

7-31-2023

## Knowledge and Pattern of Preventive Behaviors Among Relatives of Breast Cancer Patients in Yogyakarta Pre and During the COVID-19 Pandemic

Atik Triratnawati

*Department of Anthropology, Faculty of Cultural Science, Universitas Gadjah Mada, atik-tri@ugm.ac.id*

Runavia Mulyasari

*Department of Intercultural, Faculty of Cultural Science, Universitas Gadjah Mada, runavia.mulyasari@ugm.ac.id*

Follow this and additional works at: <https://scholarhub.ui.ac.id/kesmas>



Part of the [Public Health Education and Promotion Commons](#)

---

### Recommended Citation

Triratnawati A , Mulyasari R . Knowledge and Pattern of Preventive Behaviors Among Relatives of Breast Cancer Patients in Yogyakarta Pre and During the COVID-19 Pandemic. *Kesmas*. 2023; 18(5): 88-92

DOI: 10.21109/kesmas.v18isp1.6881

Available at: <https://scholarhub.ui.ac.id/kesmas/vol18/iss5/16>

This Original Article is brought to you for free and open access by the Faculty of Public Health at UI Scholars Hub. It has been accepted for inclusion in Kesmas by an authorized editor of UI Scholars Hub.

# Knowledge and Pattern of Preventive Behaviors Among Relatives of Breast Cancer Patients in Yogyakarta Pre and During the COVID-19 Pandemic

Atik Triratnawati<sup>1\*</sup>, Runavia Mulyasari<sup>2</sup>

<sup>1</sup>Department of Anthropology, Faculty of Cultural Science, Universitas Gadjah Mada, Sleman, Indonesia, <sup>2</sup>Department of Intercultural, Faculty of Cultural Science, Universitas Gadjah Mada, Sleman, Indonesia

## Abstract

Breast cancer is still one of the leading causes of death in Indonesia. The multifactorial causes of breast cancer, including heredity, carries a risk for the sufferers' relatives. Vigilance in female relatives of breast cancer patients increases due to hereditary risk factors for having the same disease. This anthropological study aimed to reveal the mosaic of breast cancer patients' female relatives' knowledge of such a risk and their efforts to prevent it. Qualitative data collection through interviews was conducted with 13 female family members of breast cancer patients in Yogyakarta aged 17-65 years. The data analysis was done through an emic approach by examining the informants' views on the situation and their solutions. All of the informants believed that breast cancer is a malignant and deadly disease if it is not detected early and not properly treated. They were all fully aware of their risk as a family member to have the same disease. Their preventive measures included medical (early examination, breast self-examination, laboratory check, or consultation with the doctor) and non-medical (changes in eating and drinking behavior, reducing stress, exercising, and wearing masks). Besides, they also made religious efforts by praying to God to be given a healthy life and for the patients to be healed and their offspring to be free from this disease.

**Keywords:** breast cancer, medical, non-medical, preventive, relatives

## Introduction

Cancer is one of the leading causes of death worldwide. Breast cancer is ranked tenth on the list of top causes of death in high-income countries, while its prevalence and mortality rates are also rising in Asia and Africa.<sup>1</sup> In the Asian context, breast cancer is often viewed as more than just a physical disease but also as attacking the survivors' mental/psychological well-being.<sup>1</sup> In discussing breast cancer in Asia, it is necessary to see the socio-cultural values to have a more holistic picture of the disease.<sup>1</sup> Many studies show breast cancer brings fear, shame, or an unordinary position to breast cancer survivors.<sup>1-3</sup> They often lack social support from their family or society members. It makes breast cancer survivors feel they cannot openly express their fear, create awareness of the disease, or even share knowledge to prevent cancer.<sup>1-3</sup> Based on the Indonesian Ministry of Health data in 2022, breast cancer deaths reached 22,000 cases.<sup>4</sup> The highest cancer prevalence is in the Special Region of Yogyakarta Province, with 4.46 cases per 1,000 people.<sup>5</sup>

Heredity as a family factor is among the important causes of breast cancer, in addition to hormones, diet, work patterns, and stress. Family history is a common cause, so those who have blood relations and are of the

same sex with the sufferers must be vigilant since they have higher risks of experiencing the same disease.<sup>4</sup> Genetic knowledge also can play out unevenly in the family. At the same time, personal relations between kin can be negotiated as "rights to know" or "not to know" about predictive heredity risk.<sup>4</sup> On the other hand, the family also serves as a support system for breast cancer patients by encouraging the patients to adhere to the therapy, medical treatment, and post-medical treatment and keeping the patients' emotions, feelings, and work patterns under control.<sup>6</sup>

During the coronavirus disease 2019 (COVID-19) pandemic, breast cancer's high morbidity and mortality caused fear and anxiety about the risk of exposure to this disease. The stress experienced by cancer patients undergoing chemotherapy during the pandemic varies from mild and severe.<sup>7</sup> Fear of contracting COVID-19 is influenced by increased anxiety, the type of cancer experienced, age, sex, treatment delays, hospital restrictions, fear of being alone, uncertainty about when COVID-19 will end, and lack of information on COVID-19.<sup>8</sup> This anxiety will affect the condition of breast cancer patients, especially in the healing process.

From the above background description, the study

**Correspondence\*:** Atik Triratnawati, Department of Anthropology, Faculty of Cultural Sciences, Universitas Gadjah Mada, Sosiohumaniora Street No. 1, Bulaksumur, Yogyakarta 55281, Indonesia, E-mail: atik-tri@ugm.ac.id, Phone: +62 812-258-5670

Received : May 03, 2023  
Accepted : July 22, 2023  
Published : July 31, 2023

questions were as follows: how are the family members' knowledge and acceptance of the breast cancer suffered by their family members? What do female family members of breast cancer patients do to prevent the possibility of developing breast cancer? This medical anthropological study was expected to provide a clear picture of family members' knowledge and preventive efforts that can be disseminated to the general public to increase breast cancer awareness. This study explored knowledge about the warning signs, prevention of breast cancer, and its determinants among the family members in Yogyakarta.

A recent study on breast cancer showed that how people make sense of living with breast cancer is shaped by the social and cultural contexts in which they live, including how women perceive, cope with, understand, and experience their disease.<sup>9</sup> This narrative was also raised by Kleinman,<sup>10</sup> who argued that understanding how breast cancer patients evaluate their illness is crucial for physicians to provide effective, empathic, and ethnically sensitive health care. The patients' interactions in their social environment and social and economic conditions inform how they make sense of their illness and shape their illness narratives.

In many cases, people with breast cancer choose treatment from traditional healers.<sup>11</sup> Many women in Asia, including Indonesia, believe in the influence of factors beyond human power, driving them to visit traditional or spiritual healers, despite the availability of modern medical care.<sup>12</sup> In this sense, the variation in religious and cultural practices and lifestyles shapes different reactions to breast cancer between ethnic groups of Asia. One study comparing Chinese and Malay cultures showed that the incidence of breast cancer among Chinese women is higher, but the mortality rate is lower than among the Malays.<sup>1</sup> Fear, fatalism, and family values strongly influenced Malaysian women's reactions to their illnesses.<sup>1</sup>

In Indonesia, cultural factors became significant problems for breast cancer patients. These include aesthetic concerns about loss of beauty with the corresponding fear of being left by the spouse. This condition often triggers inappropriate and overly aggressive use of alternative drugs.<sup>13</sup> Some of these treatments may not match their subjective expectations or informed preferences and are associated with poorer quality of life, shorter survival, regret, and in some cases, severe financial hardship.<sup>14</sup> Treatment delays often happen due to psychological, economic, cultural, mythical, and health service factors.<sup>11</sup> This study tried to understand how cultural aspects influenced breast cancer understanding and preventive behavior.

## Method

This study used ethnography methods to gather data on the family member informants' experiences treating

breast cancer patients. An emic approach was used to understand the informants' perceptions regarding their situation and how they solved the problems. In practice, it was not easy to find family members who could tell about their experience in treating breast cancer patients, especially if the patients died due to their cancers.

Snowball sampling was used to find 13 cases of female relatives of people with breast cancer willing to participate in the study. The familial relations were as a daughter (7), mother (2), elder sister (1), younger sister (1), and daughter-in-law (2) of the breast cancer patients. All informants had come to terms with the condition of having a family member who had breast cancer, including those whose family members died from the disease. They were Javanese aged 17-41 years (young group) and 41-65 years (old group), 11 people were Islam, and 2 were Christian. The participants were obtained from (1) the Indonesian Cancer Foundation in Sleman, which receives breast cancer patients from outside Yogyakarta; (2) the Yogyakarta branch of the Breast Cancer Survivor Association; (3) the institutions/universities where the authors work; and (4) the authors' relatives who gave information about people with breast cancer in their neighborhoods.

The first period of interviews and observation was conducted from July to September 2019 in the informants' house, neighborhood, or Cancer foundation to understand the informants' socioeconomic, living conditions, and expressions during the interviews. The second period was from January to March 2023 to understand the relevance of the COVID-19 pandemic to the informants' conditions. The collected data were categorized thematically, and then the data analysis and interpretation process was carried out. Then, conclusions were drawn based on the results of the analysis and interpretation.

## Results

### *Knowledge and Experience in Caring for Breast Cancer Patients*

The breast cancer patients in this study were members of the informants' nuclear family or extended family. The observation results from 13 informants showed that sadness still hangs over their hearts when talking about the condition of breast cancer relatives, especially during the pandemic, when the stress experienced increased. Although their words were optimistic, anxiety always appeared on their face.

The calamity experienced by their family members was accepted with sincere patience and resignation. They thought their family's breast cancer could be caused by many factors, such as heredity, hormones, frequent consumption of instant/canned foods or foods containing preservatives, stress, and a poor environment. They could not say with certainty which factors triggered breast can-

cer suffered by their family members.

Some informants mentioned that the patients liked instant foods or foods containing preservatives. At the same time, some said that their family members still got breast cancer despite their “clean” lifestyle in which they consumed a healthy diet. Heredity and hormonal factors were believed by most of them to cause breast cancer because they found other family members with the same health problems.

All informants believed breast cancer is a dangerous disease often considered malignant. It was because the disease can metastasize, spreading throughout the body. Therefore, although breast cancer has been removed through surgery, the metastatic phase will likely progress if the patient is not routinely checked and treated accordingly. Patients with metastases experienced grave suffering because they could not function normally due to the pain and insomnia they experienced. They could not do their daily activities properly, especially lifting heavy loads; many must lie in bed constantly.

*“My mother had to lie in bed most of the time before she eventually passed away. Although her cancer had been removed by surgery, she still suffered from other symptoms such as stroke and increased stomach acid and blood sugar. The doctor said that her cancer metastasized to her brain too.”* (ST, 27 years)

Almost all informants said that the most suitable treatment for breast cancer was modern medical treatment because it was equipped with modern medical equipment and appropriate medications. However, the patients will feel the after-therapeutic effects, such as weakness, loss of appetite, nausea, and dizziness. While, the family must be prepared to handle the patient’s condition and domestic work.

#### *Preventive Efforts*

The important role played by heredity as a contributing cause of breast cancer raised awareness on the part of patients’ relatives to think about their risk of developing the same disease. Many family members learned from the doctors who treated the patients that the heredity factor should be considered seriously. Those who were the direct descendants of the patients become aware that they have the potential to develop the same disease. One example of this awareness could be seen in the response of SM (31 years), a younger sister of a breast cancer patient, who had her breasts examined at the hospital upon finding a lump in her breast through breast self-examination. As close relatives of breast cancer patients, the informants received vital information from various media or doctors’ explanations when they accompanied the patients. The awareness that prevention is better than curation was deeply instilled in them.

The informants chose the easiest and lowest-cost preventive efforts, such as avoiding fried, fatty, instant, and roasted foods or drinks containing preservatives. Although they sometimes found it challenging, they chose this method given the risk they faced. Morning exercise was routinely performed no matter how busy they were. Walking, swimming, or elderly exercises were chosen by the 13 informants to lessen the risk of developing breast cancer. Furthermore, two informants ST (27 years) and H (36 years), practiced wearing masks and avoiding cigarette smoke because they believed environmental factors also contributed to the disease. Healthy foods like vegetables and fruits were chosen. Despite its simplicity, this method was hoped to prevent cancer effectively. A young informant (NM, 17 years) chose a very comprehensive method to prevent breast cancer, as indicated by the following statement.

*“Preventive efforts are quite easy: live a healthy life, not hold bad feelings inside, be happy, build open communication, develop a hobby, avoid stress, keep your emotions under control, and understand your body.”*

The lives of Javanese people filled with Javanese values and philosophies made the informants base their mindsets on knowledge and God as the creator and helper of humans. They believe that health, illness, disease, suffering, and healing are in God’s hands. Doctors, health workers, and traditional medicine merely serve as healing intermediaries. All informants also made spiritual efforts according to the religion they professed. They asked for healing for their family members who had breast cancer through prayers or by engaging in religious rituals to attain calm and peaceful feelings. They also prayed for freedom from this disease for themselves.

*“My mother’s condition improved due to the help of the church community and her activities as a survivor.”* (NM, 17 years).

#### **Discussion**

Indonesia has no particular breast cancer preventive program except through SADARI (check your breast).<sup>14,21</sup> Breast cancer patients experience many difficulties related to healing under normal conditions. The problems have increased during the COVID-19 pandemic. Cancer patients experience many stressors related to the COVID-19 pandemic associated with psychological symptoms.<sup>15</sup> However, all of the breast cancer patients’ family member informants from the Javanese culture tended to accept the suffering of their family members as part of God’s plan. They believed that disease and illness are trials from God and thus surrender to God’s will. Despite their resignation, patience, and acceptance of their family member’s illness, they were always optimistic that, somehow, it would be healed. They continued to

strive, seek, and look for the best ways to cure cancer for patients.

The informants' knowledge about cancer was quite adequate in the sense that informants know and understand the biological and non-biological factors that cause breast cancer. They came from a city background and higher education. The informants in this category tended to interact more intensely with the doctors and medical personnel who cared for the patients to increase their knowledge. Besides, many also seek information from other sources, including the Internet or other family members, during patients' therapy at the hospital. Most patients' families were knowledgeable about the treatments that can be used to deal with breast cancer, such as surgery, radiation, and chemotherapy.<sup>16</sup> They had an adequate understanding of their effects.<sup>17</sup>

Breast cancer patients' relatives took two main ways to lessen the patients' suffering. First, by providing moral support, including showing enthusiasm, motivation, attention, and affection; being available for patient care; accompanying patients during their treatment/therapy. Second, assisting patients with activities of daily living where they need help from others. Breast cancer patients need social support to keep them enthusiastic about dealing with their health conditions.<sup>16,18</sup> Moral support is considered the most important assistance to deal with the illness. With such support, patients gradually become enthusiastic again to live their lives, undergoing surgery, chemotherapy, radiation, and other medical treatments. In this case, family and peer support can be seen as the "social glue" of connectedness that binds the survivors together and provides mutual solidarity, which gives a social opportunity that is helpful to health improvement.<sup>19</sup>

Hopefully, these conditions will recover quickly during the COVID-19 pandemic so that breast cancer patients can be assured of the healing process, medically and non-medically. Another important lesson from breast cancer patients pre and during the pandemic is that prevention is better than cure. A healthy lifestyle and avoiding risk factors should be a trend in the community to prevent stress and other life pressures.

The informants' preventive measures to avoid breast cancer were divided into two efforts. First, using medical methods, including medical examination, lab checking, therapy, and consultation with doctors. One of the informants had her breast laboratory results checked and consulted with a doctor. However, this was not the first choice to prevent breast cancer because medical efforts were considered scary and expensive. Medical methods were believed to be the best, but not all informants feel the importance and urgency to use them as they think breast cancer is still a mystery and the exact cause is unknown. Its multifactorial causes made the informants un-

able to decide the most appropriate preventive measures confidently.<sup>11</sup>

A previous study stated a disconnection between what is already discovered and what needs to be delivered in cancer care.<sup>20</sup> In contrast, the size of the gaps in good access to care, prevention, and early detection of cancer remain salient issues to tackle cancer better and identify under-diagnosed and untreated persons.<sup>20</sup> Many informants chose to do breast self-examination as this method is considered easy, at no cost, and not scary. Lay people can practice breast self-examination to feel a lump in their breasts.<sup>21</sup>

The second method was non-medical efforts by changing their behavior to a healthy lifestyle. This method is often called complementary therapy because it complements the medical methods. The results of interviews and observation showed many informants felt shy and afraid to use medical methods, and non-medical methods often became the first choice. Furthermore, interviews and observation also showed all informants' changes in behavior, including avoiding food/drinks containing preservatives, roasted food, cigarette smoking, excessive alcohol consumption, or life pressures/stress. This healthy lifestyle also translated into spiritual actions in the form of religious rituals and acceptance of breast cancer as fate and trials from God.

There were differences in the prevention efforts made by young and old informants. Young informants were exposed to more information to make their efforts more apparent. They were also very enthusiastic about their preventive efforts. As for their older counterparts, they looked more passively because they thought that with their old age, their risk of developing breast cancer was low. Even if they change their behaviors, they tend to do them with low enthusiasm. This study only involved the informant from Javanese ethnicity with Islam and Christian backgrounds. For further studies, it is necessary to look at other ethnic backgrounds and different religious backgrounds to understand the spiritual aspects of breast cancer.

## Conclusion

This study seeks to understand more about the spiritual aspects of breast cancer through how cultural factors and norms in Javanese society influence people's understanding of cancer. The study results show that after intensive assistance to patients, breast cancer is not only believed to be a disease caused by biological (hereditary factors) and non-biological factors but instead by spiritual aspects, like destiny or trials given by God, which influence the preventive measures taken by breast cancer patient assistance. They combine medical efforts, lifestyle changes, and spiritual prevention.

### Abbreviations

COVID-19: Coronavirus Disease 2019.

### Ethics Approval and Consent to Participate

The study has been carried out following research ethics rules and has been approved by the ethics commission of Universitas Gadjah Mada, No. 349/UN1.FIB/UP2M/2022.

### Competing Interest

The manuscript has never been published in any other journal. The authors agree to follow the journal's submission instructions.

### Availability of Data and Materials

This study is based on ethnographic field research. It followed the ethical guidelines of the Universitas Gadjah Mada for social and cultural research. Because of our responsibility for safeguarding the participants' identity, following Privacy Legislation and Data Protection Laws, the ethnographic material cannot be made public in its raw and unprocessed form, such as field notes. The ethnographic data is stored on a password-protected computer, while this folder's backup is kept on a password-secured external hard drive. The data have not been deposited in a repository since they contain private and sensitive information about breast cancer patients and their families. Access to the field site and ethnographic information has been permitted solely for the principal researcher and not for any other parties.

### Authors' Contribution

AT and RM participated in the field and writing process. AT significantly contributes to methods, results and discussion; meanwhile, RM significantly contributes to the introduction, discussion, and conclusion. AT and RM are responsible for the subsequent revision, proofreading, and discussion with reviewers. Before submission, all undersigned authors have read and agreed on the manuscript's content.

### Acknowledgment

The authors thank the Faculty of Cultural Sciences Universitas Gadjah Mada for the research funding and Yayasan Kanker Indonesia Sleman District, Indonesia, for the information and research access.

### References

1. Chou C, Zeitzen MK, editors. Breast Cancer Meanings: Journeys Across Asia. Copenhagen: NIAS Press; 2018.
2. Kerr A, Ross E, Jacques G, Cunningham-Burley S. The sociology of cancer: A decade of research. *Sociol Health Ill.* 2018; 40 (3): 552-576. DOI: 10.1111/1467-9566.12662
3. Ho PJ, Gernaat SAM, Hartman M, Verkooijen HM. Health-related quality of life in Asian patients with breast cancer: A systematic review. *BMJ Open.* 2018; 8 (4): e020512. DOI: 10.1136/bmjopen-2017-020512
4. Kementerian Kesehatan Republik Indonesia. Kanker Payudara Paling Banyak di Indonesia, Kemenkes Targetkan Pemerataan Pelayanan Kesehatan. Jakarta: Kementerian Kesehatan Republik Indonesia; 2022.
5. Badan Penelitian dan Pengembangan Kesehatan. Hasil Utama Riskesdas 2018. Jakarta: Kementerian Kesehatan Republik Indonesia; 2018.
6. Gibbon S. Family medicine, 'La Herencia' and breast cancer; understanding the (dis)continuities of predictive genetics in Cuba. *Social Science & Medicine.* 2011 Jun 1; 72 (11): 1784-1792. DOI: 10.1016/j.socscimed.2010.09.053
7. Irianto, K. Ilmu Kesehatan Masyarakat. Bandung: Alfabeta; 2015.
8. Fadillah F, Sanghati S. Anxiety Levels of Breast Cancer Patients Undergoing Chemotherapy During the COVID-19 Pandemic. *J Ilmiah Kesehat Sandi Husada.* 2023; 12 (1): 136-142. DOI: 10.35816/jiskh.v12i1.914
9. Lihawa L, Zainuddin R. Tingkat Kecemasan Pasien Kanker yang Menjalani Kemoterapi di Masa Pandemi COVID-19: Literature Review. *J Akad Baiturrahim Jambi.* 2022; 11 (1): 96-108. DOI: 10.36565/jab.v11i1.457
10. Terzioğlu A, Hammoudeh W. Coping with cancer diagnosis and treatment: A comparative study on women with breast cancer in Turkey and occupied Palestinian territory. *Reprod Health Matters.* 2017; 25 (sup1): 35-46. DOI: 10.1080/09688080.2017.1378066
11. Kleinman A. Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry. Berkeley, CA: University of California Press; 1980.
12. Sarwono S. Breast Cancer Meanings: Journeys Across Asia by Chyntia Chou and Miriam Koktvedgaard Zeitzen (eds). *Bijdragen tot de taal-, Land-en Volkenkunde.* 2019; 175 (4): 577-604. DOI: 10.1163/22134379-17504009
13. Davis C. Drugs, cancer and end-of-life care: a case study of pharmaceuticalization? *Soc Sci Med.* 2015; 131: 207-14. DOI: 10.1016/j.socscimed.2014.12.007
14. Sunarsih IM. Tertundanya Pengobatan Medis Kanker Payudara di DIY [Dissertation]. Yogyakarta: Universitas Gadjah Mada; 2019.
15. Massicotte V, Ivers H, Savard J. COVID-19 pandemic stressors and psychological symptoms in breast cancer patients. *Curr Oncol.* 2021; 28 (1): 294-300. DOI: 10.3390/currenconcol28010034
16. Sitio R. Pengalaman Psikososial Pasien Kanker Payudara yang Menjalani Terapi Kemoterapi di BLUD dr. Zainoel Abidin Banda Aceh. *J Keperawatan Prior.* 2019; 2 (1): 17-32.
17. Nies YH, Ali AM, Abdullah N, et al. A qualitative study among breast cancer on chemotherapy: experiences and side-effects. *Patient Prefer Adherence.* 2018; 12: 1955-1964. DOI: 10.2147/PPA.S168638
18. Suwankhong D, Liamputtong P. Physical and emotional experiences of chemotherapy: A qualitative study among women with breast cancer in Southern Thailand. *Asian Pac J Cancer Prev.* 2018; 19 (2): 521-528. DOI: 10.22034/APJCP.2018.19.2.521
19. Hanson S, Gilbert D, Landy R, et al. Cancer risk in socially marginalised women: An exploratory study. *Soc Sci Med.* 2019; 220: 150-8. DOI: 10.1016/j.socscimed.2018.11.009
20. Foley RA, Hurard LL, Anchisi A, Anchisi S. Rising to the medication's requirements: The experience of elderly cancer patients receiving palliative chemotherapy in the elective oncogeriatrics field. *Soc Sci Med.* 2019; 242: 112593. DOI: 10.1016/j.socscimed.2019.112593
21. Marfianti E. Peningkatan Pengetahuan Kanker Payudara dan Keterampilan Periksa Payudara Sendiri (SADARI) untuk Deteksi Dini Kanker Payudara di Semutan Jatimulyo Dlingo. *J Abdimas Madani Lestari (JAMALI).* 2021; 3 (1): 25-31. DOI: 10.20885/jamali.vol3.iss1.art4