Global Academy of Multidisciplinary Studies (GAMS)
Vol 1, No 3, 2025, 157-166 *https://doi.org/10.35912/gams.v1i3.3479*

Psychosocial Adjustment of Breast Cancer Patients Post-Treatment Therapy and Mentoring. (Case Study of 4 Breast Cancer Patients in Sapkandara Community Medan)

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Article History
Received on 3 January 2025
1st Revised on 11 January 2025
2nd Revised on 16 January 2025
Accepted on 22 January 2025

Abstract

Purpose: To determine the impact of therapy, psychosocial adjustments, and assistance received by breast cancer patients in the Sapkandara Movement community in Medan.

Research Methodology: This type of research is qualitative with a case study approach to 4 breast cancer patients who are members of the Sapkandara

Results: The results showed that patients with breast cancer experienced significant physical and psychological changes after therapy, including fatigue, hair loss, stress, and emotional instability. Socially, patients tend to withdraw from their environment. Psychosocial adjustment is influenced by patients' knowledge of the disease and family support. There are three types of assistance: existential, functional, and professional; however, only existential support from the family is effective. The Sapkandara Community provides comprehensive support, including information, hospital assistance, and moral and emotional support.

Conclusions: Holistic support is crucial for patients with breast cancer, integrating family, social workers, and health professionals. The Sapkandara community plays a vital role in empowering patients and supporting psychosocial adjustment.

Limitations: This study was limited the scope of research to patients with breast cancer who were undergoing treatment, support therapy, and were members of the Sapkandara.

Contribution: This study contributes to social welfare knowledge by emphasizing the role of community-based support and social work in health settings. This study provides practical insights for policymakers, health institutions, and NGOs to strengthen psychosocial services for cancer patients.

Keywords: *Breast Cancer, Community-Based Care, Mentoring, Psychosocial Adjustment, Social Support*

How to Cite: Pelawi, M. A., & Asbi, E. A. (2025). Psychosocial Adjustment of Breast Cancer Patients Post-Treatment Therapy and Mentoring. (Case Study of 4 Breast Cancer Patients in Sapkandara Community Medan). *Global Academy of Multidisciplinary Studies*, 1(3), 157-166.

1. Introduction

Health Organization (WHO) definition that states that health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 2024; Meyers (2023)). Health development is essentially the effort of all components of the Indonesian nation to increase awareness, willingness, and ability (Mahendradhata et al., 2021)of every individual to live a healthy life to achieve the highest possible level of public health as an investment in developing socially productive human resources (BTKLPP, 2019). One of the challenges in health development today is the changing pattern of diseases (Dye, 2014). Two types of diseases arise in society: communicable and noncommunicable diseases.

The WHO reports that non-communicable diseases are one of the leading causes of death worldwide, accounting for more than 36 million deaths each year. The WHO categorizes five types of non-communicable diseases, one of which is cancer (Wang & Wang, 2020). According to data presented by the Ministry of Health and derived from Globocan, in 2020, the number of breast cancer cases reached 68,858 (16.6%) out of 396,914 new cancer cases in Indonesia. In addition, more than 22,000 deaths have been recorded (Aristizábal & Sánchez, 2020). Medan, a city located in North Sumatra, reported 824 breast cancer cases in 2021 (Lahagu, Manururng, Sari, & Damanik, 2024).

The impact of treatment after a breast cancer diagnosis includes both physical and psychological effects (Ghosh, Sarker, Saha, Islam, & Shakil, 2024; Kurrohman & Nurlita, 2024). Physically, the treatment can damage a person's self-image, such as hair loss following chemotherapy, nausea, and weight reduction (Graham, 2024). Breast cancer has become a phenomenon that requires attention from all parties. Diagnosis is often a daunting prospect for female patients (Akram, Iqbal, Daniyal, & Khan, 2017), as they fear the therapies that follow, and naturally, they fear death. After receiving the diagnosis, patients face treatments such as chemotherapy, mastectomy, radiotherapy, lumpectomy, hormone therapy, targeted therapy, and lymph node removal if the cancer has spread (Derakhshan & Karbassian, 2017). These therapies can have negative physical effects, leading some patients to hesitate in continuing treatment as prescribed by medical professionals (Linsky, Simon, & Bokhour, 2015). This observation aligns with my findings that many breast cancer patients in Medan express reluctance toward therapy due to physical side effects such as baldness, nausea and reduced bone strength.

On the other hand, patients experience profound psychological distress after receiving a breast cancer diagnosis from their doctor (Jørgensen, Garne, Søgaard, & Laursen, 2015). The diagnosis of a potentially life-threatening illness negatively impacts both physical and psychological well-being, with long-term consequences (Hernandez et al., 2018). This combination of physical and psychological effects after diagnosis and subsequent treatment also influences those around the patient. This occurs due to the lack of support from medical professionals, family, or neighbors (Davis, Lakin, Binns, Currie, & Rensel, 2021). Women with breast cancer who isolate themselves from their social environment are significantly more likely to die from various causes than women who remain socially engaged (Lewis, Newton, Kenny, & Boyle, 2024).

A cancer diagnosis presents numerous challenges for patients, including physical and emotional changes and financial and scheduling difficulties. Social workers are needed to assist patients in managing these issues. Social workers help patients from the moment of diagnosis throughout their journey, aiding them in understanding the diagnosis, accessing financial resources, advocating for self-care, communicating with loved ones about the illness, supporting treatment processes, and planning for the future (Dave et al., 2024). Hospitals typically provide social services to patients, facilitated by medical social workers, to help prevent patients from experiencing social dysfunction after recovering from their illness (Callister, Lockhart, Holtrop, Hoover, & Calcaterra, 2022). The presence of medical social workers is essential in every hospital to assist patients; however, there are no regulations mandating the involvement of professional medical social workers in the healing process. It is important to note that the role of medical social workers is crucial in improving the quality of life of patients.

Medical social workers typically assist patients in addressing their problems, whether pre-operation, post-operation, or during other treatments, such as administrative matters. Medical social workers play a vital role as companions in the patient's recovery process to provide the best healthcare services to the community. The lack of support from medical professionals underscores the importance of support from the patient's immediate family, such as spouses, children, and extended family members, such as parents and siblings. This support fills the gap left by the absence of professional support for patients with breast cancer. Baron and Bryne (2000) state that patients undergoing treatment recover faster or heal more effectively when they have family and friends who can provide help. Additionally, psychosocial adjustment is necessary for patients undergoing treatment, and they require companionship during the process. Apart from medical social workers, family support is crucial because individuals diagnosed with cancer should not face their condition alone but should be accompanied by their loved ones. A prolonged denial phase can directly affect the patient's condition, which is why support from close family or support communities helps patients more quickly accept their situation.

In general, patients need the support of medical social workers to help them regain their social function; however, this is often not provided. This observation is supported by my findings that there is no support for breast cancer patients in the Sapkandara community, where all patients are accompanied only by their families. Support from doctors is limited to the hospital setting, and no additional support systems are available for patients. This highlights the importance of conducting research on this issue to provide a clearer picture of the future and propose constructive solutions.

2. Literature review

2.1 Breast Cancer

Breast cancer occurs when certain cells in the body grow and develop uncontrollably, causing them to invade the surrounding tissues and spread throughout the body. Several factors contribute to the development of breast cancer, including lifestyle choices among women, such as junk food consumption and high-fat diets, alcohol consumption, beauty-related radiation exposure, hormonal treatments, and workplace exposure. Breast cancer in men is very rare because women's breasts undergo complex hormonal evolution, which men do not experience. With advancements in medical technology, various treatments are available for patients with breast cancer to alleviate or reduce pain, including surgery (breast-conserving surgery) or mastectomy (both simple and radical), radiation therapy, chemotherapy, hormonal therapy, and targeted therapy. Moreover, patients often experience anxiety after being diagnosed with breast cancer, leading to feelings of denial, anger, and fear of the treatment process.

Community involvement is increasingly recognized as a vital component of the recovery and adjustment of patients with cancer. Support groups and survivor networks provide emotional encouragement, health information, and peer solidarity that formal health services often cannot provide. Community-based initiatives also play a role in reducing stigma, enhancing self-efficacy, and motivating patients to adhere to treatment regimens. The Sapkandara community in Medan exemplifies how peer support can fill the gaps left by the absence of structured professional psychosocial services.

2.2 Psychosocial Adjustment

According to Moos and Tsu (as cited in Hendriksen et al., 2009), "Psychosocial adjustment can be defined as the adaptive task of managing upsetting feelings and frustrations aroused by the illness and preserving an emotional balance," meaning that psychosocial adjustment refers to the adaptive task of managing the distress and frustration caused by illness while maintaining emotional balance (Dion, Emilisa, & Citra, 2022). In line with VandenBos, "Psychosocial adjustment describes the intersection and interaction of social, cultural, and environmental influences on the mind and behavior." VandenBos describes psychosocial adjustment as the intersection and interaction of social, cultural, and environmental influences on one's mind and behavior. Psychosocial adjustment refers to the continuous changes a person undergoes when facing a chronic illness. This adjustment should not be viewed solely from a psychological perspective, as social adjustment is also necessary, especially for individuals with cancer. Psychosocial refers to the dynamic relationship between an individual's psychological and social characteristics. These two aspects are crucial in influencing human behavior, particularly in social situations. Psychological aspects can be divided into two categories: psychological factors, including emotions, stress, and trauma, and social factors, including social interactions, social relationships, and self-adjustment (Aleyda & Berliyanti, 2023).

Empirical studies have shown that structured psychosocial interventions, such as counseling, cognitive-behavioral therapy, and mindfulness-based approaches, significantly reduce anxiety and depression among patients with breast cancer. These interventions also improve coping mechanisms, resilience, and the overall quality of life. However, access to professional psychosocial care remains limited in many developing countries, leading patients to rely heavily on family and informal support systems.

2.3 Mentoring

According to Wiryasaputra, there are three types of mentoring:

a) Existential mentoring involves a universal form of companionship that all family members provide, based on empathy and the idea that every human being serves as a companion for others (Lukita et al., 2023).
b) Functional mentoring is provided by professionals other than counselors who aim to apply counseling attitudes and skills in their professions, such as doctors, nurses, and social workers.
c) Professional mentoring is provided by trained professionals such as counselors or psychologists (Raque-Bogdan, Ratchford, Garriott, Borges, & Duffy, 2020).

The social mentoring process centers on four tasks or functions, summarized as the 4P:

a) Enabling: Providing motivation and opportunities for the community (Jepson, Clarke, & Ragsdell, 2014).
b) Empowering: Focusing on education and training to strengthen the community's capacity (capacity building) (Dushkova & Ivlieva, 2024).
c) Protecting: Involving interactions between mentors and external institutions for the benefit of the community they serve (Lakind, Atkins, & Eddy, 2015).
d) Supporting: Applying practical skills to support positive changes within the community.

2.4 Medical Social Worker

Skidmore, Trackery, and Farley (1994) defined medical social work as the collaborative practice of social workers in healthcare settings and public health service programs (Noel et al., 2022). Medical social work focuses on addressing health issues related to social pressures that can lead to dysfunction in social relationships (Moore et al., 2017). Bracht (1978) explained that the scope of social work in healthcare includes health maintenance and promotion, disease prevention, and treatment (Ross & de Saxe Zerden, 2020). Furthermore, social welfare intervention methods are categorized into four levels: micro, which focuses on individuals, families, and small groups; mezzo, which focuses on organizations and communities; macro, which involves broader communities such as cities or regions; and international (global), which focuses on international communities.

Family support has consistently been identified as the most influential factor in psychosocial adjustment. Emotional, financial, and spiritual assistance from close relatives helps patients cope with the physical and emotional burdens of therapy. However, caregivers often experience burnout and stress, underscoring the need for broader support structures for patients and their families.

Medical social workers bridge the gap between clinical treatment and patients' social needs. Their roles include patient advocacy, access to resources and guidance through emotional distress. While such roles are well established in Western healthcare systems, they remain underdeveloped in Indonesia, resulting in uneven psychosocial care for patients with cancer. Strengthening professional social work services in hospitals and communities can enhance patient recovery and reintegration.

Taken together, these studies suggest that psychosocial adjustment in patients with breast cancer is shaped by the interplay of three key dimensions: (1) personal coping mechanisms, (2) family and community support, and (3) institutional or professional interventions. The lack of balance among these dimensions, particularly the limited availability of professional psychosocial support, leads to dependence on family and community groups such as Sapkandara. This framework underlines the importance of multilevel support systems to achieve holistic care and sustained adjustment.

3. Research methodology

This study employed a qualitative approach with a case study design. The selection of a qualitative approach was based on the aim to gain an in-depth understanding of psychosocial adjustment in post-therapy breast cancer patients and the support process they receive. The case study method was chosen because it enables researchers to intensively explore the experiences and psychosocial dynamics of four breast cancer patients who are members of the Sapkandara community. Data were collected through in-depth interviews, participant observation, and documentation studies. The informants in this study consisted of four breast cancer patients who had undergone therapy, their family caregivers, and the administrators of the Sapkandara community. Data analysis utilized thematic analysis techniques to identify patterns of psychosocial adjustment and forms of support received by patients.

The research involved four breast cancer patients who were members of the Sapkandara Community in Medan. Family caregivers and community administrators were included as supporting informants to provide a broader perspective on the support system available to patients. Data were collected using several techniques.

a) In-depth interviews with patients, family members, and community administrators were conducted to capture their lived experiences, emotional responses, and adjustment processes.
b) Participant observation, where researchers engaged with the Sapkandara Community to directly observe psychosocial dynamics, interactions, and support mechanisms.
c) Documentation study, reviewing patient records, community activity documents, and other relevant written sources to strengthen the data.

The data were analyzed using thematic analysis techniques, which involved identifying recurring patterns, themes, and categories related to psychosocial adjustment and mentoring. This method enabled researchers to systematically interpret narratives and highlight key factors such as family support, community involvement, and coping strategies. To ensure the credibility of the findings, this study applied triangulation by comparing data from interviews, observations, and documents. Member checking was also conducted by confirming the interview results with informants to validate their accuracy.

4. Results and discussions

4.1 Primary Informant P1

The initial diagnosis brought significant changes to the life of the primary informant (P1), a patient with Luminal B type breast cancer at stage 2A. In early 2018, P1 had already shown symptoms of cancer but was only diagnosed in 2019 through a second biopsy, which revealed the presence of a malignant tumor in the left breast (sinistra), measuring 2 cm, while a benign tumor was found in the right breast (dextra). Following this diagnosis, P1 decided to undergo total mastectomy of the left breast on April 6, 2019, coinciding with her wedding anniversary. After the mastectomy, the excised tissue was further examined, and the results indicated that estrogen (Er) and progesterone (Pr) hormones were positive, while Her2 protein was negative. Although the doctor recommended chemotherapy, P1 decided against it after a mama print test showed only a 0.05% difference between undergoing chemotherapy and not undergoing chemotherapy. In her daily treatment, P1 took medications such as Zometa and Letraz, which caused side effects like brittle bones, excessive fatigue, and difficulty moving and praying. The treatment P1 received was fully covered by the company where her husband worked, including travel expenses for one companion. However, despite the costs being covered, the psychological effects of treatment were unavoidable. P1 experienced severe stress after hearing the cancer diagnosis, but with the support of her child, who is a doctor, and a friend who is also a doctor, P1 gradually recovered and began treatment. Nevertheless, P1 felt that she did not receive professional assistance throughout the treatment. The support she received was limited to her family accompanying her during treatment. As an educator and social work lecturer, P1 was able to bounce back more quickly and began to adjust within approximately two months. P1 also actively created and wrote books, participated in competitions, and established the Sapkandara community to help other cancer survivors like herself.

4.2 *Primary Informant P2*

The primary informant (P2) was diagnosed with stage 2 breast cancer in October 2023 after experiencing pain that was initially thought to be a menstrual symptom. Upon examination, a lump was found, and the biopsy results indicated that her condition was severe. The informant felt depressed after receiving the cancer diagnosis, particularly due to the unclear information from the doctor regarding the stage of cancer she was facing, which she felt was related to the use of BPJS (Indonesian National Health Insurance). After starting treatment, P2 experienced physical changes, such as weight gain, hair loss, and fatigue. Emotionally, she often felt stressed, more vulnerable, and worried about her future. However, P2 remained motivated to recover for her children. She tried to accept her situation and surrender to God. During chemotherapy, P2 went through the process alone without family accompaniment, as her husband was working and her children were still in school. After joining the SAPKANDARA community, P2 felt more emotionally supported and received important information about cancer. SAPKANDARA provides support and education to patients and the community to prevent and understand breast cancer.

4.3 Primary Informant P3

P3, a woman diagnosed with breast cancer in 2014, initially noticed hardening in the area of her breast without any pain. P3 only sought medical attention after feeling weak, and at that time, she was diagnosed with stage 3 breast cancer. Before undergoing mastectomy in 2017, her cancer stage was reduced to stage 2. After the surgery, P3 underwent chemotherapy seven times, radiation, and took Letraz medication for five years to suppress estrogen and progesterone levels. Most of her treatment was covered by BPJS (Indonesian National Health Insurance), except for a few medications. Due to the treatment, P3 experienced several physical side effects, such as fatigue, hair loss, and soreness in the areas affected by the surgery. Emotionally, P3 experienced stress, anxiety, and profound sadness after losing her husband, who had always supported her financially and emotionally. She felt lonely and depressed after her husband's death in 2016. However, support from her children and friends, particularly her study group, helped her recover psychologically. P3 became active again in her study group after previously withdrawing for two years. Her children, particularly her daughter, played a significant role in accompanying her throughout the treatment process. They provided moral and physical support during routine check-ups and hospitalizations. After meeting with the Sapkandara group, P3 felt more open to sharing her experiences with fellow cancer patients, which helped her accept her condition. Overall, P3's journey highlights the importance of support from family, friends, and the community in helping cancer patients navigate their treatment and the adjustment process, both physically and psychologically.

4.4 Primary Informant P4

The primary informant, a breast cancer patient, was first diagnosed in December 2019 after discovering a lump in her breast. Despite having a good diet and rarely consuming junk food, she was confused about the cause of her illness. After the diagnosis of cancer, the informant tried alternative treatment for almost two years without any improvement; in fact, the lump continued to grow larger. The informant was afraid of undergoing surgery, so she chose to try alternative treatments first. After observing no progress, she decided to return to conventional medical treatment. She underwent an open biopsy that revealed a lesion, and the doctor recommended chemotherapy six times, scheduled every three weeks. After completing chemotherapy, the informant underwent surgery to remove her right breast, which took longer than usual because of her already frail physical condition. Following the surgery, she experienced a recovery period in the hospital and underwent radiation treatment 25 times. Although there was an initial improvement, a year after the surgery, she experienced shortness of breath and fatigue, leading to the diagnosis that cancer had spread to her lungs. The informant then underwent aspiration and additional chemotherapy abroad, where the doctor recommended switching the chemotherapy medication. The subsequent chemotherapy process involved eight sessions using a new, more intensive method. However, side effects such as low platelet counts and dental issues make the chemotherapy process challenging. The informant felt a significant emotional impact from the treatment, including changes in appetite and declining physical condition. Despite experiencing negative psychological changes, she strived to remain positive and actively engaged in religious practices.

The informant felt that support from her environment and family was vital. Despite weight loss and a lack of socialization due to the effects of chemotherapy, she felt surrounded by the care and support of her family. Throughout the treatment process, her family served as the main pillar of support, providing moral and spiritual encouragement to her. After six months of treatment, the informant began to accept her health condition and felt more motivated to recover. She also became active in teaching and organizational activities. Although the disease recurred, she remained grateful for the support of her family and friends, who helped her face the treatment process. The informant also expressed the importance of spiritual and social support in overcoming challenges during treatment. Hospital facilities, such as the presence of

Psychologists and religious counselors provided encouragement and advice that helped the informant cope with this difficult situation. Although the treatment journey is still long, the informant was determined to stay strong and hopeful for recovery.

4.5 Discussion

Based on this research, the authors conclude that medical therapy and psychosocial adjustments have a significant impact on patients with breast cancer. The informants (P1, P2, P3, and P4) who underwent treatment experienced physical, psychological, and social changes. Physical changes include health issues such as bone problems, fatigue, and hair loss due to chemotherapy, as well as decreased appetite and weight loss. Psychological impacts encompass negative emotions such as sadness, anger, stress, and feelings of mortality. Socially, patients tend to withdraw from their surroundings, reduce their activities, and are reluctant to share their conditions. This study emphasizes the importance of holistic support for patients, including medical, psychological, and social aspects. Although patients face difficult times in psychosocial adjustment after diagnosis, they can eventually adapt over time. This process is influenced by knowledge of the disease and family support. Some patients find motivation by meeting others with similar experiences in breast cancer community. Patients often hide their feelings and sadness, and psychosocial adjustments can take a long time to develop. Patient coping mechanisms are divided into adaptive (accepting) and maladaptive (denial). Patients with better knowledge of cancer find it easier to reach a stage of acceptance. This research also notes that the coping strategies employed by informants, such as sharing stories with fellow cancer fighters, praying, and engaging in positive activities, help alleviate the negative emotions they experience.

Support for patients with breast cancer is categorized into three types: existential, functional, and professional (Wiryasaputra, 2019). Existential support comes from the family, providing emotional support but often lacking a deep understanding of the patient's condition. Functional support comes from non-counseling professionals, such as nurses and social workers, who help patients regain functionality in their social lives. Professional support involves counselors or psychologists who assist patients in coping with the psychological impacts of the disease.

The research indicates that patients with breast cancer experience physical, psychological, and social changes, necessitating support from someone who can serve as a confidant and provide emotional support. However, this study found that family support is still not optimal, and professional support from psychologists or medical social workers is still minimal. Communities like Sapkandara play an essential role in providing support, particularly in terms of moral support and information, which is not always available from families or formal healthcare systems. Sapkandara also implements various empowerment programs, such as education about breast cancer and self-examination practices (SADARI). This study emphasizes the importance of holistic support for patients with breast cancer, which involves assistance from family, social workers, and healthcare professionals to enhance patients' quality of life. Government and policymakers must pay attention to the psychosocial needs of patients with cancer to ensure a more comprehensive healing process.

5. Conclusion

Research on the psychosocial adjustment of breast cancer patients post-therapy shows that a breast cancer diagnosis presents significant psychological and social challenges to patients. Patients experience physical changes, such as fatigue and hair loss, as well as emotional changes, such as stress and unstable emotions. Socially, they often withdraw from their environment. Psychosocial adjustment takes different amounts of time for each patient, depending on their knowledge of the disease and family support. The coping strategies used by patients include adaptive mechanisms, such as acceptance, and maladaptive mechanisms, such as withdrawal. A common strategy employed is emotion-focused coping, such as talking, praying, and engaging in positive activities. This study also highlights the importance of support for patients with breast cancer.

Existential support is typically provided by the family; however, families often do not fully understand the patient's condition. Functional support from medical social workers is also necessary; however, this study found that such support is still minimal, even though doctors and nurses play limited roles in hospitals. Communities like Sapkandara help fill this gap by providing information, moral support, and assistance during treatment. This study emphasizes the importance of support from various parties, including medical social workers, psychologists, families, and communities, in improving the quality of life of patients with breast cancer. Policy support is required to strengthen this assistance.

5.1 Limitation and study forward

This study focused solely on a small group of patients with breast cancer within the SAPKANDARA community in Medan, limiting the generalizability of the findings to broader populations. This research utilized a qualitative case study approach, which, while offering in-depth insights, does not allow for the quantitative analysis necessary to draw statistically significant conclusions. Additionally, the study relied heavily on self-reported data from participants, which could have been influenced by recall bias or personal perceptions. Furthermore, the lack of professional psychosocial support resources, such as medical social workers within the community, may have affected the psychosocial adjustment processes observed, potentially limiting the comprehensiveness of the support systems.

Future research could expand the scope to include a larger and more diverse sample of patients with breast cancer from multiple communities to enhance the generalizability of the findings. Conducting a mixed-methods study that combines qualitative insights with quantitative data could provide a more robust understanding of psychosocial adjustment in patients with breast cancer. Additionally, exploring the impact of professional psychosocial support, including the roles of medical social workers, psychologists, and counselors, could shed light on the effectiveness of more structured support systems. Finally, longitudinal studies tracking patients' psychosocial adjustment over an extended post-treatment period would provide insights into long-term support needs and adjustment patterns.

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