

Stigma and discrimination against breast cancer survivors in Indonesia: an interpretive phenomenology study

Ida Ayu Made Ari Santi Tisanasari¹ , Tuti Nuraini¹ , and Yati Afiyanti^{1*} 

¹ Faculty of Nursing Universitas Indonesia, Depok, Indonesia

*Correspondence: Yati Afiyanti. Address Faculty of Nursing Universitas Indonesia, Depok, Indonesia. Email: yatiafiyanti@yahoo.com

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ABSTRACT

Introduction: Breast cancer is the most common malignancy in women worldwide. Breast cancer and its treatment have a direct impact on all aspects of a woman's life, as well as on breast cancer survivors, thereby affecting the fulfillment of her needs. The purpose of the study is to explore stigma and discrimination against breast cancer sufferers.

Methods: This study uses a qualitative method of interpretive phenomenology. Semi-structured interviews were purposively conducted from March to June 2022 with 14 women breast cancer survivors. The process of data analysis in this study was carried out based on Braun and Clarke.

Results: The three themes identified in this study include: a short duration of survival, being labeled as a suffering person, and social discrimination.

Conclusions: Breast cancer survivors experienced stigma regarding their cancer diagnosis. Thus, highlighting the rising need of health professionals' intervention in resolving and adapting to stigma and discrimination regarding breast cancer diagnosis in Indonesia..

Keywords: breast cancer; cancer survivors; discrimination; stigma

Introduction

Breast cancer is the most common malignancy in women worldwide. In women, breast cancer accounts for almost 1 in 4 cases. The number of breast cancer cases every year also always increases (Lee et al., 2021). In 2020, it was estimated that the number of new cases of breast cancer in the world is 2,261,419 cases (Ferlay et al., 2020). The incidence of breast cancer is the highest incidence of cancer in women in Indonesia compared to the incidence of cervical cancer, ovarian cancer, and other gynecological cancers (Pangribowo, 2019). The same incident occurred in Bali Province, as described in the study by Aryana, Adiputra, Prayudi, Permatasari, Setiawan, and Kuswardhani (2018), Balinese women who experienced breast cancer were 1,045 samples. In the study of Aryana et al. (2018), it was also explained that race or ethnicity might play an

important role in the expression of certain breast cancer phenotypes. This role can be attributed to differences in genetics and lifestyle among women within each race.

The incidence of breast cancer in the province of Bali, Indonesia, is one of the highest. Based on data reported by Sanglah Hospital Denpasar, breast cancer patient visits from August to November 2020 there were 285 cancer patient visits from 1,380 patient visits at Sanglah Hospital Denpasar. The experience of breast cancer is an experience that greatly affects a woman's life. The results of recent studies confirm that it is very important to carry out health checks, address post-treatment concerns, and improve the well-being and quality of life of cancer survivors (Runowicz et al., 2016).

As in many Asian and Eastern background, in Indonesia, the view of illness or chronic disease is often influenced the culture and beliefs of the community.



Many illnesses are associated with negative views or stigma. Similarly, cancer is often viewed negatively, such as a karmic retribution, a form of God's punishment, is infectious, and so on (Orujlu et al., 2022; Phenwan et al., 2019). These negative perceptions of cancer developed into a stigma among many communities' way of viewing individuals with cancer.

Goffman (1963) first defined stigma as an attribute that leads to being discredited by society for a negative label of the person affected. The definition has since been conceptualized into different fields, including health-related stigma. According to Weiss et al. (2006), health-related stigma is a social process, characterized by exclusion, rejection, blame or devaluation resulting from experience, perception, or anticipation of negative social judgement related to a person's health condition.

The stigma that affects a woman with breast cancer can have an impact on the problem of meeting her healthcare needs. A study by Amare (2021) explains that, of all types of cancer, breast cancer is the type of cancer that has the most supportive care needs. On the other hand, many existing studies investigating cancer stigma were conducted in lung cancer patients or survivors and preferred cross-sectional methods.

An in-depth study of the stigma and discrimination among cancer survivors, in specific groups such as breast cancer, is, in contrast, relatively scarce. Especially in the unique cultural community of Indonesia, there is a knowledge gap on how the women with breast cancer were viewed or treated by their community. Meanwhile, perceptions of stigma and experiences of discrimination against breast cancer survivors are very important to understand. This study was conducted to fulfil the need to explore in depth, the stigma and discrimination experienced based on direct stories from breast cancer survivors in Indonesia

Materials and Methods

Research Design

The research design used in this study is an interpretative phenomenological qualitative research design to explore stigma and discrimination against breast cancer survivors. This research design was a concept from Heidegger which stated that the focus of hermeneutic inquiry was not the pure content of human subjectivity, rather, what the individual's narratives imply about what he or she experiences daily (Speziale et al., 2011).

Sample and Sampling

Participants in this study were determined by selecting individuals or participants using the purposive

sampling method and saturation principles. The sample in this study was selected from the women with breast cancer survivors who were indicated to have had experiences getting a stigma and social discrimination after a cancer diagnosis. The inclusion criteria for the participants were: 1) able to communicate in Indonesian language, able to understand questions, and to express their experiences; 2) had been a breast cancer survivor for at least two years; and 3) had no cancer metastasis.

Data Collection Process

The first and the third authors collected the data using in-depth interviews. The interviews were conducted in Bahasa Indonesia from March - June 2022. The study was conducted at the oncology outpatient of Sanglah Hospital Denpasar. During the interview, the women were encouraged to elaborate on their experiences of what kinds of stigma were like for them and how they responded to them. Sample questions were "What is your community's thought of the cancer diagnosis you experienced?"; "Is there any stigma from your community regarding the cancer you experienced? How did you respond to them?"

All interviews were tape-recorded and lasted between 60 to 80 minutes. The interview tapes were transcribed. The researcher avoided personal bias by using a bracketing technique during the interview process. In this technique, the researcher sets aside personal beliefs and knowledge, not making judgments about what is observed or heard, and remains open to the data as they are revealed (Speziale et al., 2011).

Data Analysis Process

The second and the first conducted the data analysis. The process of data analysis in this study was carried out based on Braun and Clarke, (2006) regarding the thematic approach to analysis, namely identifying, analyzing, and reporting patterns (themes) in the data. The first stage is to read and re-read the subsets of interview transcripts independently and capture exciting elements from the coding data by the first and the second author. Throughout this coding process, the researchers conducted debriefing and reflexive writing simultaneously to generate themes and maintain a solid and oriented relation to the participants' experiences. When the final themes were defined, a research report was written up.

Data Validity

The validity of the data in this study enhances the trustworthiness of the findings, and a number of means of credibility were established. Due to the nature of qualitative research approach, the researcher themselves is the research instrument. As the research

instrument, the researcher is obliged to fulfil the validity elements to gather representative data. One the elements of validity in qualitative research is researcher's credibility (Creswell, 2013).

The credibility of this study is established by the researchers, who are a nurse with experience in caring for women with breast cancer and members of an Indonesian cancer foundation. For these reasons, the researchers could build trust with participants by discussing the intimate details of their experiences. Furthermore, to enhance data credibility, confirmation and member-checking of the themes were established with the participants.

Results

Demographic Characteristics

There were seventeen participant candidates that fit the inclusion requirement. Of the seventeen candidates, three women expressed unwillingness to participate in the study, resulting in the final sample size of fourteen participants. The fourteen women who participated in the study ranged in age from 33 to 55 year with a mean age of 40 years. Twelve women were married and two women were unmarried (single). There was variation of educational background among the participants. Five participants had bachelor degree, three from senior high school, four from college with a diploma, and the others had master degree. Participants were workers, housewives, and civil servants. This study resulted in three themes, namely a negative view of women with breast cancer supported by three themes, including 1) short duration of survival, 2) being labeled as a suffering person, and 3) social discrimination

Theme 1: Short Duration of Survival

Several participants described that there are still many people who believe that someone will soon die when they are diagnosed as suffering from cancer. This affects the mentality of participants when interacting with other people because they are considered unfit to live. Participant 5, 47 years old, self-employed, explained that some people believe that people who have cancer will face death. She said:

"But still there are some people who believe cancer will not live long. Cancer can't be cured. Our mentality is affected too, right?" (P5)

Participant 6, a 55-year-old woman, who was a housewife, conveyed that there is still a strong stigma attached to someone with cancer, one of which is

considered a family disgrace. While in truth, breast cancer survivors also want to live a decent life like other people in general.

"I feel like I can't change people's views about cancer. I really hope that people are aware of cancer survivors, and start to realize how much we don't want to be privileged, no, but we just want to live a decent life. As survivors, we have the right to be accepted properly, not to be considered a family disgrace. Don't be thought of as someone who is so down that she is to be pitied." (P6)

Participant 7, a 50-year-old woman, who works as a housewife, explained about hearing words that someone with cancer will not last long. She affirmed:

"Once, there were people who saw me. I heard bad words, he said 'cancer is scary, it doesn't live long' and then I said 'I'm sorry, if you look at me,' I say various things, 'it's better not to look at me, okay,' I answered that. So, he kept quiet and immediately apologized." (P7)

Theme 2: Being Labeled as a Suffering Person

Several participants explained that they wanted people to stop talking about cancer patients because they did not like to be labeled as sick people. Participant 8, a 49-year-old housewife, said:

"I want to convey to the people around, please stop using the word sufferer. Because when someone is given the word lab suffers, she will label herself suffering. 'Survivors' or 'patients' is better. For example, such as patients who have finished undergoing cancer therapy. So the effect of the word sufferer as a sick person. The proof is that we can travel, we can work but why do people call me suffering like that. So, what do you feel like, it's like we were created by another group. You are a sufferer." (P8)

Participant 9, a 33-year-old woman, unmarried, explained that there is a stigma attached to women who have breast cancer, namely, they are considered to have bad luck. Here is the participant's statement:

"It seems that there is a mistake in women who have breast cancer, there seems to be a stereotype type or label minded attached that bad luck happens to women, bad behavior to women. The woman did not dare to speak up like that. To express himself sick and

when the woman is sick, maybe the work environment is not supportive, the family environment is also not supportive. So, I thought what do I need, such assistance.” (P9)

Theme 3: Social Discrimination

In young unmarried women, the experience of breast cancer has a profound impact on their lives. Young women in Bali who experienced breast cancer and must undergo a mastectomy often get stigmatized as imperfect people; this is associated with the values that exist in Balinese society, which still prioritizes appearance so that sometimes someone who has incomplete limbs, such as having one breast removed, is often the subject of discussion, especially by the general public about breast cancer. Furthermore, in Balinese society, there is often a fear of having a female partner who has breast cancer because it is considered that it will carry bad genes for the offspring in the family. Participant 11, a woman aged 34 years, unmarried, explained that, when she had breast cancer, many friends did not want to hang out, and the opposite sex was not interested in her. She explained:

“I felt like I was being shunned when I got breast cancer or like I was being left behind. I feel that many people don't want to be friends with me anymore because of my condition after therapy. I feel more like that. I am also aware that the opposite sex of men would want a perfect partner, right, while I am not perfect anymore.” (P11)

Participant 13, a 53-year-old woman, who was a housewife, explained that the people around her felt sorry for the participants when they had breast cancer. She stated:

“Yes, they feel sorry for me, right if people in the village are a bit scary to think that they have breast cancer, in the city it's normal. If you're in the village you say why you're sick like that, even though we're used to it. The proof is that we can move here and there.” (P13)

Participant 6, a 55-year-old woman, who was a housewife, conveyed that there is still a strong stigma attached to someone with cancer, one of which is considered a family disgrace. Whereas breast cancer survivors also want to live a decent life like other people in general.

“I feel like I can't change people's views about cancer. I really hope that people are aware of cancer survivors, and start to realize how much we don't want to be privileged, no, but we just want to live a decent life. As survivors, we have the right to be accepted properly, not to be considered a family disgrace. Don't be thought of as someone who is so down that he is pitied.” (P6)

Discussions

The main purpose of this study was to have a deeper understanding of the stigma and discrimination against women with breast cancer. Participants explained the need to change society's stigma about cancer survivors. Participants conveyed that there is still a strong stigma attached to women who have breast cancer, such as being considered not to live long, considered a person who suffers, considered a family disgrace, considered to have bad luck, and considered an imperfect woman. These findings were similar to several previous studies on cancer stigma in general (Huang et al., 2020; Shiri et al., 2018). In breast cancer survivors specifically, stigma impacting the self-identity, self-esteem, and body image has been proven to be a burden to the survivors' physical and emotional quality of life (Amini-Tehrani et al., 2021; Chu et al., 2020; Fujisawa et al., 2020; Yeung, Lu, & Mak, 2019).

The first theme identified in this study gathered that individuals with breast cancer have a short duration of survival or are short-lived. Similar sentiments were shown in the findings of a different study on cancer stigma (Bhattacharyya et al., 2018). Additionally, according to Nyblade et al. (2017), breast cancer and cervical cancer in women in India are considered infectious diseases both for children and even for society at large, considered as punishment, and considered incurable, and those who suffer from it will die quickly. Whereas breast cancer survivors also want to live a decent life like other people in general. In accordance with Solikhah et al. (2020), in Indonesia, women with breast cancer are considered to be dying. This causes women with breast cancer in Indonesia to feel ashamed and afraid to reveal their identity to the surrounding environment.

Unfortunately, there was no accurate statistical data on breast cancer survival rate in Indonesia to provide insight into the notion of breast cancer survivors being short-lived. According to World Population Review (2022), in its Global Cancer Survivor Rates, the survival rate of breast cancer in Indonesia was 77,70%. However, the factors influencing such value were not stated

clearly. The researchers deliberated that such finding was the result of several factors.

When facing breast cancer diagnosis, patients tended to seek medical treatment at the later stage of cancer. Oftentimes, patients seek traditional or folk medicine to treat their illness. This resulted in worse treatment outcomes. This was supported with the findings of Solikhah (2020) that stated patients chose traditional treatment before seeking medical treatment when the symptoms worsen. Additionally, the healthcare facilities in Indonesia were not equally equipped to treat cancer diagnosis. Furthermore, individuals with breast cancer who live in rural areas or provinces with less comprehensive healthcare facilities might find seeking proper medical treatment a challenge. Thirdly, while cancer treatments were covered in National Health Insurance, the coverage is applicable only when cancer diagnosis is established, other costs, such as the screening phase and many miscellaneous costs, must be covered by the individuals and their families. The cost could amount to an enormous number, which discourages the women with breast cancer to seek treatment.

The second theme identified was Being labeled as a suffering person. The participants explained that they were uncomfortable with the use of labels such as sufferer or unlucky person when addressing them. This may impair the quality of life of the participants in this study. The reality in Bali, according to the participants, is they are not allowed to participate in religious rituals anymore because they are viewed as a sick person. These labels were more prevalent in sub-culture communities or low to middle-income countries (LMIC) culture as opposed to high income countries' view of cancer. Similarly, in high income countries stigma about cancer was low or confined in small communities and small percentage of cases, for example the stigma around male breast cancer survivors (Midding et al., 2018; Vrinten et al., 2019).

The last theme identified was social discrimination. The discrimination referred to the ability to participate in social engagements or interactions. Owing to the cultural beliefs, a breast cancer diagnosis may delay a woman's marriage and hinder their interaction with family members and the community. This could negatively impact the woman's willingness to seek treatment and support in their experience with cancer, which is directly adverse to optimal outcomes. Furthermore, it can cause women with breast cancer to be isolated from their surroundings. This is consistent with the results of existing research that, in general, women with breast cancer receive negative stigma from

the general public (Dewan et al., 2021; Jin et al., 2021). Therefore, an explanation is needed for the surrounding community about breast cancer so that patients who are undergoing cancer therapy or who have completed cancer therapy are not ostracized by the surrounding community.

This study highlights the importance of adding nursing interventions to overcome the stigma that occurs in the community about breast cancer (Kang et al., 2020), such as carrying out educational programs about marital problems and relationships after a cancer diagnosis. This can increase general public knowledge about empathy and self-acceptance of cancer survivors so that there is no fear when having family members or partners who have breast cancer or other gynecological cancers (Reese et al., 2019). While cancer stigma itself has received much attention, interventions to alleviate cancer stigma negative impact, in contrast, need further exploration (Akin-Odanye & Husman, 2021). Recent research by Afiyanti et al. (2020) highlights the needs of breast cancer survivors, including explaining cancer to others and moving on with their life. The results of this study explain that breast cancer survivors have a need to explain this cancer to other people, in this case, namely the community (explaining cancer to others), and want to return to life as it should be (moving on with their life) because participants only want to return to a normal life without the bad stigma attached to her as someone who is helpless, has bad luck, disgraces her family, is close to death, or is considered an imperfect woman.

The results of this study are also expected to provide an overview to nurses and other health workers regarding the needs to accommodate psychological post-cancer treatment, especially about the stigma on breast cancer survivors. In addition, the findings of this study raise the expectation of the availability of consultation on problems experienced by patients and cancer survivors, which triggers the importance of the presence of oncology specialist nurses in existing cancer care installations. Furthermore, a specific program is needed such as comprehensive nursing care provided by nursing care providers to help cancer survivors meet their needs so that there is an increase in the life expectancy or survival rate of cancer survivors in.

Limitation of The Study

Several researchers realize that there are limitations and shortcomings in this study. The first includes the stigma issues, which are generally sensitive and tend to be ignored, especially in Eastern culture. The participants of this study might not fully to express their

feelings when discussing their experiences and preferences. The second is the small sample size, the characteristic of qualitative study, which may cause the study to be limited to a certain population, that is, in women attending the research cancer hospital. Therefore, it may not represent the general population and it is difficult to establish transferability of study results.

Conclusions

This study showed the stigma and discrimination experiences of breast cancer survivors faced. It can be concluded the breast cancer survivors received negative views from their community as a result of their cancer diagnosis. The results of this study offer insights, information, and understanding into experiences of Indonesian women with breast cancer related to the various stigmas from their community. They were blamed by the community as a dying person, a sick person, and various social discriminations, which lowered their quality of life. There is an opportunity for oncology nurses in Indonesia to assume the roles and responsibility to work with the breast cancer survivors in resolving the stigma they experienced and disseminating information to the society that breast cancer survivors are not what they are negatively assumed to be.

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Conflict of Interest

The author declares that there is no conflict of interest in this study.

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