasnya pada wanita Indonesia yang menderita kanker payudara dan menentukan norma dari DT versi Indonesia untuk distress klinis. Kami menterjemahkan versi asli dari DT ke dalam bahasa Indonesia dengan menggunakan cara f*orward and backward translation* yang mengacu pada pedoman yang ada. Maka dari itu, seratus duapuluh pasien kanker payudara di klinik rawat jalan bagian bedah onkologi mengisi lembar isian sosio-demografis standar, DT dan daftar permasalahan, *Hospital Anxiety and Depression Scale* (HADS) dan *WHO Quality of Life* (WHOQOL-Bref). Analisa kurva *receiver operating characteristic* menunjukkan suatu diskriminasi yang baik (AUC=0.81) dari nilai batas DT terhadap nilai batas HADS $\geq$15 yang telah ajeg, dan nilai batas 5 pada DT memiliki sensitifitas dan specificitas yang paling baik. Pasien yang melaporkan distress di atas nilai batas mengalami lebih banyak masalah dalam domain praktis, keluarga, emosional, spiritual/kepercayaan dan fisik dibanding dengan pasien yang memiliki distress di bawah nilai batas. Sebagai tambahan, pasien dengan kanker tingkat lanjut mengalami lebih banyak masalah emosional dan fisik. Tingkat distress pasien berkorelasi negatif dengan kualitas hidup secara keseluruhan, kondisi kesehatan umum dan semua domain kualitas hidup. Kami menyimpulkan bahwa DT adalah alat ukur yang valid untuk pemeriksaan distress pada pasien kanker payudara di Indonesia, dan kami merekomendasikan untuk menggunakan nilai batas 5 pada populasi ini. Temuan yang

khusus dari studi ini adalah adanya hubungan positif antara distress klinis dengan masalah spiritual/agama, yang serupa dengan hasil studi yang dilakukan di Korea, namun berbeda dengan kebanyakan studi yang dilakukan di negara-negara Barat yang tidak menemukan adanya hubungan ataupun hanya menemukan hubungan yang lemah. Kami menyimpulkan bahwa pasien dengan kanker tingkat lanjut harus diprioritaskan untuk memperoleh intervensi psikologis.

Bab 4 meneliti apakah wanita Indonesia yang menderita kanker payudara memiliki eksternal *Health Locus of Control* (HLC) yang lebih tinggi daripada wanita yang sehat, dan mengeksplorasi hubungan antara HLC dengan simptom-simptom kecemasan dan depresi. Pada studi ini, secara berurutan seratus dua puluh wanita yang menderita kanker payudara yang di rekrut dari klinik rawat jalan bagian bedah onkologi mengisi lembar isian demografis standar, *Multidimensional Health Locus of Control* bentuk C, dan juga *Hospital Anxiety and Depression Scale*. Sebagai kelompok pembanding, seratus dua puluh dua wanita sehat yang direkrut dari daerah Bandung mengisi lembar isian demografis standar dan *Multidimensional Health Locus of Control* bentuk C. Wanita yang menderita kanker payudara memiliki nilai lebih tinggi pada semua skala eksternal HLC, yaitu *chance, doctor, powerful others* dan *God*, dan nilai yang lebih rendah dalam internal HLC dibandingkan dengan wanita sehat. Tingkat pendidikan yang rendah berhubungan dengan nilai *chance* HLC yang tinggi pada wanita yang menderita kanker payudara, dan berhubungan dengan nilai internal HLC yang rendah dan nilai *chance* HLC yang tinggi pada wanita sehat. Waktu semenjak menerima diagnosis secara signifikan berkorelasi negatif dengan nilai *God* LHC. Nilai *God* LHC yang tinggi berhubungan dengan tingkat kecemasan yang lebih tinggi, sementara itu tidak ada sub-skala HLC yang berhubungan dengan depresi. Hasil kami menunjukkan bahwa kepercayaan yang kuat terhadap sumber kendali eksternal, misalnya Tuhan, bisa berhubungan negatif dengan penyesuaian emosional pasien. Penelitian lebih lanjut tentunya diperlukan untuk memperoleh keterangan mengenai arah dari hubungan ini.

Pada *Bab 5*, tingkat kepuasan terhadap informasi mengenai penyakit dan pengobatan, dan hubungannya dengan persepsi terhadap penyakit dan kualitas hidup pasien kanker payudara diteliti. Tujuh puluh pasien kanker payudara yang direkrut secara berurutan dari klinik rawat jalan bagian bedah onkologi mengisi lembar isian demografis standar, *Satisfaction with Cancer Information Profile*, *Brief Illness Perception Questionnaire* dan *World Health Organization Quality of Life*. Cukup banyak pasien (41%-86%) melaporkan bahwa mereka tidak menerima informasi yang cukup mengenai beberapa aspek penyakit dan pengobatan mereka, terutama informasi mengenai akses terhadap kelompok-kelompok pendukung pasien dan akibat dari pengobatan terhadap kualitas hidup jangka panjang

mereka. Dalam hal jenis dan waktu pemberian informasi, sebagian besar pasien merasa tidak puas dengan jumlah informasi tertulis yang disediakan. Kepuasan pasien terhadap jenis dan waktu pemberian informasi berhubungan secara positif dengan kepercayaan atas kendali pribadi yang lebih kuat, kehawatiran terhadap kondisi kesehatan yang lebih rendah, pemahaman terhadap penyakit yang lebih baik, dan pengaruh emosional dari penyakit yang lebih rendah. Kepuasan terhadap jenis dan waktu pemberian informasi juga berhubungan dengan persepsi terhadap kondisi kesehatan umum yang lebih positif dan kondisi kesehatan psikologis yang lebih baik. Di sisi yang lain, kepuasan terhadap jumlah dan isi dari informasi tidak lah berhubungan dengan persepsi terhadap penyakit dan kualitas hidup. Hasil studi kami menunjukkan bahwa kepuasan terhadap informasi yang diberikan berhubungan dengan hasil kesehatan yang lebih baik, meliputi persepsi terhadap penyakit yang lebih positif; dengan demikian hal ini menunjukkan pentingnya penyediaan informasi secara memadai dan mencukupi yang sesuai dengan kebutuhan-kebutuhan pasien. Meskipun demikian, dibutuhkan studi longitudinal untuk menentukan apakah ada dukungan untuk interpretasi ini.

Studi di *Bab 6* mengevaluasi hubungan antara faktor-faktor psikososial (yaitu: pengetahuan, persepsi terhadap penyakit, *health locus of control*, kepuasan terhadap informasi dan distress) dengan ketidakpatuhan terhadap pengobatan pada wanita Indonesia yang menderita kanker payudara. Tujuh puluh pasien kanker payudara yang direkrut secara berurutan berpartisipasi dalam studi ini. Mereka mengisi lembar isian demografis, *Breast Cancer Knowledge Test, Brief Illness Perception Questionnaire, Multidimensional Health Locus of Control Scales, Satisfaction with Cancer Information Profile* dan *Distress Thermometer*. Tujuh belas (24%) dari tujuh puluh pasien melaporkan bahwa mereka telah menunda untuk memulai pengobatan di rumah sakit, dan sembilan (13%) dari tujuh puluh pasien pernah absen dua atau lebih sesi pengobatan secara berurutan. Hasil analisis regresi multivariate menunjukkan bahwa memiliki pandangan negatif terhadap kanker (yaitu pandangan yang menekankan pada karakter penyakit yang mengancam) berhubungan dengan absen dari sesi pengobatan, sedangkan berkonsultasi dengan penyembuh tradisional berhubungan dengan penundaan untuk memulai pengobatan dan absen dari sesi pengobatan. Kami menyarankan bahwa para professional kesehatan perlu mengetahui persepsi negatif pasien terhadap penyakit dan kepercayaan yang tidak realistis terhadap penyembuh tradisional, dan menyediakan informasi yang jelas mengenai penyakit dan pengobatannya bagi mereka. Meskipun demikian, pentingnya hubungan antara faktor-faktor tersebut haruslah diteliti pada studi prospektif di masa datang, dan juga mempertimbangkan karakter eksploratif pada penelitian ini.

Akhirnya, *Bab 7* menyajikan diskusi umum atas temuan-temuan yang diperoleh, mendiskusikan hasil akumulasi yang berhubungan dengan tujuan dari penelitian kami, dan menyajikan implikasi untuk praktek klinis dan penelitian yang akan datang. Studi-studi yang disajikan dalam disertasi ini mengidentifikasi beberapa perbedaan budaya dalam faktor-faktor psikologis yang berhubungan dengan ketidakpatuhan terhadap pengobatan dan penyesuaian psikologis dibandingkan dengan populasi kanker negara-negara Barat, yaitu: wanita Indonesia yang menderita kanker payudara memiliki kepercayaan yang lebih tinggi bahwa Tuhan menentukan kondisi kesehatan mereka, kurang merasa puas terhadap beberapa aspek informasi yang disediakan oleh para professional kesehatan (misalnya: informasi mengenai dukungan sosial/keuangan dan ketersediaan informasi tertulis) dan memiliki kepercayaan yang lebih kuat terhadap penyembuh tradisional.

Pemeriksaan untuk distress psikologis pada wanita yang menderita kanker payudara adalah diperlukan dalam pelayanan perawatan kanker sehari-hari untuk mencegah adanya masalah-masalah psikologis yang berat dan menyediakan intervensi psikologis tambahan untuk pasien yang membutuhkannya. Para professional kesehatan perlu mengetahui persepsi negatif pasien terhadap penyakit dan kepercayaan yang kuat terhadap penyembuh tradisional, dimana merupakan faktor-faktor yang berhubungan dengan penundaan pengobatan dan ketidakpatuhan terhadap pengobatan. Ketersediaan informasi tertulis yang jelas, ringkas dan mudah untuk difahami mengenai penyakit dan pengobatannya (misal: leaflet) dapat menjadi sumber informasi yang hemat biaya dan efisien untuk melengkapi informasi lisan di klinik onkologi yang sibuk di Indonesia. Pada saat ini, kami sedang mengembangkan program intervensi psiko-edukatif yang bertujuan untuk menghilangkan penundaan dalam mencari pertolongan dan penundaan pengobatan, dan juga meningkatkan kepatuhan terhadap pengobatan pada wanita Indonesia yang menderita kanker payudara.

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About the author

Aulia Iskandarsyah was born in Bandung, Indonesia, on December 20, 1981. He received his bachelor degree (BSc) in psychology from Bandung Islamic University, Indonesia in 2004. One year later he started a master in psychology program at Padjadjaran University from which he graduated in 2007 with a specialization in Clinical Psychology (MPsi). His main interest lies in counseling and psychotherapy, and he has followed several training courses and workshops on Cognitive and Behavioural Therapy by Dr. Arend Veeninga (Padjadjaran University and Nederlandse Vereniging voor Psychotherapie). After his graduation, he worked as a lecturer at the Department of Clinical Psychology at the Padjadjaran University and also as an associate consultant at several psychological consultants in Bandung, which provide various psychological services, including assessment, training and interventions. In 2009, he started a PhD project about non-adherence among Indonesian breast cancer patients and its determinants, which resulted in this thesis. This PhD project was a collaboration between the Department of Medical Psychology and Psychotherapy, Erasmus MC University Rotterdam, the Faculty of Psychology and Education, VU University Amsterdam, and the Faculty of Psychology, Padjadjaran University Bandung. During his PhD studies, he obtained a Master of Science degree in Epidemiology after he successfully completed the Netherlands Institute for Health Sciences (NIHES) training program for PhD candidates at the Erasmus MC University in 2010. After finishing his PhD project, he continued working at the Department of Clinical Psychology at Padjadjaran University. Aulia is married to Lia Savitrie Yulianto and they are the proud parents of Reyhan Naratama Iskandarsyah (born in Rotterdam on August 12, 2011).

PHD PORTFOLIO

Name PhD Student	Aulia Iskandarsyah
Research school	The Netherlands Institute of Health Sciences (NIHES)
PhD period	2009-2013
Promotors	Prof. Dr. J. Passchier and Prof. Dr. S.S. Sadarjoen
Supervisor	Dr. C. de Klerk

1. PhD training	Year	Workload (ECTS)
Research Skills		
MSc Epidemiology, NIHES:	2009-2010	
Principle of Research in Medicine	2009	0,7
Introduction to Public Health	2009	0,7
Methods of Public Health Research	2009	0,7
Cohort Studies	2009	0,7
Primary and Secondary Prevention Research	2009	0,7
Health Economics	2009	0,7
Study Design	2009	4,3
Classical Methods for Data-analysis	2009	5,7
Analysis of Population Health	2009	1,4
Analysis of Determinants	2009	1,4
Intervention Development and Evaluation	2009	1,4
Methodologic Topics in Epidemiology Research	2009	1,4
Modern Statistic Methods	2009	4,3
Conceptual Foundation of Epidemiologic Study Design	2010	0,7
Principles of Genetic Epidemiology	2010	0,7
Methods of Clinical Research	2010	0,7
Methods of Health Services research	2010	0,7
Demography of Ageing	2010	0,7
Social Epidemiology	2010	0,7

In-depth course

English biomedical writing and communication, Erasmus MC, Rotterdam	2010-2011	2,0
MSc Epidemiology, NIHES:		
Principle of Epidemiologic Data Analysis	2010	0,7
Quality of Life Measurement	2010	0,9
Planning and Evaluation of Screening	2010	1,4
Cancer Epidemiology	2010	1,4
Principle of Epidemiologic Data Analysis	2010	0,7

National and International conferences – participation and presentation

18e Nederlandse Vereniging Psychosociale Oncologie Congres (NVPO), Utrecht. Participant.	2011	0,5
The 2nd European Organisation for Research and Treatment of Cancer (EORTC) Symposium on "Quality of Life, Symptom Research and Patient Related Outcomes in Cancer Clinical Trials", Brussels-Belgium. Participant.	2011	1,4
The International Psycho-Oncology Society (IPOS) 13th World Congress, Antalya-Turkey. Poster presentation.	2011	1,4
19e Nederlandse Vereniging Psychosociale Oncologie Congres (NVPO), Utrecht. Poster presentation.	2012	0,5
Indonesian Student Conference in Europe, Wageningen-The Netherlands, Oral Presentation.	2012	0,5
The 3rd UK-SEA-ME Psychosocial Cancer Research Network Symposium. Breast Cancer Research Project, Faculty of Medicine, University of Malaya, Kuala Lumpur – Malaysia. Oral presentation.	2013	0,5

Seminars and workshops

Faculty colloquium: Strength of Evidence: RCTs versus Observational Studies of Psychosocial intervention in Light of the Bristol Cancer Tragedy.	2010	0,15
Department of Medical Oncology – VU University Medical Centre Amsterdam		
Symposium: Neuroimaging, Genetics and Endophenotypes: Development and Psychopathology.	2010	0,5
Erasmus University MC and Postacademisch Onderwijs Sophia - Rotterdam		
Faculty colloquium: Are most positive findings in psychology false or exaggerated?	2010	0,15
Department psychology and education – VU University Amsterdam		
Symposium: Existential issues in cancer: who cares? VU Medical Centre Amsterdam	2011	0,3
Psycho-educatief Nazorgprogramma voor Borstkankerpatienten Cursus "Omgaan met Borstkanker". Nederlandse Vereniging Psychosociale Oncologie Congres (NVPO), Utrecht.	2012	0,15
1 ECTS (European Credit Transfer System) is equal to a workload of 28 hours		