

RESEARCH ARTICLE

Process of Coping with Mastectomy: a Qualitative Study in Iran

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Abstract

Background: Breast cancer is the most prevalent cancer among Iranian women and mastectomy comprises 81% of surgeries for treatment of breast cancer. Mastectomy may create feelings such as deformation or impairment in patients, cause body-image disorder, and reduce sexuality and sexual activity which in turn may entail mental disorders. The study aimed to elaborate coping processes. **Materials and Methods:** A grounded theory method was used in conducting this study. Twenty Iranian participants undergoing mastectomy were recruited with purposive sampling. An open, semi-structured questionnaire were developed. Obtaining consent, conversations were recorded and immediately transcribed after each session. Data analysis was carried out with the constant comparative method using the Strauss Corbin approach. **Results:** Analyzing the collected data, the study came up with seven main categories which affected the coping process in patients with breast cancer, namely: reactions to mastectomy; loss and death contest; reconstruction of evaluation system; consent for undergoing mastectomy; reactions and troubles after loss; confrontation of loss and health; and reorganization and compatibility with changes. **Conclusions:** The results of the study indicated: when patients become informed of their breast cancer and the necessity of undergoing mastectomy as the treatment, they probably pass through seven categories to adapt after mastectomy. Having insight about them is likely to contribute medical personnel in leading patients to the highest degree of feeling healthy.

Keywords: Breast cancer - mastectomy - coping - grounded theory - Iranian patients

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Introduction

Breast cancer, as the most widespread type of cancer among women, is the major reason of cancer death in 20-59 aged women. Today the disease is increasingly spreading all around the world and it is holding the highest position, after lung cancer, as the most prevalent cause of cancer death in females. The incidence rate for breast cancer in the studies undertaken all around the world has been reported 12.5%; it means, it is probable that one in every eight women to be at the risk of having breast cancer during her lifetime (Brunicardi et al., 2010). The cancer, with incidence rate of 22.6%, is the most commonly occurred type of cancer in Iranian females (Fazel et al., 2008). It is worth mentioning that, similar to other states of Middle East, the average age of the sufferers in Iran is 10 years lower than other areas in the world (Brunicardi et al., 2010).

Different methods for treating the disease can be used which may vary according to the degree of its severity. These methods involve surgery, radiotherapy, and chemotherapy (Lynn et al., 2006). Due to non-screening in Iran, individuals with breast cancer are ordinarily diagnosed when they are in the advanced stage of disease (Brunicardi et al., 2010). Therefore, it

stands to logic to argue why 81% of the surgeries done for treating the cancer are of mastectomy type (Fazel et al., 2008). Mastectomy can influence the physical, psychological and social aspects of the person. Following mastectomy, the patient is probably to suffer from pain, fatigue, body-image alteration, stress or depression, and self-confidence decrease (Harmer, 2000). It is also likely the patient to become deeply dependent on others, as a result of undergoing mastectomy. Change in occupational status is another aftermath which may happen, such a change has the potential to affect the relationship between patient and her family or society (Kraus, 1999). Crouch and McKenzie's work (2000), entitled as social realities of loss and suffering following mastectomy, revealed that patients undergone mastectomy suffer from feeling of not having body balance which is a major factor in physical attractiveness, and lack of mental peace as a key indicator in mental attractiveness because of fear from disease recurrence and death hazard. Both factors result in reduction of quality of life to a great extent (Crouch et al., 2000).

Quality of life is a feature which is subject to the way one copes with status quo. According to studies run, African- American women with breast cancer make use of several mechanisms to conform to

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mastectomy including saying prayers to God, avoiding interaction with pessimists, adopting positive attitude, and seeking protection from family, friends and supporting communities (Henderson et al., 2003). Ching et al. (2009) in their study, identified reconstruction as the central category in psychological conformity process of Chinese women with breast cancer. They found out the participants, in order to cope with the disease, used “fighting”, “struggling” and “tolerating” strategies (Ching et al., 2009). Similarly, Talegani et al. (2008) investigated coping process in women with breast cancer, and the following categories were elicited from the data: threat for life, religious aspects, supporting dimensions, interest in recovery, inhibiting factors against regaining health, tolerance increase, getting along with disease using facilitating and inhibiting factors affecting tolerance. All the aforementioned investigations and other similar studies have concentrated their focus on the process of coping with disease and mostly have turned a blind eye to the process of coping with therapeutic methods like mastectomy, whereas coping with mastectomy and consent for it has been of main concern in breast cancer and might entail a lot of challenges (Taleghani et al., 2008). Thus it seems necessary to conduct a study for identifying factors affecting consent for mastectomy and delving into the process which a patient goes through until she agrees with performing mastectomy and adjusts herself with changes resulting from it. Recognition of those factors may give way to improvement of the conditions for convincing the patients to undergo mastectomy. Moreover, in the least time, it may lead the patients to consent for mastectomy, restart their ordinary life, and adapt themselves with the alterations in their mental image.

Materials and Methods

The present qualitative investigation intends to unfold the process of coping with mastectomy in patients with breast cancer who had undergone mastectomy.

Since the quantitative methods is unable to respond the questions related to background, howness or whyness of, and incentive behind the individuals behaviors, the present study was conducted adopting grounded theory method to gather deeper information by investigating them and using the instruments employed in qualitative methods (Rich et al., 1999). The main purpose of grounded theory studies is to illuminate and examine the social process under question in the developing theory (Dempsey et al., 2000).

The study was undertaken over 20 Iranian women who had undergone mastectomy or lumpectomy following being recognized for having breast cancer. In as much as interview is the most current data collection instrument in qualitative methods, and interviewing with open ended questions offers the participants the possibility to express the feelings experienced on the phenomenon under study (Sasali et al., 2003). In this research study the data was gathered using semi-structured interview. A few general open-ended questions were developed which assisted the researcher to maintain the flow of conversation during interview. Prior to interview, the participants were

informed on the purpose and the method of the study, so that they could opt for staying in the study or giving up. Effort was made to establish rapport with them in order for trust to be built between the researcher and them. Initially, the participants were asked about the way their disease was recognized and the length of interval between the noticing the lump and the final recognition of the disease by the physician. Subsequently, the patient and her relatives reaction's to suggestion of mastectomy by physician and her consent for and adaptation with it were discussed. With respect to the participants' opinions, sometimes some modifications were made in the form of the questions and attempt was made to elicit more precise information by clarification requests such as could you explain more, give an example please, could you tell me what you exactly mean.

For obtaining in-depth information, interviews were done in the open form. Although the researcher was trying to maintain the flow of interview, she avoided directing the participants' responses toward a particular track. Interviews were recorded by audio recorder and transcribed immediately following each session.

Analysis and coding of each interview was done before beginning of the next interview, in a way that each interview's direction was determined by the prior interview's information. The analysis of the data was carried out via coding in two stages: open coding and axial coding. At the first stage, the researcher, reviewed the data line by line and identified the processes, broke the data into meaningful pieces, coded each main sentence (Sasali et al., 2003). At this stage primary classification of the codes was performed. Similar codes were classified together, through which totally 878 primary codes were obtained. After complete and careful review of them, similar items were coalesced and ultimately were reduced to 157 codes.

In this stage the participants' main sentences were elicited and coded. The researcher recorded the inductive codes based on the data. Axial coding was the next stage, which during it data was directed at meaning and classified according to the pattern that presented itself examining the data (Sasali et al., 2003). In the present study, during coding stage, the similarity and discrepancy of open codes were found. Conceptually similar codes were put together and the related codes formed a common category. Put differently, during this stage, the categories were revised and refined.

Ethics of study

Effort was made to observe the ethics of study, offering the participants the choice to give up whenever they wish, and by keeping their information private. The participants were assured about unanimity of their identities. For this purpose each participant was given a code.

Results

The participants of the study included 20 women with breast cancer, aged from 33-71. They underwent mastectomy. The results, obtained from analysis of the data, offered 7 categories relating to coping process in

patients undergone mastectomy which will be discussed as follows:

Reaction to mastectomy

One of the elicited categories in the present study deals with reaction to necessity of undergoing mastectomy, which encompasses the subcategories of different reactions and effective categories on each reaction. The participants produced disparate reactions as the first reaction to mastectomy which can be classified in two branches of emotional and behavioral. *"The day we took the test result to the doctor, and found out I had breast cancer and had to have my breast cut, didn't take it serious, I was thinking the doctor was kidding. Back to home, I was slowly getting what had happened. I was feeling like hell, so I started to cry"* (P16).

"I and my brother took the test result to the doctor and she said: "you have breast cancer and must get surgery. We have to remove your breast ". But my brother didn't believe. He said: maybe it's because of lab's mistake, you should retest". I gave test again and waited about one week for the result but it was the same as the first one. Then we took it to another physician' (P4).

According to the participants' reports, there are some factors that can influence the patients' reaction to mastectomy either by intensifying or modifying them, namely: Family and friends support, religious believes, impact of surgery on the individual and her family's future, and the way a physician behaves.

Encounter of loss and death

The other category induced from the results, was the loss and death contest, in which the patient was to choose between two alternatives of being alive and breast removal: *"Doctor said to me if I wanted to get rid of the disease, I had to let my breast be removed. She said I was obliged to do that cause if I didn't do that, it would spread to all parts of my body and would kill me. As there was no choice, I decided not to die only for a breast"* (P10).

The supreme importance of being alive and healthy compared to having breast was determining in this battle: *"Cause I was very scared of cancer, I had to agree. In spite of feeling down, I consent for doing surgery only because of my health"* (P 16).

Reconstruction of evaluation system

Another identified category refers to reestablishing the evaluation system by patient herself. It is obvious that following being informed about having breast cancer and the obligation of performing mastectomy as the only possible choice for its treatment, the patient encounters with the dilemma of being alive with some changes and losing her life. Hereupon the patient needs to refer to her inner self and review all of her value realities to get along with the therapeutic process of mastectomy and decide upon becoming healthy and saving her life. The statements of one of the participants verify this claim: *"When one loses her health, it doesn't matter how beautiful she is. I mean when you are patient, you won't care about appearance"*.

Presence beside spouse and children makes remaining

alive at the expense of breast loss worth for her. *"For a moment I imagined my children motherless, this thought made me crazy. I said to myself. I'll get the surgery and I must be by my children"* (p. 6).

Consent for mastectomy

The category of consent for mastectomy is affected by variables such as family or friends support, the patient's personality type, physicians' advice, incidence of the disease in a family member in the past, patient's level of education. Of the determinant factors in making patient accede performing mastectomy was pertinent to her husband's support. Adequate and wholehearted support from husband can speed up the time the patient spends on deciding upon consenting for mastectomy. *"I was going to have surgery by the next week, during that week I had my continuous support from my husband, he encouraged me to do surgery. He told: if you get surgery, you can regain your health. I wouldn't like you lose your life only because of having breast, I want you to stay alive"* (P19).

Personal factors like the patient's personality type can affect patient's consent for undergoing mastectomy: *"I am very adaptable and tolerant. These characteristics made me give assent to have surgery without any problem"*(P4).

Observing disease in close relatives and acquaintances can play an influential role in convincing the patient for getting mastectomy. Since being in contact with the side effects of disease and its late treatment in an individual who one knows might increase the patient and family's sensitivity and cause them to take an immediate action for performing mastectomy. *"It was only 5 days after the surgery that my sister got for her breast cancer, when I found the lump in my breast. I and my father referred to a physician immediately. She said probably you'll have to perform surgery. I felt blue but I didn't want to suffer like my sister and to let my disease spread"*(P8).

Having academic education particularly related to medicine and obtaining information from internet by some patients can be helpful in their quick decision making for performing mastectomy. *"I was deeply sad, only searched for something about breast cancer and doing surgery in the internet. To be honest, I was to know if there were any other ways for its treatment than surgery or not. When I felt sure that I had no other choice and when my niece who is a midwife said that undergoing surgery is its only cure, I made my mind to get the surgery as soon as possible"* (p.19).

Believing in the will of God is one of the points accentuated recurrently by participants as a factor that can help the patients consent for mastectomy and get along with it. They believe that incidence of the disease is upon God's will and is part of the destiny that God has determined for them. *"I tried not to be very grief- stricken. Told myself it is divine fate. Actually I'm a religious person and think by being extremely sad, will commit a sin"* (p.4).

Reactions and problems after loss

Following mastectomy, the patients' reactions vary depending on their physical, mental, financial, and supportive conditions. These reactions are classified under individual problems category involving change of your

mental body image and reaction to it, the effect of loss on family members and financial problems. Generally most of the patients following mastectomy and loss of one breast or both or even part of it (lumpectomy), set off reactions in the form of depression, crying, abstaining from eating, and sexual relationship shift, because of physical change in appearance and their mental body image alteration. These reactions may seem somehow normal in the primary stages following mastectomy, but after a relatively long period and in the severe cases, it should be taken as a serious mental problem resulting from incompatibility with the new situation. *"After recovery, seeing my breast removed, cried. I was feeling sad, extremely sad. My daughter said to the doctor I was deeply sad and kept crying. So doctor prescribed Nortriptyline (anti-depression drug) when she was releasing me. I had become seriously depressed and was crying all the time. But little by little, the effect of anti-depression drugs made me easy-going. Now that I recall those days, I find out that without those medicines, my condition would become worse"* (p.9). *"After surgery, the first time I took a bath and saw myself without breast in the mirror screamed and shouted. It was like I was going crazy. No one could soothe me. For three months, I was lamenting in the way that if you saw me you'd think I had lost a beloved"* (p.16).

The above mentioned points imply the very key issue that some patients, after mastectomy, produce extreme psychological and emotional reactions. These reactions are because of their mental image change. Some patients suffer from emotional tensions and think that they have lost all the signs of being a female, following physical change resulted from mastectomy. This problem can be mentioned as the most serious and terrible type of mental image change following mastectomy. *"To tell the truth I hate myself. It is two years I've had surgery but still whenever I look at myself I get sad. I'm thinking about it all the time. My breast has become malformed. It seems I'm not a woman"* (p.16).

The effect of the loss on family members causes other problems and reactions. Sometimes, after mastectomy, the reactions on the part of patients' children or husband can exert destructive effect on her coping ability. *"Now my son is depressed, because I have done surgery and I am receiving chemotherapy. I can remember my daughter tears the day after surgery. I felt extremely heavy-hearted. Now that I remember that day, still feel bitter"* (p.7).

In addition to individual reactions and problems after loss, there are also financial problems. Having financial support system could have positive psychological state on the patient, after undergoing mastectomy. Because, affording costs of surgery and therapies accompanied with it, such as chemotherapy and radiotherapy, sometimes can put family under considerable financial pressure and may in turn affect the patient's treatment process and her psychological state, it can be considered as one of the major problems of some patients after mastectomy. *"At first I was sad and lamented all the time that why they removed my breast, but later under constant financial pressure I forgot my breast loss. I wasn't even caring for my health any more. Was looking for a way to make money or borrow from someone. May be if there wasn't such a*

financial pressure, I would feel much more better" (p.15).

Contrast between loss and health

The sixth category elicited in the present study denotes the confrontation between loss and health. Following mastectomy, chemotherapy and radiotherapy sessions (if necessary) the patients usually attain adequate level of health. The relative and sometimes complete health restoring can have beneficial effect on the patients' state. The patients in this case thank God for being alive and regaining their health. They remind themselves that it was worth being alive and healthy at the expense of undergoing surgery and breast loss. *"I feel happy that I have got my health back. Nothing in the world can be as valuable as health, for human being. Thanks God"* (p.3).

The effect of the confrontation on some patients is to the extent that they interpret regaining health after mastectomy as a chance for coming to the world again and beginning a new life. *"After surgery and chemotherapy, I thought that God has blessed me with a great chance for staying alive; it was like I was born again and have got another chance for living"* (p.16).

Some patients place more value on their health than the time the disease hadn't occurred to them, and take regular referring to physician and acting performing according to her prescription and advice more serious than before, in order to regain perfect health and feel more joy and tranquility through restoring their health and confronting loss with health. *"I feel like I was born again after surgery. Now I appreciate my health more than before. Thank God... I refer to doctor on time. My chemotherapy sessions were great. When the doctor says I am in better condition and healthier, I forget all of my grief. Happy I'm healthy again"* (p.6).

Compatibility with changes and reorganization

The last category is compatibility with changes and reorganization and their subcategories make reference to factors that affect them. These factors in turn are under effect of many other determinants such as husband and relatives' support, the role of physician in patient's consent for mastectomy, time elapse, religious believes, patients' comparing herself with other women in similar condition, the degree of changes taken place, being financially able, making use of strategies that contribute to pushing negative thoughts out of mind (like listening to happy music and songs, and travelling,..).

Feeling healthy and confirming by physician could play a key role in compatibility with the changes produced as a result of mastectomy: *"the doctors' words made me calm. She said I looked better and my health was back. Because I was afraid of my disease progress, I have great feeling now"* (p.8).

Making the patients face with women similar to themselves is one of the main factors in compatibility with breast loss. It is easier and more desirable for patients to gain sympathy from a similar group than any other people. Time elapse and its effect on patients' adaptation to lack of breast, is one of the cases which has been repeatedly mentioned by the patients: *"In the beginning, I was feeling terrible, because my breast was removed. My husband*

and daughter were entertaining me. We went to picnic or sightseeing. I studied Quran. Doing these sorts of activities I was trying not to think about it. Now, two years after surgery, everything is ordinary. Sometimes, I even don't feel my breast is removed" (p.9).

Less amount of changes occurred after surgery is another effective factor which aid patients adjust to these changes. This factor has been mentioned by the patients who had lumpectomy. "After surgery and recovery, when I touched my breast and saw that only part of my breast was cut, I become very happy and burst into tears" (p.8)

Having a family with adequate financial situation and relatives' support, or making use of insurance services are effective factors in mental peace, keeping therapy, non stop of therapeutic process, and improvement of patients and their relatives' moods. "No financial pressure from my family and I received chemotherapy and radiotherapy free of charge, Because we had armed forces insurance. I saw some patients said that they didn't receive chemotherapy because they didn't have enough money. But I always went on time. It is awful to lose your health for not having money" (p.9).

The patients expressed that emotional support by their husbands is an effective factor in their return to an adequate mental state. Unequivocally, husbands as the romantic partners of women by their emotional support after mastectomy could perform a principal role in alleviating the patients' suffering. By the same token, their sympathy and accompany with women during treatment process and after that is of great importance and contributes to improvement of the patients' physical and mental states. "My husband supported me that well that I could find myself sooner than you can imagine. He said to me I and the children need you. You, yourself, are important to me is, not your breast" (p.19).

Reorganization after mastectomy and mental image modification using aesthetic techniques such as prosthesis, jelly bra,... are subcategories of this category: "That's right my husband is a faithful and very good man and supports me well. But it doesn't mean I shouldn't use the possible ways as such surgeries" (p.12).

At times the patients attach such an importance to performing aesthetic surgeries and inserting prosthesis that they ignore its high cost and its need to anesthesia and assume it as the only way to adapt and return to acceptable mental state and clear the disordered mental image. "My husband told me I must care for my health than beauty. But the truth is I'm hopeful about prosthesis and I have to insert prosthesis. Nobody can make me give up thinking about it" (p.16).

Discussion

The findings of the present study included five categories which affect consent for mastectomy and compatibility with changes followed by it in patients with breast cancer. The present study reflected that the reactions of patients to mastectomy comprise emotional and behavioral elements. To mention some of them we can refer to sadness, fear, being preoccupied with obsessive thoughts, seeking for other therapeutic techniques,

referring to numerous physicians for affirming the disease and the essentiality of performing surgery. Khademi et al. (2009) in their study found that breast cancer exerts extreme psychological effect such as sadness, feeling fear and stress for death and mastectomy (Zeyghami et al., 2009).

Seeking for other therapeutic techniques other than mastectomy has been reported many times by participants in the present study and is of common behavioral reactions when the patient learns of her breast cancer and her need for mastectomy. Engle et al. (2004) in their study, found that many patients assume they would experience a situation like organ removal after mastectomy. For this reason, they often look for treatments other than mastectomy not to lose the organ which is sign of being female and mother for them (Engle et al., 2004).

The confrontation between loss and death was another elicited category from data. The most common predicted loss for single women was having problem in getting married, and for married ones was fear of not being attractive for their husbands anymore. Zeyghami et al. (2008) conducted a study and discovered that the women with breast cancer who were aged between 33 and 43 and had mastectomy, were of lower level of quality of life. In the present study, young and single women mentioned their concern over the effect of mastectomy on their marital life in future as one of basic and effective factors on mastectomy. On the contrary, married and elderly women produced more adequate reaction to cancer and mastectomy (Zeyghami et al., 2009).

Concern over sexual problems and conflicts arising from them after performing mastectomy was of the prominent factors which could affect type of patients' reaction to mastectomy and was placed in this subcategory. Schover (1997) stated that the main preoccupations of the patients included being afraid of facing sexual problems after undergoing mastectomy and their concern over effect of mastectomy on their sexual life (Schover, 1997). Anllo (2000) and Bakool (2006) revealed that shock of being recognized for cancer and its treatment exert major effect on physical and mental states of the patients' sexual relationships (Anllo, 2000; Bakewell et al., 2006).

Reconstruction of evaluation system was another category in the present study that we came up with it. Fear of metastasis and death, accepting occurrence of disease as part of ones' divine fate, placing premium upon health, early reference of the patients to physician and getting mastectomy. Classification and reevaluation systems call for aid from their spiritual believes and confront with their fear of cancer.

Moreover, the relatives' and particularly husband's support from patient were recognized as major factors in keeping medical process and adapting to mastectomy. Physicians' directions along with bringing about peace for patients are determining in consent for getting mastectomy which itself in turn produce major effects on patient and her family and lead to swift consent for mastectomy.

Khademi et al. (2009) Identified religious background, family and medical team's support from patient, gathering information about disease and physician's advice as effective factors in taking action to treatment and tackling

crisis (Khademi et al., 2009). Arman and Rehnsfeldt (2003), in their study, came up with husband and family support as a basic factor in choosing the right way in therapeutic process and compatibility with mastectomy (Arman et al., 2003).

One of other of the other categories obtained in the present study was the reactions and problems after loss which was classified into three subcategories of personal and financial problems and the effect of loss on members of family. Moreover, feeling deficient and being different from other women and mental image alteration were identified as other common reactions to mastectomy which could affect all the dimensions of patients' life in a negative way. Fazel et al. (2008) argued that women undergone mastectomy because of disorder in their mental body image can become preoccupied with extremely obsessive thoughts which may entail their continuous psychological tension and stress.

Long term emotional tension sets the scene for compatibility disorders, inability in controlling emotions, stress and depression (Fazel et al., 2008). Interaction between loss and health was another theme that I come up with it in the current study. Necessity of health regain and feeling healthy after mastectomy cause the confrontation between loss and health. As following mastectomy and mental image alteration, patients suffer from tensions. Curing the disease, restoring health and alleviating disease symptoms can result in acceptable level of mental and psychological health in patients. The findings of Shaban et al. (2004) revealed that there was a significant relationship between pain severity of cancer and quality of life. Pain relief, feeling light-hearted and restoring health can reinforce feeling healthy and ultimately promote quality of life in patients (Shian et al., 2004).

Compatibility with changes and reorganization is the last category elicited from the data. Strong and effective supportive systems like family, spouse, physician, having relationship with other women who had already undergone mastectomy, financial supports, and ... can considerably contribute to compatibility with changes. This finding is consistent with Andolhe et al.'s (2008) study outcome, in which it was indicated adequate social support can meet the needs of women undergone mastectomy and improve their quality of life. These women need other people's support to adjust to the new situation. Theses individuals and groups could involve family members, friends, and other members of health team or similar patients. Additionally, those women who gain the full emotional support from their children will enjoy better physical and emotional state (Andolhe et al., 2008).

The results of the present study indicated that in reorganization following mastectomy, the patients try to modify the changes occurred as result of mastectomy, by using special coverings, or jelly bras, or prosthesis surgeries. Jaeun Pake (2000) conducted a study in South Korea and explored that the women who used jelly bras benefitted from more ideal state of mental image and self confidence. This case could positively affect sexual relationship and lead to satisfaction with life (Fazel et al., 2008).

In conclusion identifying the undergone process for

coping with mastectomy could help to medical personnel in directing the patients with mastectomy to find highest degree of feeling healthy.

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