

Early Detection of Breast Cancer in Indonesia: Barriers Identified in a Qualitative Study

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Abstract

Background: The lack of early detection in breast cancer management has been identified as the primary factor contributing to the high mortality rate. The introduction of BPJS Kesehatan, Indonesia's national health insurance, was intended to ensure the provision of adequate health services for breast cancer patients. This study aimed to investigate the current state of health services in Indonesia concerning the early detection of breast cancer, following the implementation of BPJS Kesehatan introduction. **Methods:** The study was conducted in 2017 in Yogyakarta, Indonesia. Subjects were recruited using a purposive sampling technique with maximum variation. The sample comprised breast cancer patients, health care professionals (HCPs), and healthy women from the general population with no history of breast cancer. The subjects' experiences and knowledge of health services regarding the early detection of breast cancer were investigated through in-depth interviews. Thematic analysis was used to synthesize the results from interviews with 25 participants. **Result:** This study identified several issues that hinder the timely detection of breast cancer. The lack of both screening and diagnostic procedures emerged as a prominent obstacle in breast cancer management. The study identified the following barriers: (1) limited community knowledge about early detection; (2). lack of urgency among patients to seek medical treatment; (3) limited access to health facilities; and (4) inconsistent adherence among health care professionals to guidelines for both screening and diagnostic procedures. **Conclusions:** This study revealed multiple factors contributing to the delay in breast cancer detection in Indonesia, leading to suboptimal management of the disease. It is crucial for the government to prioritize the improvement of enabling factors across all levels of care for early detection. These factors include initiatives to increase public awareness, improve access to health services, strengthen the referral system, and enhance health facilities.

Keywords: Breast cancer- early detection- early diagnosis- screening- health services- qualitative research

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Introduction

Breast cancer is the leading cause of death and morbidity among females worldwide in both developed and developing countries (Ji et al., 2020). The incidence has been shown to increase in the developing nations, including Indonesia (Bray et al., 2013). According to Globocan (2018), the incidence rate in Indonesia was reported at 42 per 100,000 women (World Health Organization, 2018). Similar to other developing countries, Indonesia experiences a high mortality rate because most cases were diagnosed at a later or advanced

stage (Ferlay et al., 2015; Coleman et al., 2008). In fact, the mortality rate in Indonesia exceeds the global average (Coleman et al., 2008).

The high mortality rate associated with breast cancer can be attributed to the lack of early detection, including screening and timely diagnosis (Parsa et al., 2006). Early detection is important because it allows for less intensive, less toxic, and more cost-effective treatments with improved outcomes when localized cancer is identified (Freitas and Weller, 2015). Although breast self-examination (BSE) and clinical breast examination (CBE) can raise awareness and aid in early diagnosis,

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they are no longer recommended as screening methods by the World Health Organization (WHO) (2006, 2014), particularly in high-resource countries (World Health Organization, 2006; World Health Organization 2014; Ministry of Health of Indonesia, 2015). According to Fletcher and Elmore (2003), mammography is currently considered the most effective screening method proven to reduce breast cancer's mortality rate by 20-30% (Fletcher and Elmore, 2003). The WHO (2014) therefore recommends organized, population-based mammography screening programs for women aged 50–69 years in well-resourced countries (World Health Organization, 2006).

In low-resource countries, however, the recommendation depends on the strength of the specific health system in place. If the system is robust, the WHO suggests the implementation of a universal and organized mammography screening program, which aims to detect breast cancer among the asymptomatic population. However, in countries with weaker health systems, it is more feasible to focus on improving early diagnosis of symptomatic patients. This can be achieved through a triple diagnostic strategy involving physical examination (e.g., CBE), radiology examination (e.g., mammography, ultrasound), and pathologic examination (Kharkwal and Mukherjee, 2014; Ministry of Health of Indonesia, 2015).

In 2014, the government of Indonesia launched the national health insurance program, administered by Badan Penyelenggara Jaminan Sosial Kesehatan (BPJS Kesehatan). The objective was to provide universal health insurance coverage that ensures safe, accessible, affordable, and effective healthcare for all citizens. Three years after its implementation, this study examines the adequacy of health services for breast cancer patients in Indonesia, taking into account the strength of the healthcare system. Specifically, the study investigates whether the introduction of national health insurance has been accompanied by the establishment of a national breast cancer screening program and/or increased uptake of early detection activities in routine healthcare practice. To achieve this, the study explores the experiences and knowledge of breast cancer patients, healthcare professionals (HCPs), and other stakeholders to gain insights into the current conditions of healthcare services in Indonesia, particularly in relation to screening and early diagnosis.

Materials and Methods

Study design and ethics

We conducted a qualitative study employing phenomenology as the methodological orientation. The study was conducted between May and June 2017 at Dr. Sardjito Hospital in the Special Region of Yogyakarta Province, Indonesia. Dr. Sardjito Hospital is the top referral hospital in the Yogyakarta Province, providing care to a diverse patient population with a wide range of socio-demographic backgrounds. In this study, the researchers (A.V.I., A.A.R., and two other interviewers) conducted in-depth interviews to explore the subjects' experiences and knowledge regarding healthcare services for the early detection of breast cancer. To mitigate any

potential interviewer bias, we involved a diverse group of interviewers, including both male and female.

A.V.I received a formal education in qualitative study. Prior to the study, all the researchers underwent training on the study protocol, informed consent procedure, and guideline for conducting interview. An ethical approval had been obtained from the Ethics Committee of the Faculty of Medicine, Public Health, and Nursing at Universitas Gadjah Mada, Special Region of Yogyakarta. Written consent was obtained from all participants and they were to withdraw from the study at any point during the interviews. Each participant was assigned an ID number to ensure anonymity.

Participants

Subjects were recruited using a purposive sampling technique with maximum variation to include a diverse range of individuals. They comprised breast cancer patients and their relatives, health care professionals (HCPs), and healthy women from the general population who had no history of breast cancer and no family members affected by the disease. Patients receiving palliative care were excluded, but patients in all stages of the disease were eligible for inclusion. HCPs were chosen based on their breast cancer-related expertise across different levels of care, allowing them to provide insights from both their own and their patients' perspectives. Additionally, a hospital director and a health office's representative were included offer insights from an authoritative and managerial standpoint. Women from the general population were also included to provide perspectives representing the wider community's views on breast cancer care. To minimize potential bias, all participants had no pre-existing relationship with, or knowledge of, the interviewers. They were only acquainted with the researchers through the purpose and objectives of the study. The recruitment process involved face-to-face or telephone approaches, and none of the approached participants declined to participate or withdrew from the study during its course.

Data Collection

The data in this study was collected through in-depth interviews in local languages, specifically Indonesian and Javanese. The interviews were semi-structured interviews with open-ended questions to extract the subjects' experiences. The interview questions were divided into several parts with a comprehensive list of questions related to the following topics: (i) community's knowledge and perception towards early detection of breast cancer, (ii) breast cancer patients' experience in early detection, and (iii) the state of the health care system regarding early detection of breast cancer. All the interviews were conducted after BPJS Kesehatan implementation, ensuring that the participants' perspectives reflected the care available within the insurance scheme. Sampling continued until data saturation was reached. With subjects' permission, the interviews were recorded using audiotapes. The interviewers took comprehensive notes during the interviews, recording them in the forms that included key questions to elicit in-depth responses. Each

interview session lasted 45 to 90 minutes, allowing for sufficient exploration of the subjects.

Data Analysis

The data from the audiotapes were transcribed, translated into English, and then analyzed using thematic analysis which categorizes, reconstructs, and draws conclusions from the data involving the use of thematic coding to search for patterns. As part of the coding framework development process, A.V.I and A.A.R highlighted important quotes and assigned primary codes. These codes were subsequently organized into thematic categories until no new codes emerged from further analysis of additional transcripts. Complete transcripts of the interviews can be made available upon request.

Results

A total of 25 interviews were conducted, reaching data saturation. The subjects consisted of six breast cancer patients or relatives, eleven HCPs representing both public and private health care facilities and all levels of care (i.e., general practitioners, oncologists, oncology surgeons, radiologists, radiation oncologists, nurses, lay helpers), two stakeholders from an authoritative and managerial perspective (i.e., a representative from the district health office and a hospital director) and five healthy women from the general community. The interview results are presented thematically in Figure 1 and in narrative form as follows:

*Knowledge gaps and perception towards early detection
 Misperception about screening program*

"I did not know that screening can be done even for people without symptoms." (Woman from general community)

"I did not know that breast cancer can be asymptomatic

and that there is a tool for detecting it." (Breast cancer patient's relative)

"I thought mammography is used only for women with a breast lump." (Breast cancer patient)

Although most of the women from the general community were aware of the term 'screening', none of them knew that it is aimed at detecting diseases before symptoms appear. With the exception of healthcare professionals (HCPs), most female subjects did not know that mammography could be used for screening prior to the manifestation of symptoms. They mistakenly thought that this examination solely intended for women with a breast lump only.

Similarly, the relatives of the breast cancer patients were unaware that they could undergo regular screening. These women also thought that a single screening was sufficient, particularly in the case of mammography. When the result was negative, they believed that it meant they were in good health condition indefinitely, and thus felt there was no need for regular follow-up screenings.

BSE is more popular than CBE and mammography

"Yes, I have heard about breast self-examination from many health promotions, but I have not heard about CBE nor mammography" (Women from general community)

When asked about breast cancer screening methods, the women from the general community were most familiar with BSE. The HCPs reported that BSE, locally known as sadari (pemeriksaan payudara sendiri), was the only early detection program for breast cancer that was regularly promoted by the government. After being informed by the interviewers about additional screening options (i.e., CBE and mammography), most participants still preferred BSE because it was simple and free. However, several participants expressed uncertainty about their findings, wondering whether they truly felt a lump

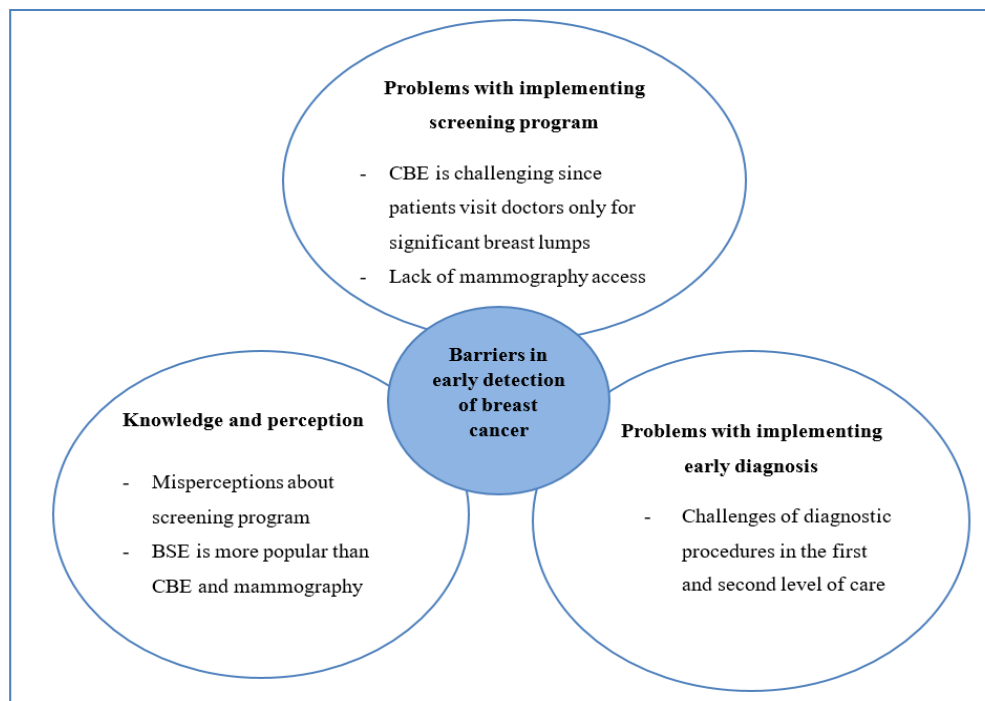


Figure 1. Interview Results

or something else.

CBE, locally known as sadanis (pemeriksaan payudara klinis), was the least popular early detection program. None of the participants had CBE for screening (in asymptomatic condition), but it was part of the early diagnostic process for participants with breast cancer. Only one breast cancer patient was aware of mammography as a screening tool, while the other two patients knew of it only as part of the diagnostic process. The women from the general community and the breast cancer patients' relatives had neither knowledge nor experience with mammography as a screening tool. This lack of knowledge about CBE and mammography may have impacted their preference for either screening method.

Problems with implementing screening program

CBE is challenging since patients visit a doctor only for significant breast lumps.

"Nine years ago, I felt a lump as big as a marble in my upper left breast near the armpit, but I ignored it. Then, in 2012 I felt the pain in my left arm, and I palpate this area until found another lump near the axis of my body as big as a chicken egg. After telling my husband, we agreed to consult to the doctor" (Breast cancer patient)

"In July 2012, I felt a lump as big as a marble in my left breast when I was taking a bath, but I ignored it and assumed it as "uci-uci" (benign nodule). After a while, my husband felt a lump in my breast and suggested me to go to the doctor." (Breast cancer patient)

All breast cancer patients reported that they ignored the first breast lump they felt. They did not think of it as a serious problem that required immediate medical attention. Most of the HCPs made a similar statement. One HCP reported that many patients often waited until their symptoms are severe before seeking help. The patients would consider the symptoms severe if they were worried about the size of the lump or if the lumps were painful or limiting their usual activities. In the case of our patient subjects, they only went to the doctor after being urged by their family members.

In Indonesia, breasts are perceived as a sensitive and private part of the women's body, so it is often considered shameful to talk about breast conditions with other people. It is also taboo to allow males to touch this body part (e.g., during examination by a male doctor), particularly when the women feel there is no abnormality in the breast. Two women from the general community revealed that they would need to ask for their husbands' permission before a male doctor could examine their breasts.

Lack of mammography access

"Mammography screening is not covered by BPJS Kesehatan, whereas diagnostic mammography is covered in selected facilities" (Oncologist)

One HCP (a radiologist) noted that Indonesia, being a low-middle-income country, has limited resources for conducting mammography. In the Yogyakarta Province, which has a population of 4 million,¹⁴ there are only seven mammography facilities, all of which are in the city center making access difficult especially for patients

from the peripheral areas. Mammography screening is not covered by BPJS Kesehatan in any health care facility, but diagnostic mammography is covered in selected facilities.

One of the HCPs working in a private hospital shared her experience of a patient with a breast lump who was scheduled for a diagnostic procedure for mammography. However, the hospital did not have a mammography unit, so the HCP referred the patient to a private laboratory located in front of the hospital. Unfortunately, the laboratory service was not covered by BPJS Kesehatan. This is because BPJS Kesehatan covers diagnostic mammography only in selected health facilities, and such private laboratory is excluded. In the end, the HCP decided to use ultrasound to diagnose the patient instead of mammography.

Problems with implementing early diagnosis

Challenges of diagnostic procedure in the first level of care

"When a patient comes with a breast lump, I will conduct a physical examination. If I suspect the lesion as malignant, I will refer the patient to the district hospital" (General Practitioner)

A general practitioner stated that he typically conducts a physical examination to determine whether a breast lump is suspected to be malignant or benign. If it is malignant, he would refer the patient to a higher-level health care facility. However, as it is not possible to refer the patient directly to a specialized oncology team available at a third-level hospital, he would refer the patient to a second-level hospital instead. If the breast lump is suspected to be benign, he would not offer any referral to the patient.

This kind of practice by general practitioners has often been criticized by other HCPs. A radiologist and an internist argued that it may cause under-diagnosis of breast cancer because physical examination alone cannot definitively diagnose malignancy. A triple diagnostic procedure, consisting of physical, radiology, and pathology examinations, is necessary to reach a definitive diagnosis. Since radiology examination is not offered in first-level healthcare, patients should be referred to a higher-level facility. If the radiology examination indicates that the lump is malignant, the patient should then undergo a fine needle aspiration biopsy (FNAB) for pathology examination to reach a conclusive diagnosis.

Challenges of diagnostic procedure in the second level of care

"Most times, the surgery procedure for women with a breast lump in a secondary hospital is done with a diagnostic purpose, which we do not recommend" (Oncology Surgeon).

A lack of resources was found regarding the availability of pathologists in the second level hospitals. One HCP (an oncology surgeon) stated that, in the Yogyakarta Province, only a few second-level hospitals have a pathologist on staff. Thus, a surgeon must send the specimens to higher-level hospitals for a definitive diagnosis of patients suspected of having breast cancer.

This process is time-consuming, so patients must wait longer to learn about their condition and receive treatment.

Furthermore, oncology doctors (i.e., an oncology surgeon, a radiologist) at third-level care facilities reported that they had received referrals from second-level care facilities for patients who had already undergone breast surgery. They mentioned that many of these breast surgeries had been performed without the standardized triple diagnosis, and that the surgery itself had been used to confirm the diagnosis. This practice had disadvantaged patients by subjecting them to an invasive and potentially unnecessary procedure because definitive diagnosis could have been achieved through less invasive measures.

The oncology surgeon estimated that approximately 70-80% of referral patients had undergone surgery in the second level of care without the standard procedures. For example, lymph node removal was not performed, even though this is essential to identify cancer cells that may have spread to nearby lymph nodes. The reason why this surgeon in the second level of care did not conduct standardized procedures could be the lack of mammography facilities and pathologists.

One HCP said that doctors in the second-level care facilities could refer patients to third-level facilities for diagnostic mammography. However, in most cases, they were reluctant to do so because of the lengthy administrative and waiting times. As a result, doctors often used ultrasound as this is the only imaging modality available in the second level of care. However, the HCP added that both mammography and ultrasound should ideally be used together for breast cancer diagnosis.

Discussion

This study aimed to explore the knowledge and experiences of patients, HCPs, and stakeholders regarding health care services for the early detection of breast cancer following the implementation of BPJS Kesehatan. Through the interviews, the community's knowledge and perception were explored. This study found there is a misconception in the community regarding the term 'screening', as they were unaware that it is aimed at an asymptomatic population to identify individuals with an abnormality suggestive of cancer (World Health Organization, 2006; World Health Organization, 2014; Ministry of Health of Indonesia, 2015; Fletcher and Elmore, 2003; Kharkwal and Mukherjee, 2014; Ministry of Health of Indonesia, 2015; Badan, 2019; Shetty, 2015). Most non-HCP respondents were unaware of the availability of preventive examinations.

Furthermore, this study also found women were more familiar with BSE as a screening method rather than mammography or CBE. The World Health Organization (2018), however, only recommends BSE for raising awareness among women at risk, but not as a screening method due to its limited efficacy in reducing mortality rate (WHO, 2018). Several studies have also found that women lack knowledge about the available breast cancer screening methods (Binhussien and Ghoraba, 2018; Izanloo et al., 2018). This could indicate that health promotion programs provided to the community are

inadequate, even after BPJS Kesehatan implementation. It may also imply that increasing health literacy with respect to prevention is not a priority for the governments.

A study by Kardinah et al., (2014) in Indonesia showed that CBE could be as effective as mammography in detecting breast cancer. However, our study found that there are challenges to implementing CBE, either as a screening strategy or as an early diagnosis strategy, in Indonesia. Breast cancer patients often do not go to the doctor immediately after they feel a breast lump, but rather wait until they consider it to be a significant problem. According to a report by Kesehatan (2020) on screening practices, Indonesian women are reluctant to go to a doctor for symptoms of breast cancer due to social norms of taboo, shame, and fear (Badan, 2018). This also indicates low health literacy among the community, which can lead to a lack of urgency to seek medical treatment (Dewi et al., 2019; Widayanti et al., 2020; Widjaja et al., 2018).

Furthermore, during our interviews, a general practitioner (GP) stated that he would only refer patients with breast lumps detected through clinical breast examination (CBE) to the next level of care if he suspected the lumps to be malignant through physical examination. Although our study cannot conclude that this practice is widespread, it does not align with the guideline by the Ministry of Health (2015) that women who present to primary health care (PHC) with a breast lump, or any change in the shape or consistency of the breast, should be immediately referred to the next level of care for further examination (Ministry of Health of Indonesia, 2015). Cazap et al. (2016) revealed that a common issue in low- and middle-income countries is the GPs failure in PHC to recognize a potential cancer case (Cazap et al., 2016). Thus, the government must ensure all GPs understand and comply with this rule.

This study also found a lack of diagnostic resources in the second level of care, such as the availability of pathologists. Cazap et al., (2016) said that one important aspect of accurate diagnosis is the availability of skilled pathologists in diagnosing cancers. This starts with adequate handling of tissues using modern techniques, which is accessible only at some specialized referral centers. Furthermore, Hari et al., (2016) revealed that image-guided biopsy was superior to palpation-guided biopsy. This procedure can be done by a radiologist who specializes in breast imaging, which is available in the third level of care. However, this study found that many patients were not referred to the third level of care for more available standardized diagnostic procedure (Hari et al., 2016). This finding is similar to the statement in the Ministry of Health bulletin, which said that one factor that delays early detection is doctor's reluctance to make referrals (Ministry of Health of Indonesia, 2015).

This qualitative research has explored experiences, awareness, and knowledge of subjects from various backgrounds through one-on-one interactions between the researcher and participants. Yogyakarta Province was chosen because of its diverse socio-economic and educational backgrounds as this province covers both urban and rural areas. However, it is important to note that Yogyakarta Province has a high Human Development

Index (HDI) compared to other provinces in Indonesia. Therefore, the results of this study may give an optimistic view of the situation relative to the Indonesian population in general.

This study had some limitations. First, it did not measure the level of knowledge about early detection of breast cancer. Second, it did not collect quantitative data to detect changes in breast cancer screening after the implementation of BPJS Kesehatan. A mixed-method study design could be used to conduct an implementation study that would explore in more detail the current situation with respect to programs for early detection of breast cancer in Indonesia. This type of research could also identify potential approaches to improve the current situation. This would include evaluating the acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage, and sustainability of such programs (Peters et al., 2013).

This study identified several issues that delay the detection of breast cancer in Indonesia. These include the lack of both screening as well as diagnostic procedures, insufficient resources, varying adherence to guidelines in health care facilities, and a lack of knowledge in the community about early detection. These factors have led to suboptimal breast cancer management. To improve breast cancer management, BPJS Kesehatan must focus on improving enabling factors at all levels of care.

Author Contribution Statement

Ajeng Viska Icanervilia: Conceptualization (support), Methodology (support), Formal analysis (lead), Investigation (lead), Data Curation (lead), Writing - Original Draft (lead), Writing - Review & Editing (lead). Lina Choridah: Conceptualization (lead), Methodology (lead), Validation (lead), Formal analysis (support), Writing - Review & Editing (support), Supervision (lead), Project administration (lead), Funding acquisition (lead). Antoinette D.I. van Asselt: Review&Editing (lead). Johanna P.M Vervoort: Review & Editing (support). Maarten J. Postma: Review & Editing (support). Anggraeni Ayu Rengganis: Formal analysis (support), Investigation (support), Data Curation (support), Writing - Original Draft (support), Writing - Review & Editing (support). Kardinah: Review & Editing (support).

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Ethical Consideration

An ethical approval had been obtained from the Ethics Committee of the Faculty of Medicine, Public Health, and Nursing at Universitas Gadjah Mada, Special Region of Yogyakarta. Written consent was obtained from all participants and they were to withdraw from the study at any point during the interviews. Each participant was assigned an ID number to ensure anonymity.

Availability of data

Complete transcripts of the interviews can be made available upon request.

Conflict of Interest

There was no conflict of interest in this research.

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