

A Qualitative Study: Early Detection of Breast Cancer in Indonesia (After Universal Health Coverage Implementation)

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Abstract

Objectives

Early detection is of vital importance in breast cancer management. BPJS Kesehatan, as Indonesia's national health insurance, is expected to provide an adequate health service for breast cancer patients. This study aimed to obtain insight into the current conditions of health care services in Indonesia, related to early detection of breast cancer, particularly after BPJS Kesehatan implementation.

Methods

The study was conducted in 2017 in Yogyakarta, Indonesia with a wide range of socio-demographic backgrounds. Subjects 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 with breast cancer. The subjects' experiences and knowledge of health care services regarding early detection of breast cancer, were investigated through in-depth interviews. The thematic analysis guided the result synthesis from semi-structured in-depth interviews with 25 participants.

Results

Despite more patients with earlier stages presenting in high level of care after the implementation of universal coverage, this study identified the lack of both screening as well as diagnostic procedures as a prominent obstacle in breast cancer management. Study results indicated a lack of knowledge and misperception among the community about breast cancer screening. Also, problems in implementing early diagnosis were revealed such as the lack of urgency and access for patients to get a proper diagnostic procedure. Furthermore, varying adherence to the guidelines in all levels of care were found.

Conclusions

This study identified several issues that cause delay in the detection of breast cancer in Indonesia. All these factors lead to suboptimal breast cancer management. BPJS Kesehatan (the national health insurance) must focus its attention on the improvement of enabling factors in all levels of care for early detection (i.e. increasing awareness, access, referral system and facilities).

1. Introduction

Breast cancer is the leading cause of death and morbidity among females in both developed and developing countries (1). The incidence has been shown to increase in the developing world, including in Indonesia (2). According to Globocan (2018) the incidence rate in Indonesia was 42 in 100,000 women (3). As in other developing countries, a high mortality rate was found in Indonesia because most cases were diagnosed in a later stage (4, 5) and the rate is found to be higher than the average global rate (4).

The lack of early detection, which includes screening and early diagnosis, has been seen as the main cause of the high mortality rate (6). Early detection is important because when localized cancer is identified, treatment is generally less intensive, less toxic, less expensive, and results in improved outcomes (7). Although breast self-examination (BSE) and clinical breast examination (CBE) can be useful methods for raising awareness and early diagnosis, they are no longer recommended by the World Health Organization (2006, 2014) as screening methods, particularly in high-resource countries (8–10). 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% (11). The WHO (2014) therefore recommends an organized, population-based mammography screening program for women aged 50–69 years in well-resourced countries (9).

However, for low-resource countries, the recommendation depends on the strength of the specific health system. If the system is strong, the WHO suggests the implementation of a universal and organized mammography screening program. This program is aimed to detect breast cancer among the asymptomatic population. However, if the health system is weak, the improvement of early diagnosis of symptomatic patients is more feasible (9). It includes using a triple diagnostic strategy of (i) physical examination (i.e. CBE), (ii) radiology examination (i.e. mammography, ultrasound) and (iii) pathologic examination (12, 13).

In 2014 the government of Indonesia launched the national health insurance, implemented by *Badan Penyelenggara Jaminan Sosial Kesehatan* (BPJS Kesehatan). It was expected that this universal health insurance coverage would accommodate and assure safe, accessible, affordable, and effective health care for all. Three years after implementation, this study examines whether Indonesia has provided an adequate health service for breast cancer patients aligned with the strength of the system. Notably, it is important to understand whether the introduction of national health insurance has come along with availability of a national breast cancer screening program and/or increased uptake of early detection activities in regular practice. Therefore, this study aimed to gain insight into the current conditions of health care services in Indonesia, particularly related to screening and early diagnosis of breast cancer by exploring the experiences and knowledge of patients, health care professionals (HCPs), and other stakeholders.

2. Methods

2.1 Study design and ethics

The study was conducted between May and June 2017 in Dr. Sardjito Hospital, Special Region of Yogyakarta, Indonesia. Dr. Sardjito Hospital is the top referral hospital in the Yogyakarta Province and hence covers a patient population with a wide range of socio-demographic backgrounds. The subjects' experiences and knowledge of health care services regarding early detection of breast cancer, were investigated through in-depth interviews. Prior to the study, ethical approval had been obtained from the Ethics Committee of the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada,

Special Region of Yogyakarta. Written consent was obtained from all subjects and they were free to stop the study at any time during the interviews. Each participant was given an ID number to ensure anonymity.

2.2 Participants

Subjects were recruited using a purposive sampling technique with maximum variation. Subjects 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 with breast cancer. Patients receiving palliative care were excluded, but otherwise patients in all stages of the disease were eligible for inclusion. HCPs were chosen based on their breast cancer-related expertise in different levels of care, to speak about both their own and their patients' perspectives. A hospital director and a health office's representative were included to speak from an authority and managerial perspective. Women from the general population were included to reflect the community's perspective on breast cancer care.

2.3 Data Collection

The data in this study was collected through in-depth interviews in the local languages (Indonesian and Javanese). The study was designed using semi-structured interviews with open-ended questions to extract subjects' experiences. The interview questions (see appendix 1) 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 condition of the health care system with regard to early detection of breast cancer. All interviews took place after BPJS Kesehatan implementation, and regard care available within the insurance scheme. Sampling continued until data saturation was achieved. The interviews were recorded using audiotapes with subjects' permission.

2.4 Data Analysis

The data from the audiotapes were transcribed and translated into English and then analyzed using thematic analysis which categorizes, reconstructs, and concludes the data using thematic coding to search for patterns. During the coding framework development process, A.V.I and A.A.R highlighted important quotes and extracted primary codes. The codes were then categorized based on the themes until the end of data analysis (i.e. no new coding emerged from examining additional transcripts). Complete transcripts of the interviews can be made available upon request.

3. Results

A total of 25 interviews were conducted. This number was achieved after ensuring data saturation. Subjects consisted of three breast cancer patients, three breast cancer patients' relatives, eleven HCPs from both public and private health care facilities and from all levels of care (i.e. general practitioner,

oncologist, oncology surgeon, radiologist, radiation oncologist, nurse, lay helper), two stakeholders from an authority and managerial perspective (i.e. health district office representative, hospital director) and five healthy women from the general community (woman from general community). The interview results are presented thematically in Figure 1 and narrative as follows:

3.1 Knowledge and perception towards breast cancer's early detection

3.1.1 Misperception about screening program

"I did not know that screening is done 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 for women with a breast lump only." (breast cancer patient)

Although most of the women from the general community had heard about the existence of and the term 'screening', none of them knew that screening is aimed at detecting a disease even before any symptoms have appeared. Most female subjects (except HCPs) did not know that mammography can be used for screening before symptoms emerge. They thought that this examination was used for women with a breast lump only.

As for the relatives of the breast cancer patients, they also did not know that they could do regular screening. These women also thought that if they did a screening, it was sufficient to have it once only, particularly for mammography. When the result was negative they believed that it meant they were in a healthy condition forever, so they deemed it unnecessary to retake it regularly.

3.1.2 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 the women from the general community were asked about what screening method they knew, they confirmed to be familiar with BSE as a screening method rather than CBE and mammography. According to the HCPs, BSE, locally known as *sadari* (*pemeriksaan payudara sendiri*), was the only early detection program for breast cancer, which was promoted regularly by the government. After being informed by the interviewers about additional options for breast cancer screening (i.e. BSE, CBE, and mammography), most participants still preferred to conduct BSE because it was simple and free. However, several participants stated that many women were uncertain towards their findings, whether they truly felt a lump or something else.

CBE, locally known as *sadonis* (*pemeriksaan payudara klinis*), was the least popular early detection program. None of the participants had CBE for screening (in asymptomatic condition). However, participants with breast cancer had CBE as part of their early diagnostic process. Among them, only one breast cancer patient knew mammography as screening tool, whereas the other two patients knew mammography as a part of the diagnostic process, not as a screening tool. The women from the general community and the breast cancer patients' relatives had no knowledge of, nor experience with mammography as a screening tool. Their lack of knowledge about CBE and mammography may have impacted their preference for either screening method.

3.2 Breast cancer patients' experience in dealing with early detection

3.2.1 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 said when they first felt a breast lump, they ignored it. They did not think of it as a serious problem that needed to be consulted immediately with a doctor. Most of the HCPs made a similar statement. One HCP specified that many patients waited until the symptoms they had were severe enough before seeking medical help. They would consider it severe if they were worried about the size of the lump or if the lumps were painful or limiting their usual activity. Our patient subjects went to the doctor after being pushed by their family members.

In Indonesia, a woman's breast is perceived as a sensitive part of the body, so it can be considered shameful to talk about breast conditions with other people. It is also taboo to let males touch this body part (i.e. doctors' examination), particularly when they 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.

3.2.2 Lack of mammography access

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

One HCP (radiologist) mentioned that as Indonesia is a low-middle income country, it has limited resources in conducting mammography. In the Yogyakarta Province with 4 million inhabitant (14), there are only seven mammography facilities, all of which are in the city center making access difficult especially by 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 told her story of working in a private hospital. When she had a patient with a breast lump who was going to undergo a diagnostic procedure with mammography, she could not do it in that private hospital because mammography was not available. Then, she would like to send her patient to a private laboratory with mammography facilities in front of the hospital, but she failed. This happened because BPJS Kesehatan covered diagnostic mammography only in selected health facilities, not including that private laboratory. In the end, she decided to use ultrasound for diagnosing her patient, instead of mammography.

3.3. Health care system with regards to breast cancer’s early detection

3.3.1 Lack of an appropriate 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 mentioned that he usually conducts a physical examination to check if the breast lump is suspected to be malignant or benign. If it is, he would refer the patient to a higher-level health care facility. It is not possible though to refer the patient directly to a specialized oncology team available in a third level hospital. Instead, he should refer the patient to a second level hospital. However, if the breast lump was suspected to be benign, he would not offer any referral to the patient.

This kind of practice by general practitioners was often criticized by other HCPs. A radiologist and an internist said that it may cause under-diagnosis of breast cancer because physical examination cannot decide malignancy; it must be diagnosed with a triple diagnostic procedure: physical, radiology, and pathology examinations. Since radiology examination is not offered in first-level healthcare, patients should be referred to a higher-level facility. If the radiology examination indicated the lump to be malignant, a patient should have a fine needle aspiration biopsy (FNAB) for pathology examination to reach a conclusive diagnosis

3.3.2 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. The HCP (oncology surgeon) stated that, in the Yogyakarta Province, only a few second-level hospitals have a pathologist in place. Thus, a surgeon would have to send the specimens to higher level hospitals to obtain a definitive diagnosis of a patient suspected with breast cancer. This process is time-consuming, so patients must wait longer to find out about their condition and receive treatment.

Furthermore, according to oncology doctors in the third level of care (i.e. oncology surgeon, radiologist), they received referral patients from the second level of care who had undergone surgery in the second level of care. They mentioned that many of those breast surgeries were done without the standardized triple diagnosis. In fact, the surgery itself was performed to confirm the diagnosis. This practice had disadvantaged patients due to an invasive and potentially unnecessary procedure because definitive diagnosis could be achieved through less invasive procedures.

The oncology surgeon also said that approximately 70-80% of those referral patients had undergone surgery in the second level of care without using the standard procedures. For example, they did not conduct lymph node removal in which ideally lumps removed must include parts of nearby lymph nodes that potentially also contain cancer cells. 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 a doctor in the second level of care could make a referral to the third level of care for a diagnostic mammography. However, in most cases, they were reluctant to do so due to a long procedure (i.e. administrative and waiting time) that the patients should take. So, the doctor finally used ultrasound only as this is the available imaging modality in the second level of care. However, she added that both mammography and ultrasound ideally should be used together for breast cancer diagnosis.

3.3.3 More patients with earlier stages present in third level of care after BPJS Kesehatan implementation

“After BPJS Kesehatan implementation, we have an increased number of breast cancer patients in the tertiary hospital” (General practitioner in Oncology Wards)

One HCP mentioned that BPJS Kesehatan helped low-income patients to afford the high cost of diagnostic and treatment procedures. One HCP, who worked in a tertiary hospital, said that there is an increase in the number of breast cancer patients treated in her hospital. Furthermore, there was a shift in the breast cancer pattern after BPJS Kesehatan implementation. Three HCPs indicated there were more

breast cancer patients who present earlier to the tertiary level hospitals, resulting in an improvement of the treatment process and patients' prognosis. Unfortunately, this rising number of breast cancer patients is not yet supported by adequate resources, such as enough specialist doctors in the oncology department.

4. Discussion And Conclusion

4.1 Discussion

This study aimed to explore the knowledge and experiences of patients, HCPs, and stakeholders dealing with health care services, particularly related to early detection of breast cancer after BPJS Kesehatan implementation. From the interviews, first the community's knowledge and perception were explored. This study found there is a misperception in the community regarding the term 'screening', such as unawareness of the fact that screening is aimed at an asymptomatic population to identify individuals with an abnormality suggestive of cancer (8, 15). Most respondents (non-HCP) in this study however were unaware of the possibility of having a preventive examination of some form.

Furthermore, this study also found women are 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 (16). Several studies also found a lack of knowledge among women about the available breast cancer screening methods (17, 18). This could indicate inadequacy of health promotion programs provided to the community, even after BPJS Kesehatan implementation. It may also imply that increasing health literacy with respect to prevention is not a main priority of governments.

A study from Kardinah (2014) in Indonesia showed that CBE was approximately as effective as mammography in detecting breast cancer (19). However, our study found a challenge for implementing CBE, either as screening strategy or as early diagnosis strategy, in Indonesia. Breast cancer patients did not go to the doctor immediately after they felt a breast lump, but rather waited until they considered it to be a significant problem. According to the report from BPJS Kesehatan (2020) on screening practice, Indonesian women were reluctant to go to a doctor for symptoms of breast cancer due to social norms of taboo, shame, and fear (20). In addition, it also indicates low health literacy among the community which cause the lack of urgency to seek for medical treatment (21–23).

Furthermore, a GP that we interviewed referred patients (with breast lumps detected through CBE) to the next level of care only if the GP suspected the lumps to be malignant through physical examination. Although from our study we cannot conclude that this practice is widespread, it is not in line with the guideline from the Ministry of Health (2015) that women who present to 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 (10, 13). Cazap et al. (2016) revealed that a common issue in low- and middle-income countries is the failure of GPs in PHC to recognize a potential cancer case (24). Thus, the government must ensure all GPs understand and are aligned with this rule.

This study also found a lack of diagnostic resources in the second level of care (i.e. pathologist availability). Cazap et al. (2016) said that one important aspect of accurate diagnosis is the availability of pathologists skilled in diagnosing cancers (24). This starts with adequate handling of tissues using modern techniques, which is accessible only at some specialized referral centers. Furthermore, Hari et al (2016) also revealed that image-guided biopsy was superior to palpation-guided biopsy (25). This procedure can be done by a radiologist specialized in breast imaging which is available in the third level of care. This study found that many patients were not referred to the third level of care for more available standardized examination (25). This finding is similar to the statement in the Ministry of Health bulletin, which said that one factor that delays the early detection is doctor's behavior, in hesitating to make a referral (26).

Despite the shortcomings in the early detection of breast cancer in Indonesia, several HCPs in our study highlighted that more breast cancer patients present earlier for treatment after BPJS Kesehatan implementation. Although these statements were qualitative and not derived from registry data, they suggest that in the three years after its implementation, BPJS Kesehatan has achieved great progress in its coverage and in improving the equity of access to health-care services. Almost 76% of the Indonesian population had universal health coverage in 2018 (27).

This qualitative research has explored experiences, awareness, and knowledge of subjects from various backgrounds through one-on-one interaction between the researcher and participant. The Yogyakarta Province was chosen because of the diversity of socio-economic and education background of the population as this province consists of urban environments but also rural areas. However, in the context of the Indonesian population, the Yogyakarta province is considered to have a high development index (HDI). Thus, the results of this study may give an optimistic view of the situation relative to the Indonesian population in general.

A limitation of this study was that it did not measure the level of knowledge on early detection of breast cancer. It also did not collect quantitative data to detect changes after the implementation of BPJS Kesehatan in breast cancer screening. Conducting an implementation study using a mixed-method study design could explore in more detail what the current situation is with respect to programs for early detection of breast cancer in Indonesia. This type of research may also find potential approaches to improve the current situation. This will include evaluating the acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, coverage, and sustainability (28).

4.2 Conclusion

4.3. Practice Implications

This research shows the evident delay of breast cancer's early detection in Indonesia. The lack of both screening as well as diagnostic procedures remains a prominent obstacle in breast cancer management. All these factors lead to suboptimal breast cancer management. Thus, it may explain the high mortality rate in LMIC as compared to HIC. For the refinement of breast cancer management, BPJS Kesehatan

must focus its attention on the improvement of enabling factors in all levels of care, such as increasing awareness, access, referral system and facilities for early detection.

Declarations

- **Ethics approval and consent to participate**

Prior to the study, ethical approval had been obtained from the Ethics Committee of the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada, Special Region of Yogyakarta, Indonesia. Written informed consents were obtained from all subjects and they were free to stop the study at any time during the study. All methods were carried out in accordance with relevant guidelines and regulations.

- **Consent for publication**

All authors have approved the manuscript for publication under BMC Public Health Journal.

- **Availability of data and materials**

The dataset used in this study is available upon request from the corresponding author.

- **Competing interests**

The authors declare there are no competing interests.

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- **Authors' contributions**

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

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Figures

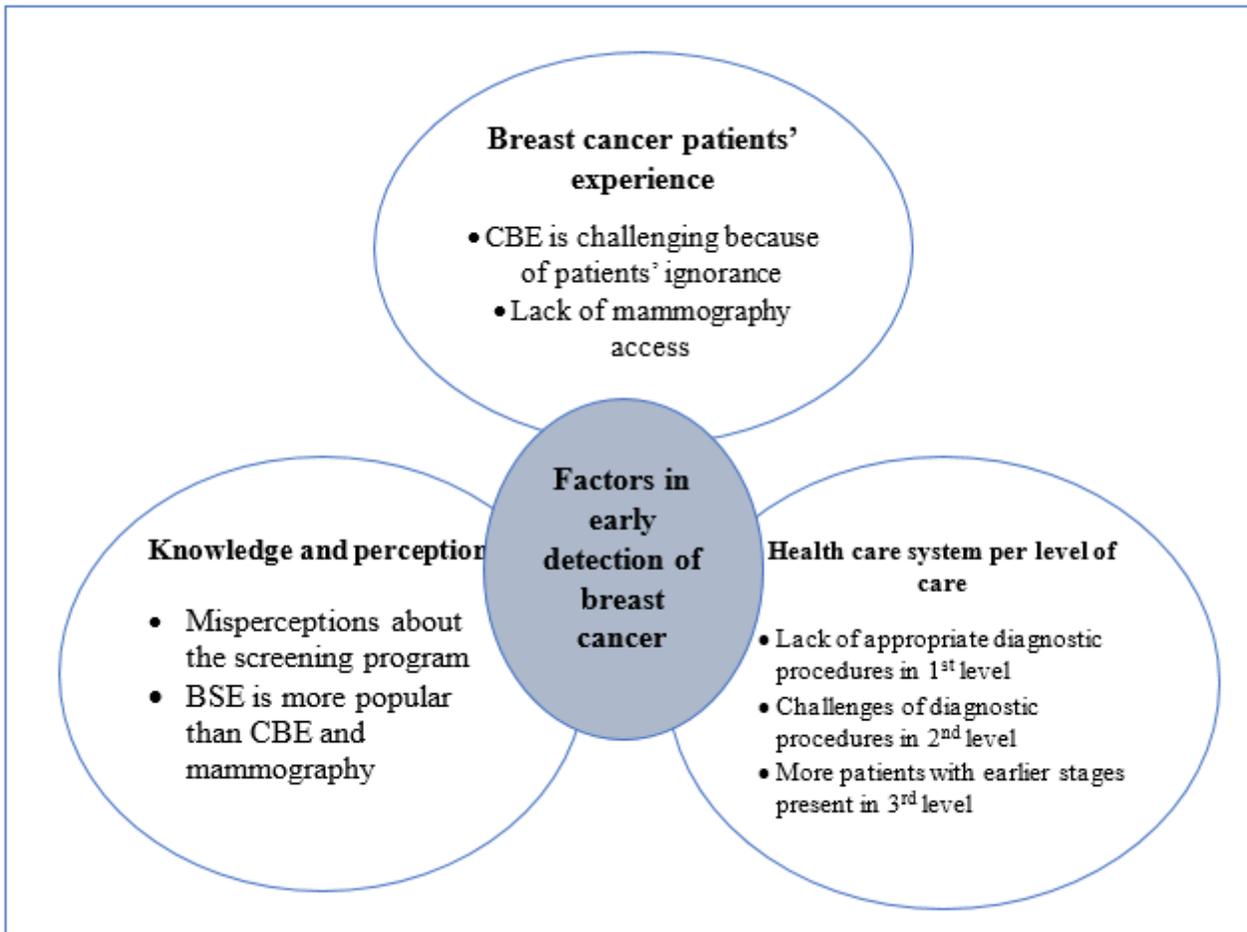


Figure 1

Summary of the study results

Supplementary Files

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