

# Breast cancer stigma among Indonesian female: a case study breast cancer patient.

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## Research article

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# Abstract

Background: Stigma of cancer patients was identified with death, making cancer is the most feared diseases by mankind worldwide especially cancer patients and their families. A critical evaluation of the breast cancer stigma regarding breast cancer screening behaviour is poorly understood, so we aimed to analyse the stigmatization of breast cancer patient in Indonesia for reducing morbidity and mortality of breast cancer. Methods: A qualitative study using focus group discussion and in-depth interviews with thematic analysis was conducted in this research. Results: The informants endured the pain of their breast and kept the referral letter which the medical doctor advised to medical treatment for three months later due to their embarrassment. Traditional healing using scrapping as known 'kerokan' and consumed some traditional drink were done by most informants to decrease the pain on their breast. Finally, most informants were diagnosed in an advanced stage when they returned to the health facilities. In addition, financial difficulties were noted as barriers of breast cancer screening in such Indonesia. Conclusions: Feeling fear and shame when diagnosed with breast cancer were identified in this study. Alternative treatment using scrapping as known 'kerokan' lead the first seeking help for breast cancer symptoms due to financial difficulties among patient of breast cancer. Diagnosed in an advanced stage was revealed by most of the informants after they returned back to health facilities.

## Background

The stigma of cancer patients was identified with death, making cancer is the most feared diseases by mankind worldwide especially cancer patients and their families. Breast cancer is known as the most common cause of cancer death among women across the world, including in Indonesia. Whereas the incidence of breast cancer is accounted the second rank, representing 1.4 million new cases in the globe (2), (3),(4). Based on World Health Organization (2014), of all non-communicable diseases deaths in Indonesia, 13% are caused by cancer. More importantly, breast cancer is the first diagnosed in women in Indonesia with advanced stage. According to the World Health Organization, breast cancer can be successfully treated by breast cancer diagnosed in an early phase and changes lifestyles. Numerous previous studies revealed that most patient cancer who diagnosed at an advanced stage associated with a poor prognosis (5), (6),(7).

Most breast cancer deaths in developing countries in such Indonesia was resulting from a significant poor awareness of breast cancer disease (1), lack of biomedical treatment (8), and breast cancer stigma (9). Breast cancer stigma and misconception of screening methods were identified as potential factors delayed medical help-seeking behaviour in patients with breast cancer signs and symptom (10).

More addition, Indonesia, as developing country with no routine national program of mammography or clinical breast examination, due to the limited health care facilities, mostly breast cancer patients are diagnosed at an advanced stage reported by Health Ministry of Republic Indonesia data in 2016. Indonesian consist of many groups and culture, so breast cancer stigma was strongly influenced by culture and belief. A critical evaluation of the breast cancer stigma regarding breast cancer screening

behaviour is poorly understood, so we aimed to analyse the stigmatization of breast cancer patient in Indonesia for reducing morbidity and mortality of breast cancer.

## Methods

### *Study design and sample population*

This study was conducted on October 2017 in Yogyakarta Province. Using purposive sampling, eight women with breast cancer were interviewed in the PKU Muhammadiyah hospital Yogyakarta. Purposive sampling was used to set the data that suitable for the purposes of the study by choosing the informants carefully (11). The selection of the informants was conducted after called the list of the breast cancer patients who are got treatment from that hospital. From fifteen persons on the list, there were eight breast cancer survivors who agree to be interviewed.

### *Data collection*

In this study, used focus group discussion (FGD) and in-depth interviews to collect the data. Focus group discussion was used to explore information about the perception of breast cancer patients to the disease, family support, and health insurance to cover the medication (12). The discussion was provides shared meaningful information from other survivor and it was a support system. The in-depth interview was used to complete and synchronized the information from the discussion about the role of the family member to support their life. Family members were in-depth interviewed to explore their role to the quality of life breast cancer patient.

### *Data analysis*

Each informant was identified in the part of data analysis and all the data managed by the researcher. All the audio recorded interview sections were transcribed in informants' language (Indonesian language) by the research assistants (13), (14). All the transcriptions were checked with the recordings by the researcher and it identified relating to the aim of the study for each topic by the research framework (health belief model). Related to different information, a triangulation of data sources was done to the two family members from different informants who were interviewed. Finally, all data in this study were identified and analyzed based on the data's theme.

## Results

### *Demographic features*

The Indonesian women who aged over 30 years old with breast cancer participated in this study. The numbers of primary informants in this study as much as six breast cancer fighters. All informants work as housewives. The majority of informants diagnosed with stage 3 breast cancers. A detail description of informant information presented in Table 1.

### *Early Diagnosis of Breast Cancer*

The majority of informant experience different feelings at the time of the first diagnosis of breast cancer. A complaint felt by the majority of informants was pain in the breast and or chest to pierce into the back and detect a lump in the breast. Treatment of the informant at the time of feeling pain in the breast was a scrapping as known '*kerokan*'. The pain in the breast is considered a symptom of colds. This is evidenced from the in-depth interviews of informants are:

"... .. Starting at the beginning of 2016 to do the examination in the surgical poly with breast complaints hurt when held-up to the pain to the back. Sometimes chest pain to the left of the concern arises if suffering from heart disease. After being diagnosed it turns cancer. informants claimed to care about health, often doing BSE. But from the pain of a lump appeared in the left breast. informants had moved from hospital to another hospital until asked to check with FNAB examination, ultrasound, and biopsy. The breasts have been lifted one. " (ISMDH, 51 year).

Another informant confessed the secret of his experience since mid-2013. Complaints are felt was sore like a cold and find a lump on the palpation of the breast. The informant was afraid to check up the health status to the doctor. Felt ashamed that the doctor did palpation. They prefer to do traditional self-healing to cure it (reduce the pain in the breast). Traditional treatment that was did consume white turmeric, boiled soursop leaves, consuming Japanese ants, and Moringa leaf. After taking the traditional medication, the lump in the breast was getting bigger but the informant does not tell other family members.

The informant ventured to medical treatment and met a female doctor. The first doctor she met directly diagnosed that the informant was exposed to breast cancer and then referred to the hospital. Informant was diagnosed with stage 3 cancer. At the time of reference, the informant did not go directly to the hospital and kept the referral letter for 3 months. During the 3 months, the informant felt the chest pain and red rash, the nipple out of the blood and the mucus, the nipple peeled and wounded and given the ointment purchased alone at the pharmacy, finally the informant felt the need to go to the hospital again and ask for referral letter back to health facility. Doctors suggest that go to the hospital very soon before the disease getting worst. The doctor's words made the informant felt the spirit to seek treatment after

four years of keeping her own secret. Informants need time to communicate with close relatives (husbands and children) that would be operated.

### *Psychological, Attitude, and Social Support (Family members and neighbour)*

Most of the informants feeling shocked when diagnosed getting breast cancer. They tried to hide it from their family. Feelings of acceptance of destiny are also experienced by some informants, but concerns about the high cost of treatment. The informant felt helpful with national health insurance, although the financing assistance provided by national health insurance did not completely cover all types of services. Laboratory examination and early-stage examination were not paid by the insurance. This is evidenced by the in-depth interviews as follows:

"... Gain motivation from friends who suffer from the same pain even younger than informants, get support from children, so do not feel alone, close family support added more closely during the pre-time- and post-operation process." (ES, 47 years)

### *Communication between doctor and patients*

Most of the research informants explained that they need details information about the disease from the doctor. Four of informants said that the doctor was not telling the disease clearly. In some informants mentioned that doctors who handle them are not communicative in conveying the health condition of patients, so they feel worried about the health conditions. This is evidenced based on the results of in-depth interviews on informants as follows:

"... Doctors should provide as much information as possible about the illness and stages suffered by the patient, provide a transparent explanation of the results of the lab so as not to make the patient feel anxious guessing and guessing about cancer they are experiencing."

## **Discussion**

Breast cancer has a second highest on incidence rate across all types of cancers and rank as the fifth cause of cancer deaths overall (15). Delays in presentation and diagnosis are major determinants of breast cancer survival (16). Perception towards breast cancer screening and diagnose have an important role due to early diagnose of breast cancer. Women who had a correct belief regards to breast cancer will

enjoy an improved quality of life after receiving the breast cancer treatment including breast cancer screening (17). On the other hand, this research found that Indonesian women had a negative perception towards breast cancer screening because of fear and shame.

Previous research also showed that the fear of discovering cancer, embarrassment, and fear of the screening procedure were among the most commonly reported as personal or cultural barriers to using the screening service (18). Other research found that fear of suffering the disease gained the highest score from all reason for fear, it might contribute in the lower willingness to women to have screening and to know about their disease (19). Asian women are generally more private in their perception of their body and less receptive to revealing their private parts even to health personnel (17). That is the reason why many informants on this research feeling shame due to breast cancer screening. The feeling of shame lead Indonesian women to do the complementary alternative treatment as known '*kerokan*', consume white turmeric and Japanese ant. Complementary alternative treatment is valued more convenient, widely available and affordable compared to modern medicines (17).

Another barrier that Indonesian women on this research faced is financial barriers because Indonesian health assurance as known BPJS did not completely cover all types of services. Several articles mentioned that low income as one of the key barriers to early diagnosis. Even though health assurance can help covering the service but it is also noted that most women with an income are able to afford their own transportation hence improving the accessibility to a health care centre (17).

This research not only discovers the barriers on Indonesia women on breast cancer screening but also how they deal with breast cancer status. On this research informant have social support from family and other cancer survivors to faced breast cancer, they also strengthen their self by having a pray. Adequate social support from closed people such as family, friend and neighbour were significantly improved quality of life of breast cancer patients (20). Support from the peers can tend to disclose more personal information, discuss more private stories, and exchange more support emotionally, meanwhile they seek help less but provide more, and shifted their interest from cancer diagnosis to cancer treatment (21). These supportive resources can be emotional, physical, informational, and companionship-related (17). Prayer may invoke a relaxation response, which in turn may positively affect health and overall well-being (17).

We acknowledge that our limitation in this study is taking a sample of informants from health facilities. The informants may reflect certain characteristics of women who may have better health seeking behaviour than other women. Therefore, conducting this study in the community would give a better representation of the breast cancer screening on Indonesian women.

In conclusion, feeling fear and shame of breast cancer were identified in this study. Alternative treatment using scrapping as known '*kerokan*' lead the first seeking help for breast cancer symptoms due to financial difficulties among patient of breast cancer. A better understanding of early breast cancer symptoms could help people to prompt breast cancer's treatment.

# Declarations

## Acknowledgements

The authors thank all participants who participated in this study.

## Author contribution

SS, RM, FPU and LH were involved in the study conception and design, including drafted the manuscript. SS, RM and FPU performed the analyses. All authors responsible collected the data, have read and approved the manuscript.

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## Availability of data and materials

The datasets used and /or analysed during the current study are available from the corresponding author on reasonable request.

## Ethics approval and consent to participate

All procedures performed in the study were in accordance with the ethical standards of the institutional research committee and the 164 Declaration of Helsinki and its later amendments. This study was approved by the Ethics Committee Ahmad Dahlan University with number 011704048. The researcher was ensured the privacy of the informants by erasing all names of the informants and gave the informed consent before focus group discussion (FGD).

## Consent for publication

Not applicable

## Competing interests

Authors declare that no conflict of interest.

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## Tables

Table 1 Demographic characteristics breast cancer patients

No.	Informants' Initial	Age	Job	Stadium
1.	ES	47	Housewife	Stadium 3
2.	SPR	44	Housewife	Stadium 3
3.	RKH	57	Housewife	Stadium 3
4.	ISMDH	51	Housewife	Stadium 3
5.	SJY	43	Housewife	Stadium 3
6.	KSWT	57	Housewife	Stadium 3