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Experience of Patients Post Mastectomy: A Qualitative Study



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Abstract

Background Inadequate psychological and emotional support for breast cancer patients after mastectomy. So that many participants stated that they still experienced self-confidence, fear, denial, body image, and rejection of their body changes. Therefore, the author is interested in conducting a study entitled the experience of post-mastectomy patients. The purpose of this study is to explore how patients experience after mastectomy.

Methods This study used a descriptive qualitative method with a phenomenological approach. The population studied was women with breast cancer who had undergone mastectomy. The sampling method was purposive sampling. There were six participants who participated in this study with predetermined inclusion criteria and exclusion criteria.

Results The results of this study showed five themes including: first, positive value. Second, postoperative risks. Third, changes in physical mobility. Fourth, sexuality barriers and fifth, mental readiness.

Conclusions In conclusion, this study provides an overview of the experiences of post-mastectomy patients and increases knowledge in helping to improve the quality of life of post-mastectomy breast cancer patients.

Keywords: breast cancer, experience, mastectomy, qualitative

Introduction

Breast cancer is the most common type of cancer in women and the leading cause of death from the disease overall (Jahan et al., 2019). Breast cancer is divided into two parts, namely invasive ductal carcinoma and invasive lobular carcinoma. According to global data, breast cancer is the leading cause of death in women and its epidemiology is growing

uncontrollably. The incidence of breast cancer is relatively high both domestically and abroad (Marfianti, 2021). Breast cancer is the leading cause of death, with 2.1 million cases in women. In 2018, there were 627,000 deaths from breast cancer. In Asia breast cancer accounts for 16.7% of all cancer cases (Bray et al., 2018; Sung et al., 2021).

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Mastectomy is a procedure performed under general anesthesia to remove lumps in the breast area. Problems faced before or after mastectomy include significant psychological and physical changes caused by breast cancer such as depression, anxiety, decreased quality of life, immune system dysfunction, hopelessness, traumatization, and fear of death (Tania et al., 2019). Patients usually experience problems with psychosocial well-being after a mastectomy. This is because individuals who have undergone mastectomy will experience problems with body image, lack of confidence, low self-esteem, altered emotions and sexual function. Because they believe that there is no guarantee that they will be cured of breast cancer, patients with this disease will also experience fear (Agung et al., 2016; Anggraini Dewi et al., 2023; Dharmayanti et al., 2020; Tri Puspita et al., 2017).

Methods

This research used descriptive qualitative research with a phenomenological approach. The study was conducted in HOT clinic from June 19, 2024 to July 3, 2024, at Gunung Jati Regional Hospital Cirebon. The population studied was women with breast cancer who had undergone mastectomy at Gunung Jati Regional Hospital Cirebon. The activity studied was the experience of post mastectomy patients. The data collection technique used purposive sampling as many as 6 patients. This research has been approved by the ethics committee with letter number No. 034/LAIKETIK/KEPPKRSGJ/VI/2024.

Results

This study involved post mastectomy clients totaling 6 (six) participants. The number of participants is in accordance with the saturation

The results of the literature review show that there has been no research related to the experience of post mastectomy patients in Cirebon City and until now there is no valid data related to the prevalence of patients with breast cancer who have undergone mastectomy. However, the results of a preliminary study conducted on patients with breast cancer who underwent mastectomy at Gunung Jati Cirebon Regional Hospital, which is a referral hospital in the Cirebon region, showed that 6 patients with breast cancer undergoing mastectomy who were interviewed said that in addition to the psychological, physical and psychosocial decline they also had some acceptance of their psychological, physical and psychosocial impacts. This study aims to explore more deeply how post-mastectomy patients experience. Therefore, the author is interested in conducting a study entitled “the experience of post mastectomy patients”.

The instrument in this research was a semi-structured indepth interview approach. Voice recorders, field notes with interview guides, and blank notes to record the participants' conditions, attitudes and facial expressions were the tools used during the interview procedure. The data analysis used in this study used an adaptation of Collaizi's method to determine keywords, categories and themes from the interviews conducted during the research. At the end of the research phase, the researcher followed up with the participants to get clarification on the identified themes to ensure that the findings were accurate.

of data obtained from the analysis of participants' answers. The participant characteristics table is as follows:

Table 1. Participant Characteristics

participant code	Participant	Age	Duration of Disease	Frequency of Post Mastectomy	Chemotherapy Frequency
P1	Ms. K	48	4 month	4 month	3 time
P2	Ms. E	32	4 month	4 month	3 time
P3	Ms. N	47	7 month	3 month	3 time
P4	Ms. D	29	2 month	4 month	3 time
P5	Ms. C	50	1 years	4 month	3 time
P6	Ms. K	42	1 years	5 month	1 time

Table 2. Characteristics of Triangulation

participant code	Triangulation	Age	Jobs	Relationship with Participants
T1	Mr. B	36	Labor	Husband Ms. E
T2	Mr. M	51	Labor	Husband Ms. N
T3	Mr. U	32	Trader	Husband Ms. D
T4	Ms. I	40	Housewife	Sister Ms. K





In this study, 5 themes were obtained related to the experience of post-mastectomy patients. The five themes include 1) Positive Value 2) Postoperative risks 3) Physical mobility changes 4) Sexuality barriers 5) Mental readiness.

Table 3. Theme 1

Code	Coding	Category	Theme
P1	Gratitude		Positive values
P6	Introspection	Acceptance	

Positive values. Participants showed a strong attitude of acceptance. They felt a sense of gratitude to be grateful for the opportunity to live that was still given by God. In addition, participants also understood how important it is to maintain a diet for good health. To prevent this from happening again, this caused participants to become more introspective. The following are some of the participants' statements that represent the perception category:

"...Yaallah I'm still given another chance to live, I don't like it..." (P1, Ms. K, 48 years old)
 "...The diet now has to be maintained, it's not like in the past, whatever you eat, now you have to be able to protect your body from disease, not everything can be eaten, it's like this." (P6, Ms. K, 42 years old)

Table 4. Theme 2

Code	Coding	Category	Theme
P2	Despair		
	Not confident		
P3	Depression		
	Social isolation		
P1			
P2			
P3		Impact of operation	
P4	Pain		
P5			
P6			
P1			Postoperative risks
P2			
P3			
P4	Stiffness		
P5			
P6			
P3	Fear of disease		
P5	Fear of death	Frightened	
P2	Traumatized		

Postoperative Risks. Participants who have undergone mastectomy surgery may feel insecure about their changed physical condition. They struggle to accept major changes, such as the loss of breasts, which greatly affects identity and self-image. They experience feelings of hopelessness and emptiness when depression strikes. They are also afraid of being judged badly by others

when they go out. In addition, they also often experience sadness which makes them feel helpless and confused about how to continue living. This can be seen from the participants' statements in the following interviews:

"...I was depressed, Yaallah how could I be like this, I once did not leave the house for 1 month, I did not do anything, finally my friends played at the house..." (P2, Ms. E, 32 years old)
 "...Yes, it's just like that so I don't dare to go out more. I don't feel confident, I don't usually hang out with friends..." (P1, Ms. K, 48 years old)
 "...Yes, it's hopeless. I mean, why was I given a disease like this, why do I have to be like that..." (P1, Ms. K, 48th)
 "...Yes, the sadness is like feeling hopeless because I have removed one breast..." (P4, Ms. D, 29th).

The same statement was also made by a triangulated participant who stated that his wife said she was sad because she lost her breasts. The following is an excerpt of the triangulation participant's statement from the results of the interview conducted.

"...yes the sadness of having to lose her breast..." (T1, Husband of Ms. E, 36th)
 "...I feel sad because there is no one breast..." (T3, Husband of Ms. D, 32 years old)

Participants who have undergone mastectomy surgery often have a fear of death and the possibility of the disease recurring. In addition, given the level of malignancy of the disease they are facing for their lives. These fears can also be exacerbated by personal experiences or stories from others who have experienced something similar, as well as by uncertainty about the effectiveness of follow-up treatment and long-term prognosis. This can be seen from the following interview results:

"...A disease called cancer is like a malignant disease, yes, I'm afraid, as a living person, everything is a disease but I don't know if the disease is this severe...(while crying)" (P3, Ms. N, 47th)
 "...Fear of recurrence of the disease..." (P4, Ms. D, 29th)
 "...Afraid of not being old like that, because the children are still young..." (P6, Ms. K, 42 years old)
 "...Most of them died so we cried, cried because they said it wouldn't be long..." (P5, Ms. C, 50 years old)
 "...Fear of traumatizing the child..." (P2, Ms. E, 32 years old)

The same statement was also made by a triangulated participant who stated that his wife and brother said they were afraid of his illness and death. The following is an excerpt of the triangulation participant's statement from the results of the interview conducted.

"...so my wife is afraid, afraid that the disease will grow again..." (T3, Husband of Ms. D, 32 years old)
 "...Yes, she is most worried that she can't be helped, what will happen to her child, what her husband is afraid of is her child, she thinks it's not long..." (T4, Sister of Ms. K, 40 years old)





Participants who have undergone mastectomy surgery often experience serious postoperative side effects. Significant changes are seen in body image which may have an impact on self-confidence. Feelings of stress and hopelessness may be frequent psychological effects that make it difficult for them to adjust to the changes and move on with their lives. The healing process may also be hampered by their feelings of isolation. Some also believe that their illness is incurable. As the following statement suggests:

"...Depression, yes, because I can't do everything, bad thoughts, dizziness, thinking about anything, food doesn't go in, so I cry and cry, I don't have the spirit to live like that, ..." (P3, Ms. N, 47th)
"...After the action, if I feel insecure, let alone with people, sometimes even with my own husband, sometimes I don't care, it's like, oh my God, how come I'm a woman like this without breasts, sometimes with my husband I like to be insecure..." (P2, Ms. E, 32 years old)
"...Yes, I don't trust myself like this, so seeing people can go anywhere now I stay at home and don't go anywhere..." (P3, Ms. N, 47th)
"...In the beginning, I was desperate, desperate, yaallah I can recover or not, can recover or not, ... (stroking chest)" (P2, Ms. E, 32 years old)

The statement was also made by a triangulated participant who stated that his wife felt insecure after undergoing mastectomy surgery. The following is a quote from the triangulated participant.

"...at first, yes, my wife felt like she was not confident, but the more here, thank God, the better..." (T3, Husband of Ms. D, 32 years old)

In addition, there are significant changes in psychological effects and self-confidence. Postoperative pain that occurs and lasts for a long time can affect their daily activities and quality of life in general. The following interview results can be seen below:

"...Yes, it's here, chest arm pain, so it's like the arm was still a bit numb yesterday. And now it still feels fast and furious...(pointing to the pain area)" (P1, Mrs. K, 48 years old)
"...There is a pain like itching inside, itching like that..." (P2, Ms. E, 32 years old)
"...If you are tired, you move a lot, pain..." (P3, Ms. N, 47 years old)
"...Yes, sometimes it feels like a twinge..." (P4, Ms. D, 29 years old)
"...Yes, sometimes..." (P5, Ms. C, 50 years old)
"...If it hurts, it's at the surgical site..." (P6, Ms. K, 42 years old)

The impact of surgery in addition to the feeling of pain that arises and persists, a sense of stiffness around the incision area may be caused by the side effects of surgery. The following interview results can be seen below:

"...When I first got out of surgery, I couldn't even shake my hair, I couldn't even do this, but when I sunbathed

"in the morning, I didn't move it, but there was a little numbness, even though mosquitoes didn't feel it...(while demonstrating)" (P2, Ms. E, 32 years old)
"...After the surgery, the hand was stiff and hard to move..." (P4, Ms. D, 29 years old)
"...Yes, it was stiff..." (P5, Ms. C, 50 years old).

Table 5. Theme 3

Code	Coding	Category	Theme
P1			
P2			
P3	Limited	Mobility	Physical
P4	Activity	Barriers	Mobility
P5			Changes
P6			

Physical Mobility Changes. Mobility barriers involve a number of factors that affect a person's ability to move or perform physical activities smoothly and efficiently. After undergoing a surgical procedure, participants often experience barriers such as limited activity. This makes participants not to do activities that make themselves feel uncomfortable and must be able to adjust to new activities now.

"...Maybe I get tired easily now. So if I'm tired, I rest and sleep..." (P1, Ms. K, 48th)
"...Activities are going on but limited, so what used to like to go out at night now I don't..." (P2, Ms. E, 32 years old)
"...I can't do anything, nothing, now I just worship first, I can't sweep, I can't do anything now..." (P3, Ms. N, 47th)
"...Before the operation I was selling, after the operation I didn't do anything, mostly washing dishes, sweeping..." (P4, Ms. D, 29 years old)
"...I rest, I don't work, my husband, my husband washes, sweeps, my husband cooks...(with a smile)" (P5, Ms. C, 50 years old)
"...Right now I don't do anything, I just sit and sleep and rarely go out...(look of acceptance)" (P6, Ms. K, 42 years old)

The statement was also expressed by triangulation participants who stated that the wife's daily activities were partly replaced by her husband due to activity restrictions. The following is an excerpt of the triangulation participant's statement from the results of the interview conducted.

"...Yes, it is replaced by me, every day I cook, wash, take care of my wife, I don't even work..." (T2, Husband of Ms. N, 51 years old)
"...Yes, sometimes she replaces me, she is sick..." (T3, Husband of Ms. D, 32 years old)

Table 6. Theme 4

Code	Coding	Category	Theme
P1	Not		
P2	Confident		
P3			
P4	Natural	Sexuality	Sexuality
	Thing	Behavior	Barriers
P5	Distance		
P6			





Sexuality Barriers. A person's sexuality behavior includes various aspects that represent their habits, preferences, and interactions in sexual and interpersonal situations, as well as the factors in which these aspects affect their relationships in general. Their past circumstances and experiences may have an impact on these sexuality behaviors. The following interview results can be seen below:

"...Yes, maybe this is mas as long as I've had surgery, I'm sorry I haven't done it again? Yes, because I don't feel like it. So I'm not sure, but fortunately my husband understands, so I haven't done it again like that. After all, I don't understand how it will be. But for now I don't want to. I don't feel confident yet, I don't feel confident yet. But my husband understands..." (P1, Ms. K, 48 years old)

"...Well, I guess I'm the one who doesn't enjoy being a woman, isn't it true, the name doesn't have any breasts...(laughing smile)" (P2, Ms. E, 32 years old)

"...Yes, it's not like it used to be, it's just less passionate...(shy face)" (P4, Ms. D, 29 years old)

"...It's already like this, it's normal, my husband doesn't get angry..." (P3, Ms. N, 47 years old)

"...No, I haven't done it for a long time..." (P5, Ms. C, 50 years old)

"...I don't know yet, because I feel sorry for..." (P6, Ms. K, 42 years old)

The statement was also expressed by triangulation participants who stated that there were differences regarding sexual behavior. The following are excerpts of the triangulation participants' statements from the interviews conducted.

"...Yes there is, but I also understand that my wife is like that, so it's okay..." (T2, Husband of Mrs. N, 51 years old)

Table 7. Theme 5

Code	Coding	Category	Theme
P1			
P3	Appearance	Self	
P4	Change	Rejection	
P6			Mental
P2			Readiness
P5	Acceptance	Self	
		Acceptance	

Mental Readiness. The rejection of the self towards changes in appearance makes participants look for efforts to cover up their shortcomings. According to participants, they have to cover up their shortcomings in various ways so that these shortcomings are no different from before. The following is a statement of participants experiencing self-rejection taken from the interview results.

"...Yes, I'm right, sorry, I used to wear bras that didn't need to be padded, but now I have to wear bras so it's a hassle, it's just a hassle to take it off, take it off, I use the hijab, I have to be able to get around. for example, the rectangular one has to be tilted so that it can cover the deflated one ..." (P1, Ms. K, 48 years old)

"...The difference is from clothes, hijab or what to wear, it has to be long-sleeved, in the past wearing hijab could be neat or what, now it's not, it has to be all covered now, you can't wear short-short ones, so it doesn't look like it's covered, if you wear a short veil there's no one side, it's ugly so just go with it..." (P3, Ms. N, 47 years old)

"...For example, everywhere I go, I wear a hijab that covers my chest so I don't look like that..." (P4, Ms. D, 29 years old)

"...Yes, if you don't have this, use anything to make it good, use foam or something..." (P6, Ms. K, 42 years old)

The statement was also expressed by triangulation participants who stated that there were differences in the way they looked. The following is an excerpt of the triangulation participant's statement from the results of the interview conducted.

"...so if you go anywhere, you have to wear something covered..." (T3, Husband of Ms. D, 32 years old)

Some people eventually accept themselves, which is characterized by a deeper understanding and appreciation of themselves. The following interview excerpts are taken.

"...It's just normal mas, yes, I'm still like this, so that's why your people are like this, style bae, I'm like this mas, so you're sick like a person who's not sick, col, I'm like this then what..." (P2, Ms. E, 32 years old)

"...Important, just yes wes mengeneken...(while laughing)..." (P5, Ms. C, 50 years old)

The statement was also expressed by the triangulation participants. The following are excerpts of the triangulation participants' statements from the interviews conducted.

"...no, I think it's normal..." (T1, Husband of Ms. E, 36 years old)

Discussion

This study found that patients who have undergone mastectomy appreciate their experience and express their gratitude and accept sincerely everything that happens to them and ask for a way to ask for healing and feel relieved after the disease. Acceptance that involves introspection can have a significant positive impact on patients' psychological well-being. An attitude of patience, resignation, sincere acceptance of the situation and gratitude for the existing circumstances. Understanding that everything we have is a gift from Allah SWT (Jatimi et al., 2020).

Participants who were in this situation realized their shortcomings and chose not to dwell on them in order to be rated as having excellent self-acceptance which is a real acceptance of their circumstances and the ability to have a better life in the future. Acceptance is the result of the ability to face reality and not just give in





to despair. This is in difference with research research by Irfan & Masykur (2022) showing that strong social support from family and friends plays an important role in accelerating the process of self-acceptance in women after mastectomy.

Postoperative risks are risks that must be faced after performing mastectomy surgery. Risks associated with this include possible infection, discomfort, bleeding and swelling at the surgical site as well as patients may experience an abnormal body image which can adversely affect their mental and emotional health. In general, one of the most basic human feelings is the fear of illness or death.

This is also in line with research conducted by Mastura *et al* (2022) which states that nursing problems that arise when caring for patients with postoperative breast cancer include discomfort, risk of infection, compromised skin integrity, decreased physical mobility and deficiencies in self-care. Patients who have undergone mastectomy are at risk of experiencing problems with their body image having difficulty adjusting emotionally to major physical changes and experiencing other psychological harms that reduce their overall quality of life (Chang *et al.*, 2021).

The study also found that participants experienced significant changes in their physical mobility towards daily activities leading to adjustments in physical activity limits such as doing household chores. Some also experienced decreased participation in social activities and hobbies they previously enjoyed, with a greater focus on rest and self-care. The results highlighted the significant impact of mastectomy on daily quality of life with many participants experiencing changes in their independence and domestic roles following surgery.

After undergoing mastectomy, patients require targeted rehabilitation care to help them restore physical mobility and improve their quality of life. To reduce the unfavorable effects of postoperative physical changes, this strategy combines appropriate pain management with physical therapy that includes strengthening and stretching exercises (Chang *et al.*, 2021). In the other hand, Lacomba *et al* (2010) found that early physiotherapy therapy can be beneficial in decreasing the likelihood of side effects including breast engorgement and increasing the range of motion of post mastectomy patients.

In this study, it was also found that there was a sense of insecurity and uncertainty in performing intimate activities post-surgery, feeling not ready or not sure to do it again. However, they were relieved that their partners

understood the situation and provided the necessary support. There were also expressions about the changes in the experience of being a woman without breasts affecting their confidence and arousal. Nonetheless, they emphasized that their husbands did not object or feel angry about the situation, despite the pity that arose in that context. This damage can be exacerbated by partners' sexual expectations and behaviors, social attitudes towards the disease and negative views of cancer survivors (Fouladi *et al.*, 2018).

However, this is in contrast to research conducted by Huberts *et al* (2023) which showed that patients often do not get enough information about how undergoing a mastectomy can disrupt their sexual life or coping mechanisms. They are also aware of their physical strengths and weaknesses that symbolize femininity, sexuality, resulting in an "imperfect" body.

This study shows that there is discomfort experienced in using a bra that must be given additional foam or cloth to cover the missing part of the chest which makes it feel troublesome because it has to take off and put on the bra frequently. In addition, they also have to adjust how to wear hijab, choosing a rectangular hijab that can cover the chest well and choosing clothes with long sleeves and that are not tight to hide their physical changes. Self-acceptance of one's appearance after mastectomy has been identified as an important component in the psychological adjustment process.

Research similar to this was conducted by Kocan & Gursoy (2016) a person's body image can be negatively affected by changes in appearance which can result in a number of psychological problems. Some people who reject changes in their physical appearance after mastectomy often experience psychological difficulties feeling a loss of identity and unable to accept these changes as part of themselves. Research shows that those who achieve a high level of acceptance of their physical changes usually experience an improved quality of life and are better prepared to cope with life after mastectomy (Wender, 2020).

Conclusion

In this study, the experiences of post-mastectomy patients were discussed in five main themes based on the results of the interviews. The themes found include positive values such as self-acceptance which includes gratitude and introspection. Postoperative risks



included physical complications such as pain, stiffness, and impaired body image that significantly affected quality of life. Changes in physical mobility were also a cause for concern as many patients stated that they felt less energetic and needed to change their daily activities. Physical and psychological changes that impact on personal relationships and self-confidence can create barriers to sexuality. Changes in appearance also underlie the self-denial and self-acceptance of how they look after surgery. It is intended to advance knowledge about the experiences of post mastectomy patients and provide more comprehensive care and improve mental preparedness in the face of physical changes and social pressures that impact on self-perception and daily functioning.

Limitations

In the process of conducting this research there were some limitations in the research procedure that may have impacted the results of the study, including Participants' lack of ability to understand statements during the interview and participants may have felt uncomfortable during the interview.

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Author's contributions

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: IY, SS, HSM, AM, TH; Involved in drafting the manuscript or revising it critically for important intellectual content: IY, SS, HSM; Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content: IY, SS, HSM, AM, TH; Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: IY, SS, AM. All authors read and approved the final manuscript.

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Availability of data and materials

The data that support the findings of this study are available from the corresponding author, [IY], upon reasonable request

Declarations

Ethics approval and consent to participate
Not applicable

Competing Interest

The authors declare no competing interest

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