

EXPLORING POSSIBLE CAUSES FOR DELAYS SEEKING MEDICAL TREATMENT AMONG INDONESIAN WOMEN WITH BREAST CANCER

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ABSTRACT

Introduction: The duration of time delay of breast cancer patients can be significantly long, depending on the affecting situation and environment. A study on the profile of cancer patient time delay of breast cancer cases undertaken at the Oncology Hospital in Surabaya Indonesia showed that patient delay was highest with 36,18%, while referral delay was 25% and treatment delay was 13,16%.

Objective: This study aimed to explore the underlying causes for the delays seeking medical treatment experienced by Indonesian women with breast cancer and what kinds of non-medical treatment were pursued instead.

Methods: This study used qualitative methods with in-depth interviews among 20 participants to reveal the causes of delaying medical treatment by patients with breast cancer. Subjects were chosen from women diagnosed with breast cancer who had delayed their medical treatment for various reasons and were currently undergoing medical treatment at a hospital.

Results: The underlying causes for the delay of medical treatment were varied, including psychological reasons (fear of surgery, being worried about adverse effects of the medicine, making troubles to the other people, afraid of losing breast, or losing husband); lack of knowledge about cancer (unfamiliar with the symptoms of cancer, possible cancer cure by nutritious food, more trust in alternative medicine, myth, participant's husband did not approve her surgery, only rely on prayer, forgot if she was sick); factors deriving from health service system (limited facilities, a false diagnosis, queue rooms/radiotherapy/for hospitalization, the radiotherapy equipment was out of service, patient unable to walk, high out-of-pocket cost, and doctors were not communicative). During time delay, some patients have also sought non-medical treatment with herbal medicines, non-herbal medicines, and non-conventional treatment (laser, reiki, acupuncture, and vest treatments).

Conclusion: Many factors affect the delay of medical care among patients with breast cancer. Often, these delays influence the patients to seek alternative treatments.

Keyword: Breast cancer patient, Delay of medical treatment, Non-medical treatment.

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INTRODUCTION

Cancer is a disease with significant social, economic, psychological, and spiritual impact. In 2012, the estimation of cancer morbidity and mortality ranked breast cancer among Indonesian women as the highest [1]. Results of the Basic Health Research (*Riskesdas*) in 2013 showed that cancer prevalence in the Special Region of Yogyakarta was 4.1% of the population. This prevalence was the highest rate in Indonesia and even exceeds the national annual prevalence of 1.4% [2]. Registration of tumors at Dr. Sardjito General Hospital in 2015 showed that among the ten most prevalent cancers according to organ or location in men and women, breast cancer ranked number one. Similarly, among the ten most prevalent cancers according to organ or location in women, breast cancer also ranked the highest. Distribution of breast cancer based on age showed the highest annual prevalence is between the ages of 45–54-year-old [3]. Many people in the Indonesian society have no proper knowledge about cancer. This fact may be the cause for patients delaying to seek treatment and presenting late to hospitals with an advanced stage of cancer [4].

There is an illustrated model of research which calculates total delay for all variations of physical disease. There are several levels of delay,

namely, appraisal delay, illness delay, scheduling delay, and treatment delay [5]. The duration of time delay can be significantly long, depending on the affecting situation and environment. A study on the profile of cancer patient time delay of breast cancer cases undertaken at the Oncology Hospital in Surabaya showed that patient delay was highest with 36.18%, while referral delay was 25%, and treatment delay was 13.16%. One significant factor relating to patient delay in breast cancer cases in this study was tumor size. Direct and indirect patient's arrival had no significant influence on patient delay. Alternative medicine had significant influence on medical treatment delay [6]. These delays bring the patient to be in stages of denial, anger, bargaining, depression, and then finally reaching some acceptance [7]. These processes may cause patients to look for other options before seeking medical treatment. Myths about cancer and alternative medicine contribute to not optimal cancer management, due to the patients receiving misinformation and as a result, delaying seeking professional medical treatment.

This study aimed to explore the underlying causes of delays for seeking medical treatment by Indonesian patients with breast cancer and what kind of non-medical treatment the patients have sought instead.

METHODS

This study used qualitative methods with in-depth interviews to reveal the reasons for delaying medical treatment by patients with breast cancer in Indonesia. The researcher is a master of public health and first vice chair of the Indonesian Cancer Foundation Yogyakarta Special Region Branch. This research was conducted because many patients with breast cancer present at hospitals in advanced stages of the disease in Indonesia.

Subjects were selected from patients diagnosed with breast cancer and undergoing medical treatment at Dr. Sardjito General Hospital, Yogyakarta, Indonesia, who had a history of delayed medical treatment for various reasons. The sample population was 20 patients who were differentiated into the following categories: Those living in Yogyakarta, Indonesia, and its surroundings and those living in areas at least 2 h away from city center via public transportation; those younger than 50 years old and those older than 50 years old; and those with education up to high school and those with education higher than high school. Subjects were interviewed using interview guides. Data was transcribed verbatim. Analysis start from code, category and theme. The data was arranged in narrative sentences, interpretation, summarized and evaluated.

The study protocol was approved by the Medical and Health Research Ethics Committee Faculty of Medicine Universitas Gadjah Mada (KE/FK/226/EC/2016) in March 2016. Informed and written consent form was obtained from each participant before the interview.

RESULTS

Causes of delay

There were a number of underlying causes for the delay of medical treatment, which included causes related to psychological factors, lack of knowledge about cancer, and the limitation of the existing health service system. There were 18 causes for the delay of medical treatment. The causes are presented in Table 1.

Seeking of non-medical treatment

While delaying seeking professional medical treatment, patients sought out a variety of non-medical treatments such as herbal medicine, non-herbal medicine, and non-conventional treatments, which are presented in Table 2.

Alternative medicines provided by traditional healers could be in the form of herbal medicine or non-herbal medicines. One of the traditional healers gave fermented solution from herbal medicine, containing fermented herbal material and yeast.

There was one religious leader (*imam*) who as a healer not only provided spiritual motivations but also provided herbal capsules and stew, cotton swabbing of lumps, prayed on water, and according to local folklore, was known for transferring the diseases of four people to eggs. There was a naturopathic doctor who also offered alternative medicines using white turmeric capsules. The doctor has a history as a stage IV breast, ovary, and lung cancer patient. Instead of seeking medical treatment, her grandma gave her white turmeric as a raw vegetable and she felt better.

Other medication (non-conventional treatment)

Aside from medical treatment, some participants prefer other forms of intervention including laser, reiki, acupuncture, and vest treatments. Involving laser treatment, a participant stated that she had already undergo four laser therapies by a doctor with no significant effect, and then the doctor recommended surgery. Concerning reiki treatments, this practice requires practitioners to handrub the back of the patients along with making prayers and prescribing a fruit juice recipe with a variety of fruits every week. Acupuncture was done by puncturing a needle into patients' skin and applying heat or electrical stimulation at acupuncture spots. One participant who underwent this method felt that the lump in her breast got bigger. She then switched over to

medical treatment. To attempt the alternative vest treatment, three participants purchased the vests. But in the end, only one participant actually wore the vest.

According to evidence-based medical research, there are several levels of delay, namely, appraisal delay, illness delay, scheduling delay, and treatment delay. The duration of time for delay can be long, depending on the affecting situation and environment. Total time of delay for all cases (n=20) was between 1 month to 10 years: Categorically, eight persons waited between 1 and 6 months, 1 person waited 6–12 months, 10 persons delayed 1–5 years, and 1 person delayed more than 5 years.

DISCUSSION

Causes of delay

One or multiple adverse effects of cytotoxic drugs are experienced by all cancer patients who are undergoing chemotherapy [8]. The stories of the suffering caused by the adverse effects of chemotherapy have been heard by new patients and considered as a frightening experience. This perception may hinder the patient's intention to immediately seek any medical treatments. Moreover, one study showed that breast cancer also left psychosocial impacts, which involve patients' worries, sexuality, and body image. Breast cancer management was often delayed because of the several reasons [9]. Essentially, they needed time and help to accept the reality of their condition and finally seek professional and conventional medical treatment. Examining the sociodemographic factors and reasons associated with delays in breast cancer presentation, a study of Nigerian women found the delay of treatment was often due to ignorance of the illness and fear of removal of their breasts [10].

Lack of knowledge about cancer symptoms will contribute significantly to delays in medical treatment [11]. One study showed that women who delay treatment up to 60 days after the diagnosis of advanced cancer significantly bear the risk of death [12].

Another study examined the power of suggestion in traditional Javanese healing treatment, showing that suggestions arise from both the patient and the healer. Even though patients often feel uncomfortable because of their illness, they still have a hope of recovery [13]. The patients sometimes will improve nutritious food intake in an effort to cure their cancer without seeking the available conventional medical treatment, even though some participants have doctoral level of education as seen in this study's findings.

The factors causing errors in patients' perceptions include inaccurate or insufficient information, and this was a major factor in misinterpreting the possibility of an alternative cure [14]. Many patients believe in alternative medicine because the information often comes up repeatedly in an intimate setting, while in more clinical settings such as hospitals, the medical information given reflects heavily on the doctor's business and busy schedule.

In Javanese and Asian culture, the husband is the head of the household, so the necessary decisions must involve the husband including medical treatment decisions. This arrangement is not beneficial for most patients because the cancer will quickly develop. As one expert explained Javanese society in general still holds the view that the position of a wife is dependent on the husband. This dependency pattern implies that women are considered not independent and are unable to determine their life direction and make decisions related to personal health and family issues [15].

For a successful intervention, it is necessary to develop better dialogue between health-care workers and patients about the treatment process. An expert from the American Board of Internal Medicine describes the professional elements of medical practice as altruism, the essence of being professional, best attention to the patient, and respect for others including patients, families, other doctors, and other health-

Table 1: The causes of medical treatment delay

Factors	Contributing causes
Psychological factors	Fear of surgery Afraid of the adverse effects of the medicine Being troublesome to other people Losing her breast or her husband
Lack of knowledge of cancer	Unfamiliar with the symptoms of cancer Cure cancer by nutritious food Belief in alternative medicine Belief in myth Participant's husband did not approve her surgery Only rely on prayer Forgot if she was sick
Health services	Limited facilities A false diagnosis Queue rooms/radiotherapy/for hospitalization The radiotherapy equipment was out of service Patient unable to walk Cannot afford the cost Doctors were not communicative

Table 2: Non-medical treatment

Alternatives	Kinds of alternatives
Alternative herbal medicines	Herbal medicine to be boiled, as capsule, solution, or scrub and fermented solution
Alternative non-herbal medicines	Transferring disease to goat or eggs Sucking it with leech Pulling out the disease Taking disease out with cotton and with spoon Puncturing and rubbing feet Flapping hands on the floor Wiping back with tissues Stomping wood with feet
Other medication (non-conventional treatment)	Laser, reiki, acupuncture, and vest treatments

care workers [16]. Due to the traditional paternalistic hierarchy, the professionalism of doctors needs to be improved, and sometimes it is necessary for someone to advocate or mediate between the doctor and the patient.

According to research about the influential factors on delays in seeking medical services, other influential factors are age, education level, family income, and availability of health insurance [17]. As a result, doctors need to clearly explain the importance of taking medication and making consultation with their doctor regularly. Not knowing the importance of early diagnosis of cancer and treatment, patients often delay seeing a doctor on the grounds that doctors will not find the disease and it will be a waste of time and money [18].

Class A hospitals as cancer referral centers which also serve patients from outside of the Special Region of Yogyakarta cannot serve a large number of patients immediately. According to the person in charge of the Radiotherapy Department, the hospital only has two radiotherapy equipment to serve 80 patients each day, with each session running about 15–20 min. Radiotherapy service can require between 25 and 30 visits, causing patients' waiting time to backlog to more than a year.

There is an opportunity to do radiotherapy in other cities which also serve health insurance patients with faster waiting time, but many patients do not use the opportunity because it increases their out-of-pocket cost for transportation and lodging. According to a recent press release about the Indonesian National Health Insurance (NHI) [19] and the explanation of the hospital director, there was a surge in NHI program participants. This increase resulted in long queues because the hospital facilities have not been upgraded to accommodate this change in policy. This fact resulted in patients who came from outside the city to have increased costs for lodging and/or transportation.

Because of the increased number of patients and the added burden on the radiotherapy equipment, it was reasonable to have delays if the device needs to be repaired. Based on the management of the infrastructure of radiology and radiotherapy equipment, the quality of radiology services is not only determined by the quality of the human resources of the service providers but also depends on the quality of facilities, infrastructure, and equipment used [20]. Therefore, the ability of the radiographer to manage increased patient load, in particular, maintaining radiology infrastructure within the limits of his or her authority, greatly determines the quality of the results of the services provided. If the radiographer declares that the device is unfit for use, it must be repaired first to maintain the quality of patient care, and this shutdown of equipment leads to further delayed treatment for the patient.

One participant signed up six times to consult with a doctor at the hospital and was unsuccessful because the number of patients for doctor consultation was limited. This delay happened because the doctors also have other activities such as visiting the inpatients, coordination meetings, teaching, seminars, symposia, and other reasons, so they were forced to limit the daily number of patients served. Under these present circumstances, the hospital expects the patients to be willing to wait to receive services by the existing specialists.

Patients unable to walk cannot perform laboratory tests and that handicap results in not getting the medicine covered by health insurance, despite the advice that the treatment should not be interrupted. This situation has indicated the need for home services that can perform health and sampling laboratory examination. Concerning palliative care policy, in response to the increase of diseases such as cancer, degenerative diseases, stroke, HIV/AIDS, especially for the advanced stages of illness, palliative care is needed in addition to currently available services to facilitate promotive, preventive, curative, and rehabilitative efforts [21]. It is necessary to improve the quality of life of patients and their families. Ideally, palliative care can be adequately done in a patient's home (home care). Certainly, at this time, the homecare services are not covered by health insurance.

Essential drugs are sometimes unavailable, and this situation often happens in community health services in Indonesia. This dilemma is not in accordance with regulations on the standard of pharmaceutical service in hospitals which state that the organization of pharmaceutical services in the hospital shall ensure the availability of pharmaceutical preparations, medical devices, and consumables that are safe, beneficial, useful, and affordable [22]. According to the rational use of medicines protocols, drug planning in medical facilities including pharmacies, hospitals, and health centers should be done properly to prevent any occasion of running out of stock or inability to meet the potential demand.

Health insurance can be an important factor for meeting the patients' needs and utilization of health services. Today, there are new regulations of the NHI in Indonesia concerning access to health services [23]. Sindo, in a press release about a study conducted on ASEAN costs in oncology departments [24], published the results that showed cancer treatment costs brought major impact on the ASEAN society and is a major cause of poverty throughout Asia.

Due to limited facilities, this difficult situation has demanded from the patients additional money and strong motivation to continue seeking conventional services. Furthermore, to prevent further delay in medical treatment, family support is needed.

In this study, some participants only rely on prayer without receiving proper treatment. This faith-based belief is in line with another research which stated that there exists an excessive faith in religion, and trust in spirituality, which ends up in delaying seeking medical treatment [25]. One expert inferred that psychotherapy which is aimed to cure mental illness needs to not only rely on medical devices and best practices but also on combining religious aspects as well to be successful in such situations [26].

According to a researcher concerning the factors for delay among patients with breast cancers in screening at medical facilities, there are some factors that correlate significantly with delayed treatment, and these concerns include education, cost affordability, information exposure, spouse/family supports, and screening behavior (e.g. never conducting breast self-examination) [27]. Contrarily, in an analysis of factors affecting delays in treatment of breast cancer, one study found no correlation between related factors such as knowledge, occupation, fear, family support, health insurance, transportation cost, with seeking treatment except hospital behavior, family history, and education, which were weakly correlated with delays in breast cancer treatment. They also found no other significant factors affecting treatment delays in patients with breast cancer [28]. These results are in direct contradiction with the multifactorial findings of this study.

Non-medical treatment

Out of 20 participants, as many as 19 (95%) people sought alternative medicine. Most participants were of average to higher education level. This finding is suggesting that educational background did not necessarily affect medical or non-medical treatment-seeking behavior. The Basic Health Research (*Riskesmas*) in 2013 stated that in Indonesia, as much as 30.4% of households seek out alternative medicine. A higher number was found in Yogyakarta, and the highest was in South Borneo at 61.3%.

The local religious network *Ulama* not only provides spiritual motivation, and alternative healers, but also grants prayer services and provides herbal medicines, capsules, stew, and cotton swabbing for lumps, while some spiritual leaders are known to pray over water and recent folklore records one man (*imam*) transferring the disease of four people to eggs. Another naturopathic doctor is known to offer alternative medicines using white turmeric capsules, for example, but the doctor continues keeping anamnesis and taking account of medical examinations by another doctor.

Many studies have been done to investigate the properties of plants as potential anti-cancer drugs against breast cancer. The active ingredients of the plants include phenolic compounds such as tannins, flavonoids, and phenolic acids, which possess anticancer properties [29]. The existence of crude herbal powder in capsules produced by herbalists or naturopathic doctors is in violation of quality requirements of traditional medicines, which state that drugs in the form of capsule can only consist of the extract of active ingredients [30].

A recent research stated that some of the reasons patients seek alternative medicine are family and friends' recommendation, family sanctions, felt compatibility and benefits, and faith in a healer. These factors together strongly influence Malaysian and Asian culture [31]. This issue is a common occurrence in developing countries with limited health facilities and a health system different from modern Western medical practices. Some participants stated that they seek alternative medicines because of family and friends' recommendations, commercial advertisements, compatibility with the medication, and faith in healers. These patient testimonies are in line with a study on the correlation of self-efficacy with treatment-seeking behavior in breast

cancer patients which found that the healthy behavior of patients with breast cancer is affected by both external factors, including their family and environment and internal factors, such as patient perceptions of their condition and sense of self-efficacy [32].

Other medication (non-conventional treatment)

Laser radiation has specific attributes: monochromaticity, high coherence, and polarization. These properties result in the extensive use of lasers in medicine. Laser devices can be assigned into three basic groups by means of their level of energy: High, medium, and low energy. All of these types of radiation are used in modern medical practices [33].

Reiki is traditionally considered to be effective for the relief of pain, dyspnea, and anxiety. Patients who request reiki usually feel increased calm, peace, and well-being. Reiki is received by the gentle touch of hands and can be used in most conditions because it is noninvasive and the patient is fully clothed [34]. One healer who gave reiki treatment also gave a fruit juice recipe with a variety of fruits every week. Fruit is a food with high nutritional value and antioxidant content known to have antitumor and anticancer properties, which can make the body feel fresh and better.

Acupuncture is the stimulation by subcutaneous puncture of specific points on the body. The method can vary, but the most well-known type in the United States is the insertion of thin metal needles through the skin into nerve ganglia based on a traditional oriental practice [35]. The efficacy of this practice continues to attract current attention and debate.

A cancer vest is a device recently created for breast cancer treatment. According to the inventor, the device is an electrical capacitance volume tomography that works as a low electrical power current which is focused to a certain nerve spot on cancer. Doctors and oncologists are very cautious in addressing the findings that claim it can cure breast cancer without any clear empirical evidence. Starting in January 2016, the Indonesian Ministry of Health forbade vest practice until enough evidence was given to support its availability. The vest itself does not have any marketing authorization and based on a regulation about marketing authorization of medical devices and household supply every medical device and/or household medical supply imported, used and/or distributed in Indonesia territory must have prior marketing authorization [36]. All of the participants that underwent the above alternative treatments (laser, reiki, acupuncture, and vest) were not getting any improvement and ultimately switched to medical treatments.

A study on perceptions about breast self-examination among women with risk of cancer found that there was a positive correlation between perceived benefits to perform breast self-examination, perceived barriers of women with cancer risk to perform breast self-examination, and their behavior in performing breast self-examination. However, after further analysis, those variables did not strongly correlate with actual breast self-examination behavior. The strongest correlated variables were respondents' knowledge, respondents' education, and accuracy of information about breast self-examination [37].

CONCLUSION

Factors causing patients with breast cancer to delay seeking medical treatment included the following: Psychological factors, lack of knowledge, and limited access to health services. In response, the patients sought non-medical treatment such as herbal medicines to be boiled and prepared traditionally, turmeric capsules, salves or scrubs, and fermented solutions. They also used non-herbal treatments, such as faith healing with some alternatives involving transferring their disease to goats or eggs, sucking it out with leeches, pulling out the disease by pinching, taking disease out with cotton swabs or with spoons, puncturing and scraping feet, flapping hands on the floor, wiping back with tissues, and stomping on wood with bare

feet. Some participants prefer other non-conventional alternative medicine practices recently made popular with commercial Internet advertisements (laser, reiki, acupuncture, and vest treatments). Based on the widespread availability of these various alternatives, this study's findings reveal the importance of appropriate community education about cancer treatment and prevention and the recommendation that increased availability of modern, evidence-based health services must be achieved with national promotional programs.

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AUTHOR'S CONTRIBUTIONS

All authors contributed equally to the writing and revising of this article.

CONFLICT OF INTEREST

The authors state that there is no conflict of interest in this study.

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