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Determinants of early breast cancer presentation: a qualitative exploration among female survivors in Indonesia

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ABSTRACT
Objective: Early presentation with breast cancer symptoms is crucial to the effectiveness of treatment and the affected women's long-term survival. However, in Indonesia, 60–70% of breast cancer patients first present themselves to the hospital in an advanced stage. Knowledge about the determinants of breast cancer early presentation could inform efforts to promote healthcare seeking at earlier symptomatic stages. In the current study, we explored the psychosocial determinants of early presentation among female breast cancer survivors.
Methods: Face-to-face semi-structured interviews were conducted with 23 female breast cancer survivors in Surabaya, Indonesia (mean age = 49.8 years). Directed content analysis approach was used to analyse the data.
Results: Half of the respondents underwent breast cancer screening prior to onset of symptoms. Nine determinants of breast cancer early presentation were reflected in the women's responses: (lack of) knowledge, perceived behavioural control, previous health related experiences and risk perceptions, attitudes and beliefs, norms, competing priorities, financial issues, instrumental factors, and health provider factors.
Conclusion: Health promotion efforts should focus on both internal and external psychosocial determinants related to the breast cancer early presentation, and on involving women's social environment as target for education. Additionally, providing accessible and affordable healthcare is important for early presentation.

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Introduction

It is estimated that in Indonesia, breast cancer has become the major type of cancer among women, placing first in the rankings and accounting for 30.9% of all new cancer diagnoses in 2018, and constituting 11% of all cancer related deaths (IARC, 2018). Treatment in an early stage of breast cancer gives a better prognosis for long-term survival (Xiong et al., 2001), however, similar to other developing countries, poor treatment outcomes among breast cancer patients in Indonesia are reported, largely due to the late presentation of the disease. Previous research in Indonesia revealed that approximately 60–70% of breast cancer patients come to the hospital at an advanced stage, and 35% of presented with metastasized tumours (Irawan et al., 2008).

Previous studies have shown that several demographic, psychosocial, and cultural factors are associated with late presentation, for example lower education, being unmarried, and having a lower income were found to be associated with breast cancer late presentation and treatment adherence (DiMatteo, 2004). Moreover, psychosocial and cultural factors were also found to be significant barriers to achieving an early diagnosis and effective treatment of breast cancer. For example, utilization of traditional therapy and a negative attitude towards clinical treatment were associated with patient delay in the Malaysian population (Norsa'adah et al., 2011). Additionally, studies among African women in developing countries identified several main barriers to achieving early presentation: poor knowledge about symptoms and risk factors, a fear of cancer treatments, embarrassment in disclosing symptoms to healthcare professionals, and taboos and stigmatization surrounding the breasts and breast afflictions (Gullatte et al., 2010; Jones et al., 2014). Furthermore, lack of social support from family members and spouse, as part of a supportive social network, were shown to contribute to delay in presentation with breast cancer among women in Uganda (Odongo et al., 2015).

To the best of our knowledge, qualitative research about the factors that contribute to breast cancer early presentation among breast cancer *survivors* is lacking, especially for the Indonesian population. Indonesia is marked by a high degree of religious, cultural, and social diversity, as well as limited health care services. Exploring both the perceived subjective and objective barriers and facilitating factors that contributed to these survivors' breast cancer early presentation is important. The knowledge gained from this research could be used to improve the proportion of breast cancer prevalence identified at an early stage, allowing for more effective treatment.

To understand the influences of the psychosocial determinants of breast cancer early presentation, behavioural theories such as the Theory of Planned Behaviour (TPB) could be considered. According to TPB, the most proximal determinant of health-related behaviour is one's behavioural intention to engage in the behaviour (Ajzen, 1991). Behavioural intention, in turn, is determined by attitudes towards the behaviour, subjective norms, and perceived behavioural control. Importantly, the variables predicting intention are modifiable through health promotion and education, which makes it relevant to identify them in the context of early breast cancer presentation. In the current research, we therefore included these variables, as well as breast cancer survivors' accounts of their lived experiences from the first time they noticed a symptom to their diagnosis. Identifying influences from both the individual and socioecological context (i.e. cultural, environmental, and provider related factors) would be

beneficial to understand the multiple factors that determine survivors' early presentation, which in turn is essential to plan effective interventions to promote early presentation to healthcare providers and BSE practice.

Methods

Respondents and study setting

The respondents were recruited through social media advertisements, the breast cancer communities in Surabaya ('Reach to Recovery Surabaya' and 'Wisnuwardhana Breast Cancer Foundation'), and through referral by other respondents. Data were collected between July to November 2018. Inclusion criteria were (a) aged 18–65, (b) breast cancer survivor, (c) residing in Surabaya at the time of diagnosis, and (d) having presented in an early stage of breast cancer. To determine the early presentation, we used a 3-month interval between first noticing a symptom and the first medical consultation as the golden standard, since the literature indicates that a delay of presentation with symptomatic breast cancer of 3 months or more is associated with lower survival (Burgess et al., 1998; Richards et al., 1999).

The breast cancer survivors who met the inclusion criteria and who were willing to participate provided their telephone number, and were subsequently contacted by the interviewer to schedule the interview. Prior to interview, the interviewer explained the study purpose and all respondents provided written informed consent to participate in the study. A total number of 44 breast cancer survivors who met the inclusion criteria were approached, and 23 women (mean age 49.8 years) agreed to participate.

This study was approved by the Ethical Committee of Health Research, Faculty of Public Health, Airlangga University and the Ethics Research Committee of Psychology and Neuroscience at Maastricht University (approval code OZL188 10 02 2018 s35). The interviewers conducted semi-structured interviews in comfortable places for both the interviewee and the interviewer: the interviewee's home, a meeting room in the interviewee's office, a café, a meeting room at Oncology Hospital Surabaya, or a consultation room in the Faculty of Psychology Airlangga University. If the interview was conducted in a public place like a café, a comfortable seating area was created in the corner of the room, outside hearing distance of other people, so the respondents' privacy could be respected.

Materials and analysis

The demographic information and illness background of respondents was queried: age, marital status, level of education, employment, family monthly income, family history of breast cancer, and health insurance status. The interview protocol was constructed using the TPB as a conceptual framework and contained questions on attitudes, subjective norms, and perceived behavioural control towards breast cancer early presentation supplemented with questions about women's knowledge on breast cancer symptoms, risk factor, and its screening and treatment modalities; and their healthcare-seeking behaviours. All abovementioned questions allowed the respondents to reflect on their lived experiences prior to their breast cancer diagnosis, and upon first noticing symptoms (see Appendix A).

The face-to-face semi-structured interviews approximately took 30–80 min to complete. All interviews were conducted in Bahasa and were audio-recorded with the permission of the respondents. They were transcribed verbatim, and ATLAS.ti version 8.3.1. was used to analyse the data.

For data analysis, we used a directed content analysis approach, where coding categories were derived from existing theory and salient prior research, and were defined both before and during the coding of the data (Hsieh & Shannon, 2005). Besides this theoretical deduction of codes, additional codes were induced from the chunks of text. The texts were thoroughly read and tentative categories were deduced, revised, and eventually reduced to two themes: the internal and external factors related to breast cancer early presentation. The first and third author discussed the codes, categories, and themes until agreement on the themes was reached. Sample texts were also discussed with second and fourth authors, after translating them first into English, to discuss results and verify coding.

Results

Sociodemographic and illness variables

Demographic and illness variables are summarized in Table 1. The majority of the respondents were married and had a university education, worked as a private employee, and can be considered as having a higher economic position. Most respondents had been diagnosed with an early stage of breast cancer and had no family history of breast cancer. More than half of the respondents had health insurance. Others financed their own medical expenses.

Twenty-one respondents indicated various kinds of symptoms prior to being diagnosed with breast cancer. Most of them stated that there was a lump or solid part in their breast or in the area near it. Some of these women also stated this was a painful spot. One other symptom mentioned by a respondent was fluid coming out of their nipple. Other symptoms that were mentioned were being physically exhausted, feeling extremely cold, and a feeling of having a low immune system (e.g. being hospitalized several times in a short amount of time). The respondents first realized their symptoms when they were doing BSE, accidentally touched the lump while e.g. showering, or a lump being found by the partner. Two respondents did not show any symptom before being diagnosed: One of these women consumed hormone replacement therapy (HRT) due to her previous health problem, thus her personal doctor recommended her to do routine mammography. Another respondent intentionally went for a mammography since there was a promotion for mammography price reduction. For these two respondents, the breast cancer diagnosis was made based on these mammography results. For the other respondents, the diagnosis was made from a combination of mammography, USG, and/or fine needle aspiration biopsy (FNAB).

Upon noticing the first symptom, various types of health seeking behaviours were performed by the respondents: searching for information by browsing the internet or asking relatives who had had the same breast problem; or engaging in non-medical behaviours, e.g. taking traditional medication; and ignoring their symptoms. Most respondents undertook action to receive a first consultation with the doctor to get an

Table 1. Demographic characteristics of study respondents.

Variable	n (%)
Mean age	49.8
Breast cancer stage	
1	2 (8.7%)
2	14 (60.86%)
3A	5 (21.74%)
No answer	2 (8.7%)
Marital status	
Single	2 (8.7%)
Married	19 (82.6%)
Divorced/widowed	2 (8.7%)
Education	
Senior high school	5 (21.74%)
Diploma-3	2 (8.7%)
Bachelor degree	15 (65.21%)
Master degree	1 (4.35%)
Employment	
Unemployed	6 (26.09%)
Public employee	4 (17. 39%)
Private employee	13 (56.52%)
Family monthly income	
< Rp 3,000,000	1 (4.35%)
Rp. 3,000,000–10,000,000	9 (39.13%)
> Rp. 10,000,000	13 (56.52%)
Age when first diagnosed with breast cancer	
20–29	2 (8.7%)
30–39	7 (30.44%)
40–49	9 (39.13%)
50–60	5 (21.74%)
Family history of breast cancer	
No	18 (78.26%)
Yes	5 (21.74%)
Health insurance	
No	11 (47.83%)
Yes	12 (52.17%)

examination, between one day and three months after noticing the first symptom, and it took between one day and one month after this first consultation to get the diagnosis. However, two respondents indicated a significant diagnosis delay: 6 months, and three years respectively, due to initial false negative test results. Some respondents tried to find a second opinion to confirm their diagnosis.

Qualitative results

We grouped the factors related to breast cancer early presentation that emerged from the interviews; these included behaviour associated with the breast cancer early detection as well as receiving a medical examination. Nine categories are reflected in our data, forming two themes: internal factors, and external factors.

Theme 1: Internal factors

Within this theme, several subthemes were examined, i.e. breast cancer related knowledge, perceived behavioural control, previous health-related experiences and risk perceptions, and attitudes and beliefs.

Breast-cancer-related knowledge

Some respondents indicated a lack of knowledge about breast cancer, but when probed, some could explain what breast cancer was, the symptoms, or which treatments would be available. Further, they indicated that breast cancer could be detected at an earlier stage by performing BSE or by undergoing a mammography. They gained the breast cancer-related knowledge from various sources: mass media (newspaper, television, radio, magazine articles) and social media (Facebook, Instagram). Other sources of information mentioned included: receiving health education in women's community meetings (PKK[1]) or church, a leaflet from a healthcare facility, information provided by their health practitioner or a public figure, or having relatives who suffer from breast cancer. The women indicated that the information they gained served as a valuable source for their breast awareness and according to them, was associated with their early presentation: 'I know BSE from my reading … I often did that. One day, when I performed BSE … and I found the lump [in my breast]' (p. 17).

Perceived behavioural control

Upon being asked whether they felt they were able to act upon noticing a symptom, some respondents indicated that they were confident they could visit the doctor to have a breast cancer examination. 'I was sure I could go alone. I can go to the doctor' (p. 7). Some respondents also indicated that they had the confidence to do BSE: 'It is a simple thing, it is a very simple thing that we can do, I mean we can do it while having a shower or lying in the bed before sleeping' (p. 17).

The respondents thus indicated that if they perceived that they had control over their behaviour, the early presentation would be more likely to occur. However, some respondents reported that they did not have any information about where they could go or what they should do if they noticed a breast cancer symptom, something which could have delayed their early presentation.

Previous health related experience and risk perceptions

The women with previous health related experiences reported having greater awareness about any abnormality in their body, and indicated a higher risk perception. These health related experiences and risk perceptions led to seek medical attention early. As one woman stated: 'I have endometriosis … My doctor asked me to take HRT and warned me to have a regular mammography. I didn't know what mammography was, but I did that as suggested' (p. 12).

Only three respondents reported that they felt that they had an increased chance of getting breast cancer prior to be diagnosed (e.g. due to genetics), but most women indicated a low risk perception.

Attitudes and beliefs

Most of the respondents indicated that they had a positive attitude towards early presentation and breast examination. This might have caused them to present with early-stage breast cancer, which in turn allowed fast diagnosis, fast treatment, and a speedier recovery: 'I think these [doing BSE and having doctor examination] are

positive things, … the earlier we know our diagnosis, the better the treatment' (p. 14). In contrast, a few respondents expressed a negative attitude towards breast cancer screening, mainly because of fear for the diagnosis.

Some respondents indicated awareness of the benefits of a healthy lifestyle to prevent cancer. In contrast, some women reported thinking that breast cancer is something scary, and that therefore one should never think about an illness otherwise it will happen to them. Others mentioned that breast cancer was a taboo subject; that it was a curse or a punishment; and that in general individuals in society perceived that getting breast cancer was not a high risk. To sum up, the respondents mentioned that the combination of negative attitudes, (folk) beliefs, and lack of knowledge about risks and symptoms among women in their social surroundings contributed to the inhibition of early detection and presentation.

Theme 2: External factors

In this theme, we studied norms, instrumental support, competing priorities, health provider factors, and financial issues as external determinants of women's early presentation behaviour.

Norms

The majority of the respondents indicated that significant others (e.g. spouse, friend) persuaded them to go to the doctor to have a medical examination. Moreover, the women indicated that they were influenced by the behaviours of others in their direct social network, both positively and negatively. The influence from the environment could relate to both their absenteeism of early detection: 'The people I knew, none of them did routine BSE or mammography … we didn't understand [if there were procedures to detect breast cancer earlier]' (p. 12); or their early presentation performance: 'My colleagues asked me to have breast examination since one of our colleagues survived from breast cancer' (p. 3).

Competing priorities

Some respondents expressed that early presentation was significantly related to their daily schedule: the behaviours were more likely to occur when they felt that they had the time to perform them. Conversely, if they perceived that they had competing priorities, they would postpone these behaviours: 'I asked my son to find information about the service hour in Kayoon, but I have to wait until my work is done … I plan to visit the clinic after my work is done' (p. 18).

Instrumental support

Respondents mentioned that having assistance from others to have breast cancer examinations (e.g. accompanying them on the visits) would improve the likelihood to engage in such behaviours. The women indicated that such instrumental support could also be facilitated by their workplace: 'When my office had an anniversary celebration, we had the doctor from Kayoon here in the office, I had a pap-smear and CBE, the doctor was well experienced' (p. 18).

Health provider factors

According to some respondents, when they perceived that healthcare providers were accessible, their likelihood of visiting it was improved. However, the difficulty of accessing it at a time convenient to them would contribute to a delay: 'I went to a hospital, but that time the doctor was not there … I planned to come back, but … I didn't know, I didn't go' (p. 2).

Furthermore, the respondents reported that part of their decision to have a medical examination following their symptom presentation was related to the healthcare provider status, which according to them it made them feel reassured and safe, e.g. being familiar, female, or known for their competence: 'I went to this doctor, our family know her. And fortunately, a female doctor' (p. 1).

Financial issues

Most of our respondents went to a private hospital and/or medical lab to get their diagnosis and paid it for themselves, or used private or national health insurance (BPJS Kesehatan[2]). Most of the women in our sample who have a relatively high income, indicated that financial budget was not perceived to be a barrier for a breast cancer examination: 'I have the money, so I go for an examination. I think it would only cost a small amount of money' (p. 23). Furthermore, a respondent with a low economic background also indicated that financial issues were less significant compared to her motivation to identify what her symptom was, in the context of early detection behaviour, even though she could not pay for the examination only by herself: 'No [I did not count the cost of mammography as a barrier] … I have to [perform mammography]. I have my families donated money to pay my mammography' (p. 16).

Interestingly, some respondents indicated that they thought if they used basic health insurance the possibility of a false negative diagnosis was increased: These respondents went for an initial examination by using public health insurance and ended up with a non-breast cancer diagnosis. Further, they tried to find a second opinion, without using basic health insurance, which ultimately resulted in a breast cancer diagnosis: 'I used BPJS, I chose the best doctor, general surgeon, for the examination. He said it was only benign cyst. But later, I knew there was a breast cancer in my breast from another doctor examination. Without using BPJS. I hate BPJS' (p. 4). Thus, this indicates a lack of trust in the quality of care under the public healthcare system when they used basic health insurance.

Additionally, discount rates for having mammography would also improve the likelihood of engaging the screening behaviour. Some of the respondents indicated that they had a health insurance that helped them in their decision to go for an examination. Thus, although financial barriers were not directly identified as a barrier to go for breast cancer screening among our respondents, they did acknowledge that for others, with less financial means or lower quality health insurance, not having the funds to pay for the screening could constitute a risk factor for delays and late presentation.

Discussion

The aim of this current study was to explore factors related to breast cancer early presentation among breast cancer survivor in Surabaya Indonesia. Our study examined nine determinants related to breast cancer early presentation: breast cancer related knowledge, perceived behavioural control, previous health related experiences and risk perceptions, attitudes and beliefs, norms, competing priorities, financial issues, instrumental factors, and health providers factors.

Respondents in our research differed in their knowledge about breast cancer and its symptoms. Some respondents showed inadequate knowledge about symptoms, severity, stages, risk factors, medical treatments and cancer service pathways. This lack of knowledge also caused lowered awareness of their vulnerability, and the seriousness of the disease, which negatively influenced the likelihood of early presentation. This result is in line with studies in other developing countries that found lack of knowledge to be a significant predictor of breast cancer delay (Agarwal et al., 2009; Al-Dubai et al., 2012; Iskandarsyah et al., 2014). This finding may be a result of limited public health education programs for women in Surabaya, limiting knowledge of breast cancer, and in some cases causing women to have misleading beliefs about the causes and cure of breast cancer.

Most of our respondents had received their information about breast cancer from mass media, and only a few reported getting information from health education meetings or leaflets. This result is in line with a study among Chinese women, which indicated that media campaigns, e.g. through radio, television, and newspapers, was an effective way to improve knowledge and increase the practice of breast health-related behaviours (Sun et al., 2007). Thus, as an initial effort to increase knowledge among a larger population, media-based health education campaigns could be considered as an effective channel to improve breast cancer awareness. Importantly however, as noted by Wakefield et al. (2010) 'concurrent availability of and access to key services and products are crucial to persuade individuals motivated by media messages to act on them' (p. 11). Furthermore, social media (i.e. internet-based communications, tools, and aids) are potential channels for health promotion that can be use to improve breast cancer literacy. One systematic review on social media's effects on health promotion and behaviour change, indicated that there is clear evidence that social media can be effective to improve health knowledge, behaviour, and outcomes, which meet both individual and population health needs (Korda & Itani, 2013).

Health insurance coverage and affordability were, probably also due to the composition of this sample (middle to high income), not considered to be a barrier to achieve breast cancer early presentation. Those who were not covered by health insurance perceived that the benefits of breast examination outweighed the financial expense, and they were willing to pay in order to identify their breast abnormality. In contrast, some women also stated that they thought that the basic healthcare insurance offered in Indonesia – used mainly by individuals from lower socio-economic positions – would not allow them to receive adequate, high quality care, and even possibility of false negative screening outcomes. This latter finding reflects results from a systematic review (Unger-Saldaña & Infante-Castañeda, 2009) that found that socio-economic position is related to delay in screening behaviours if women are from ethnic minorities,

lower educated, live in rural areas, have a lack of health insurance, and experience barriers to access healthcare.

Our findings further suggest that the accessibility of healthcare services, e.g. arranging transport, distance from home to healthcare service, as well as the ease of making appointments at the facilities seemed to stimulate early presentation. This is in line with research indicating that that positive perceptions of accessibility to healthcare impact positively on help-seeking behaviour (Facione & Giancarlo, 1998), while poorer access to healthcare service appears to be a barrier to early presentation (Caplan, 2014). Furthermore, women in this study indicated that they were more likely to delay making an appointment if they had competing priorities, e.g. childcare, employment, or family commitments. Moreover, access to healthcare was influenced by women's perceived behavioural control: having the confidence, ability, and knowledge about what to do when they noticed a symptom. This confidence in turn is likely to be influenced by trust in their physician and concern over the care they received. Indeed, previous research showed that patient-doctor communication in South Asia is generally perceived as dissatisfying by patients, due to the doctors' paternalistic/one-way consultation style where there is not much room for questions the patient may have (Claramita et al., 2013). This likely also caused our respondents to be hesitant to ask the health care provider for further information about their disease, and/or treatment plan.

Furthermore, our results indicated that negative attitudes and beliefs, and social influences caused some women to perceive breast cancer as something scary and related to punishment, which contributed to an aggravated delay in actioning screening behaviours. This was also found in other Asian populations, where cancer is a taboo subject, a shameful and contagious disease, and related to moral wrongdoing (Iskandarsyah et al., 2014; Karbani et al., 2011; Rajaram & Rashidi, 1999). These beliefs may result in some women realizing that breast cancer is a serious illness, but being less likely to perceive that it can be cured, which increases the risk of them not visiting healthcare services after the onset of symptoms. Given the finding that women also lack knowledge, further health education should focus on increasing breast cancer literacy, including not only providing information on the severity of breast cancer, but also its better prognosis if detected earlier. In particular, such a focus on the positive outcomes of early detection could alleviate women's fear of a diagnosis, thereby preventing the delay in seeking treatment after the onset of symptoms (Stapleton et al., 2011).

Interestingly, our data suggest that most of the women in this sample have positive attitudes toward breast cancer early presentation, which possibly increased the likelihood that they sought medical consultation once they noticed any bodily change(s). This positive attitude seems to shape their help seeking behaviour: Our respondents indicated that they firmly believed that if there was something wrong with their body, they should go to the doctor immediately to identify what their symptom(s) implied, thereby increasing the chance of speedy recovery. This finding is in line with previous research using the TPB to predict behavioural intentions for screening behaviour which showed attitudes to be the strongest predictor (Cooke & French, 2008).

Importantly, early presentation in our sample was more likely for women who indicated they received (social) support from their environment, both in the form of

perceived norms about screening behaviour, as well as instrumental support. The women indicated that when they perceived that most women in their environment engage in a breast cancer early presentation practice, their likelihood to perform this behaviour increased. Furthermore, support from their environmental surroundings, e.g. having others as companion to a doctor visit, or facilitation of breast cancer screening from their workplace, were associated with an increased likelihood to perform early presentation. The Indonesian population is typical of a communal society, which is characterized by a strong family support system (Claramita, et al., 2013). In these societies, the family and the close social circle of a woman play a major role in shaping and facilitating health-related behaviours, such as breast cancer early presentation.

Limitations

Although our results offer insight into breast cancer early presentation, and as such inform future health promotion efforts, several limitations should be considered. First, the respondents resided in an area that provides a comprehensive breast cancer treatment to patients, which can only be afforded by a population with a high social economic position. Our findings are, therefore, not generalizable to other populations, i.e. those with lower socio-economic positions. This also suggests that in Indonesia, breast cancer early presentation and effective treatment may mainly be accessible – or, affordable – for women with higher socio-economic positions. There is therefore a need for easily accessible and high quality healthcare services in areas where women with a lower socioeconomic background work and reside. The lack of knowledge present in our current, highly educated, sample, furthermore suggests that this lack may be even greater among the less well-educated population in Indonesia. Second, the time frame between the onset of the symptoms and the diagnosis was obtained from respondents' self-report, which may contain recall bias and may not accurately reflect the actual time between the onset of symptoms and their first medical examination.

Conclusion

This study has identified several modifiable psychosocial, environmental, structural, and cultural determinants which both hinder and facilitate breast cancer early presentation. We suggest that breast cancer education should not only include information about breast cancer and its symptoms, but should also focus on increasing women's risk perception, and on improving the skills to recognize normal and abnormal breast anatomy. Given the impact of women's social environment and social norm on breast cancer early presentation, breast education should provided not only to the women, but also their social environment, i.e. their partner and extended family, should also be involved. Additionally, our findings also suggest the need of accessible and affordable healthcare, especially for those with lower social economic positions or living in rural areas, to facilitate early presentation.

Notes

1. PKK: Pembinaan Kesejahteraan Keluarga (Women's Family Welfare Movement), a nation-wide women's NGO that seeks to reach every married woman in a certain geographic area.
2. BPJS Kesehatan: Badan Penyelenggara Jaminan Sosial Kesehatan (Social security agency for health), a government insurance companies which administers the Indonesian health insurance.

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Data availability statement

Due to respondents' consent, data are not publicly available.

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Appendix A: Overview of the interview protocols

Breast cancer knowledge

1. Prior to diagnosed with breast cancer, please explain what did you know about breast cancer:
   a. What is breast cancer
   b. Symptom(s)
   c. Risk factor(s)
   d. Screening method(s)
   e. Treatment modalities
2. Where did you get those information from?

Illness recognition, intention, health seeking behaviour

3. Please explain how did you recognise your breast cancer symptom(s)
   a. What did the symptom(s)
   b. How did you recognise the symptom(s)
   c. What did you plan/intend following onset symptom
   d. What did you do following onset symptom

Perceived behavioural control

4. What stimulated you to perform no 3d.
5. What inhibited you to perform no 3d.

Attitude toward breast cancer early presentation

6. Before you've been diagnosed with breast cancer, what did you feel about breast cancer early presentation: performing breast cancer screening and having medical examination right after onset symptom

Subjective norms

7. After onset symptom, did you told it to other person?
   a. To whom
   b. What did they want you to do
   c. What did you do regarding to 7b
8. Before you've been diagnosed with breast cancer, what did your family or community members think about performing breast cancer screening?
   If the significant others express no opinion then stop.
   If the significant others have any opinion, continue with:
   a. What did they want you to do regarding performing breast cancer screening
   b. What did you do regarding 8a