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Psychosocial and Cultural Reasons for Delay in Seeking Help and Nonadherence to Treatment in Indonesian Women With Breast Cancer: A Qualitative Study

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Objective: The aim of this study was to explore reasons for delay in seeking medical help and nonadherence to treatment in Indonesian women with breast cancer. **Method:** Semistructured 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 nonadherence 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 nonadherence 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, nonadherence, Indonesia

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 (Ferlay et al., 2010b; Moore et al., 2010; Umbas, 2009). Although the incidence of breast cancer in Indonesia is lower than in developed countries, the mortality rate is higher (Ferlay et al., 2010a). 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 (Anderson & Jakesz, 2008; Leong et al., 2009). 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 (Irawan, Hukom, & Prayogo, 2008; Ng et al., 2011; Wakai et al., 2000).

In addition to a delay in seeking medical help, nonadherence 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 multidimensional 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

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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; Sabaté, 2003). Non-adherence to treatment may appear in the following forms: (a) not initiating a recommended treatment, (b) not attending or coming late to appointments, (c) not completing behavioral recommendations, (d) not taking medication as prescribed, and (e) terminating the treatment prematurely (Levensky & O'Donohue, 2006). A study in the U.S.A. found that early discontinuation and nonadherence to adjuvant hormonal therapy was associated with increased mortality (Hershman et al., 2011). 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 (Sitaesmi, Mostert, Schook, Sutaryo, & Veerman, 2010). A study in retinoblastoma patients found that 31.5% of patients temporarily refused medical treatment, whereas 18.2% refused treatment permanently (Sitorus et al., 2009).

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 (DiMatteo, 2004). 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 (Agarwal et al., 2009).

Each culture has its own system of beliefs, perceptions, and ideas about health and illness (Helman, 1994), 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 (Byer & Myers, 2000; Horne, 1999). Marked by a high degree of religious, cultural, and social diversity, Indonesia provides a unique sociocultural environment which influences people's perceptions, attitudes, and behaviors in daily life (Sitorus & Budhwar, 2003). 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 nonadherence (Sitaesmi et al., 2010; Sitorus et al., 2009). To the best of our knowledge, qualitative research that systematically explores the psychosocial and cultural factors for nonadherence 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 nonadherence 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 nonadherence to treatment in Indonesia.

Method

Participants

This study was part of a larger quantitative study in which the potential determinants of nonadherence 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 nonadherence 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 nonadherence 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 (Charmaz, 2008). This approach was chosen given the lack of prior knowledge about nonadherence in the Indonesian culture. To obtain good quality data we conducted semistructured interviews to explore patients' experiences during their diagnosis and treatment. Interviews were conducted by seven master students in clinical psychology who first received a 2-day interview training session 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 semistructured interview. Each interviewer was supervised by the first author during their first interview and received feedback afterward.

First, 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. Afterward, 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 toward western and traditional medicine particularly in relation to the patient's disease, and the perceived benefits of, and barriers to, treatment and nonadherence to medical recommendations. The semistructured 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 3-month interval as our gold standard, because there is strong evidence that a delay in presentation of symptomatic breast cancer of 3 months or more is associated with lower survival (Burgess, Ramirez, Richards, & Love, 1998; Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999). 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 nonadherence was defined if patients were absent from two or more consecutive treatment sessions at HSH (Adisa, Lawal, & Adesunkanmi, 2008).

We used a thematic analysis that refers to the principles of the Grounded Theory (Braun & Clarke, 2006). To achieve data analysis consistency, we used a qualitative software program ATLAS.ti version 5.2 (Muhr, 2004). 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.

Delay in Seeking Help, Treatment Delay, and Treatment Nonadherence

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

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%)
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%)

receiving a cancer diagnosis, 21 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 Nonadherence

We constructed a theoretical model to describe factors related to delay in seeking medical help and nonadherence to treatment (see Figure 1). Eight themes emerged from our data; these themes were categorized into three clusters, namely: (a) factors related to patients (lack of awareness and knowledge, cancer beliefs, and treatment beliefs); (b) factors related to treatment (financial problems, emotional burden, and severe side effects); and (c) 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.

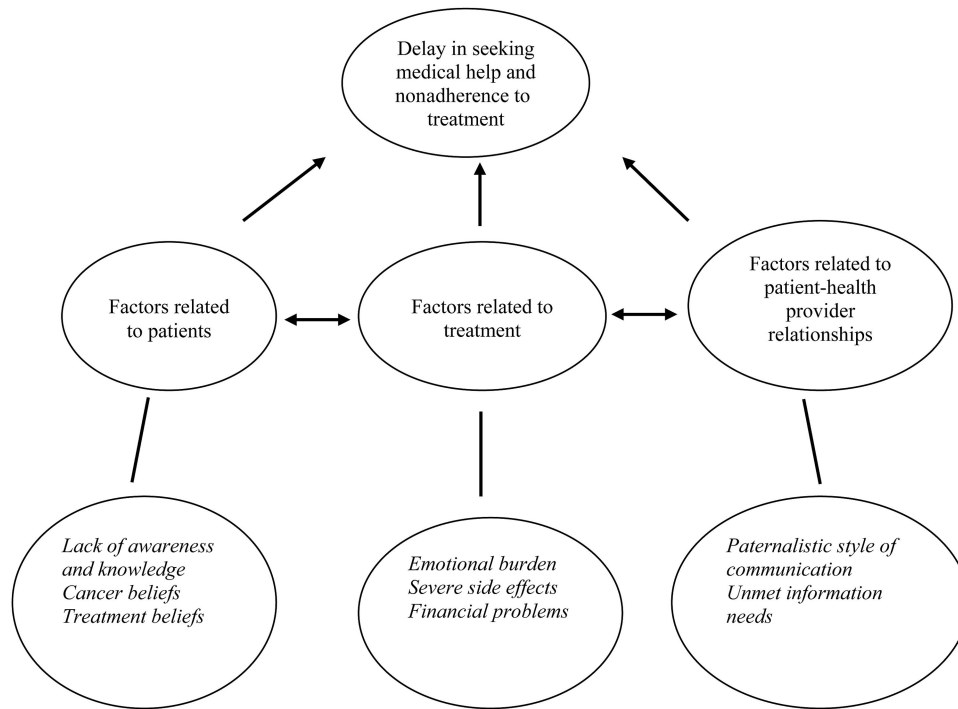


Figure 1. Generated theoretical model of factors related to delay in seeking medical help and nonadherence to treatment.

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 toward 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 nonassertive 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 nonadherence 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 nonadherence 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 (Agarwal et al., 2009; Al-Dubai et al., 2011; Coughlin & Ekwueme, 2009; Hisham & Yip, 2004). 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 (Agarwal et al., 2009; Hisham & Yip, 2003; Kissal & Beser, 2011). Currently, printed material (e.g., leaflets and brochures) and electronic sources (e.g., Web sites) 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 TV, 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 (Sun, Zhang, Tsoh, Wong-Kim, & Chow, 2007).

Perceptions and beliefs about symptoms, disease, and health determine how individuals understand and respond to their illness (Johnson et al., 1999; Kleinman, 1989). 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 U.K. and Canada (Johnson et al., 1999; Karbani et al., 2011). 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 (Hisham & Yip, 2004).

Indonesians are well known for their religiosity (Sallquist, Eisenberg, French, Purwono, & Suryanti, 2010); 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, and Markwardt (2008) and Barton-Burke, Barreto, and Archibald (2008) 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 (Harandy et al., 2010) and supports another argumentation that reliance on God to cure cancer may discourage women from seeking medical care (Dein, 2004).

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 (Agarwal et al., 2009; Hisham & Yip, 2004; Navon, 1999; Wanchai, Armer, & Stewart, 2010). 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 TV 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 (Agarwal et al., 2009; Hisham & Yip, 2004; Sandelin, Apffelstaedt, Abdullah, Murray, & Ajulu-chuku, 2002), 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 medical treatment for breast cancer as expensive (Wanchai, Armer, & Stewart, 2010). 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 (Sitaresmi et al., 2010; Sitorus et al., 2009).

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 the cancer itself. A previous study in child leukemia patients also found that severe side effects were one of the main reasons for treatment abandonment (Sitaresmi et al., 2010). 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 nonadherence (Kennard et al., 2004). 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 toward their 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 (Claramita, Utarini, Soebono, Van Dalen, & Van der Vleuten, 2011). Moreover, having lower education and coming from a rural area seems to amplify women's inferior attitude toward 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 (Kim, Kols, Bonnin, Richardson, & Roter, 2001).

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, and Weinman (2006) 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. First, 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. Second, 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 nonadherence 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 nonadherence 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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