

Qualitative Inquiry into Determinants of Decision Making for Therapeutic Mastectomy Amongst Pre and Peri- Menopausal Women, at Urban Gujarat

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Abstract:

Introduction : Breast Cancer (Ca Br) is one of the most common cancer amongst women globally as well in India. Amongst various available modalities of treatment, the most common treatment being advised in Ca Br is mastectomy which is commonly associated with a lot of emotion and mental challenges. For Ca Br patients, any decision in this regard forms an integral part in the diagnosis, confirmatory and treatment phase. The present study aims to explore the psychosocial determinants to undertake surgical decisions. **Objective:** To explore the psychosocial determinants and dilemma of undertaking decision for surgical intervention in Ca Br cases amongst pre and peri-menopausal women. **Methods:** The participants of pre and peri- menopausal women with Ca Br were selected purposively from a tertiary care hospital. The inclusion criteria included patients with Ca Br who underwent a therapeutic mastectomy and willing to be a part of the study were included. Qualitative Inquiry method was used for data collection and Content analysis was done using Atlas.ti. **Results:** Five themes emerged from the content analysis. It was observed that patriarchy dominates as decision-makers; surgical decision – is it a 'No-brainer' thing?, the big emotional burden on shoulder, motivators & demotivators, and inspiration. Women's passivity as decision-makers along with emotional distress conditions like fear of loss of femininity was always accompanied. Strong support system and will power were the major motivating factor for participants. **Conclusion:** The study gave a prominent and complex view on determinants of undertaking surgical decisions. Findings from the study would contribute to better strategizing the management of patients in a local context from all aspects and not just from the clinical lens.

Keywords: Breast cancer, mastectomy, decision making, premenopausal, peri-menopausal

Introduction :

Breast cancer is the most common cancer occurring in females worldwide, representing nearly a quarter (25%) of all cancers in India.^[1] It ranks as the fifth cause of mortality around the globe^[2] where 18% of all females have been affected and over a million incident cases occur annually worldwide^[3]. The rate of incidence in India is 25.8 per lac population, whereas the mortality rate is 12.7 per lac population^[1]. With the increasing incident rate, breast cancer has become the most common cancer among urban females of India^[4]. A survey carried out by the Indian Council of Medical Research (ICMR) in the metropolitan cities from 1982 to 2005 had shown that the incidence of breast cancer has almost doubled.^[1] The annual rate of incidence increases

by 0.5-2% in India, though preferentially it is more among younger age, contrasting the age-adjusted rate in western countries. The median age of breast cancer patients is postmenopausal in western countries, whereas in India, about 50% of patients are of premenopausal age.^[4] The average age of diagnosis is 10yrs younger in the country when compared to the western world.^[5]

Most of the females diagnosed with non- metastatic breast cancer are advised breast conservation surgery (also known as lumpectomy) or mastectomy.^[6] For breast cancer patients, making decisions forms an integral part of diagnosis, confirmatory and treatment phase.^[7] The decision of treatment choice is based on the clinical as well as non- clinical factors. Factors like age, income, residence, education,

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women's attitudes and beliefs about cancer recurrence, the chance of survival, body image and sexuality, are associated with cancer surgical decision.^[6]

Charles & Colleagues in 1999 designed three models for decision making for treatment choice. The models were a paternalistic model, a shared model, and an informed model. According to the paternalistic model, the doctor's decision is considered to be the best. It assumes that the doctor knows the best and will suggest appropriate treatment options. The second model is a shared model, where there is a shared decision between the physician and patient, but in Asia, there is an elongated version of the shared decision, where along with the patients; family members are included. And the last model is informed model, in which physician just informs the patients about the treatment choices available, and no further participation of physician is present in the decision-making process. [7]

Diagnosis of this grave chronic disease is often emotionally challenging for patients, with a lot of emotions being pouring in like that of fear, despair, distress, anxiety, depression, grief, hopelessness, helplessness and a high degree of passivity. Research studies have shown that mastectomy causes more trauma than the disease itself.^[2] Though several studies in developed countries have explored aspects of the support system, body image, psychological reactions and quality of life.^[8] But in developing countries like India to the best of knowledge, there are empirically no studies documented regarding the psychosocial determinants of undertaking decision for therapeutic mastectomy in breast cancer patients of pre and peri-menopausal women. Hence the present study aims to explore the psychosocial determinants to undertake surgical decisions.

Methodology:

The study was conducted in a tertiary care health facility in urban Gujarat. The participants were pre and peri-menopausal women selected purposively. Women with no history of the menstrual period during the last 12 months and women with a history of hysterectomy or oophorectomy (not related to breast cancer treatment) were classified as postmenopausal, the women except these were considered pre and peri-menopausal women. The study included pre and peri-menopausal female participants aged more than 18 years, and who were diagnosed with breast cancer and had undergone a therapeutic mastectomy for the same.

Qualitative inquiry using Key informant interview (KII) method was used as the participants who were patients had better insights about the experiences they undergo during the decision-making process. The data was collected till saturation in responses was achieved. According to Alan, 2008 [9] numbers in qualitative research are not important in ensuring adequate samples as the concern in qualitative sampling is about the depth of the data; not with the empirical generalization. Interviews were done in a separate room with the participants. We used a piloted semi-

structured topic guide, which was prepared based on the review of literature. All the interviews were conducted in vernacular language and audio recorded with adequate privacy. Each interview lasted 40-45 minutes. The researcher also took detailed notes to facilitate transcription. Written informed consent was sought before the start of the interview.

Transcription was done in Gujarati (Vernacular Language) and then translated into English. Data analysis was done inductively, simple content analysis was done using Atlas. ti 7.5.4. The approach involves reading and familiarizing with the data, coding, emerging sub-themes from the codes and finally consolidating sub-themes into major themes. All procedures performed in the study were carried out according to the ethical standards of the institutional ethics committee and ethical clearance for conducting the study was obtained from the Indian Institute of Public Health Gandhinagar (IEC No: 10/06/STUD/2019).

Results :

Participant's Profile :

Five participants participated in the present study. The age ranged from 42 – 50 yrs. Three participants were married, living with their spouses, one participant was a widow and the last one was unmarried. All the participants were literate, though 2 of them completed their primary education, the other 2 studied till secondary education, and only one was graduated. Three of the participants belonged to middle socioeconomic class, whereas the other two belonged to the lower socioeconomic class. Three out of five participants were of premenopausal age at the time of diagnosis, whereas the other two participants were of peri-menopausal age. Out of five, four participants had kids.

The themes emerged from the analysis were

1. Patriarchy dominates as decision-makers
2. Surgical decision – is it a 'No-brainer' thing?
3. The big emotional burden on shoulder
4. Motivators & Demotivators
5. Inspiration

Patriarchy dominates as decision-makers

The first theme illuminates the subordinate status of women as decision-makers. All the participants reported that men were the primary decision-makers from disclosing the information regarding the Ca Br to selecting health center for seeking treatment. Two of the participants reported that they weren't informed about being having the disease at the time of diagnosis to avoid panicky or disappointment in them (participants). Below are some excerpts of the theme.

"My son takes the decision, he says that I put my onus on him, so he will take the decision" Mrc

" My husband didn't let doctor inform me about the disease. After I did chemo and all, when my hair loss occurred, I came to know about it, he was like I would be get worried, which is why he won't tell" (Mrs. B)

Surgical Decision – Is it 'No-Brainer' thing?

This theme reflects the relationship of women undergoing therapeutic mastectomy with decision making about surgery and what all it took in making sense for that decision making. During the interviews, the participants mostly relied on the decisions of the health professional. The 'No- Brainer', is a colloquial term that is used to describe a little or no cognitive effort required.

"Whatever the doctor said, we do" (Mrs. B)

"Our doctor was very good, we did exactly as the doctor advised" (Ms. E)

Participants reported various health professional (HP) factors affecting the credibility of whose decision to rely on, though no option was sought for surgical treatment by participants. The various HP's factors like trust/distrust on the doctor, Dr's assurance, and their experience affected the decision from whom to seek treatment.

"We took the immediate decision when we meet the second doctor, and for the first doctor as he was young, so we didn't rely much on his decision and thought his service, or experience must be less" (Ms. E)

"Everybody (family) said that my husband was expired there in the xxx hospital and I wanted to go for an operation, but as my husband who was operated there, got expired, my family advised me not to get operated here. They (family) said doctors are good in Ahmedabad and in here we can't trust as this happened" (Mrs. D)

"I think it should be left to the doctor. The doctor one thing, the doctor should a doctor. If you only think of treating, if such a doctor is there then we should trust him and go on. Doctors should be trusted, that is the most important" (Mrs. C)

Some of the participants also had experienced is a deliberation phase, which included the expert opinions of different doctors.

"We have a known doctor here, he is an oncologist from the xxx hospital. We showed the reports to him (after surgery and chemotherapy), then he suggested to take radiation also. He told that you might need to take 20-25 around, but if you will take it is good for you, don't procrastinate" (Ms. E)

The big emotional burden on shoulders

This theme illuminated the emotional fragility of the participants which was felt like an emotional burden on their shoulders. All the participants reported emotional breakdown moments, starting from intuiting being having cancer to concern about the loss of femininity. Along with this participants also reported the family's agony which included fear among family members.

"I came to office that day (when symptom was felt), but in the office when my colleague asked what why I look lost? I told her that damn I feel a lump here, will it be a cancerous lump?" (Ms. E)

(When the diagnosis was confirmed) "I was like I don't want to live, I just want to die, and said to the doctor to give some

injection as I don't want to go home. I just want to die" (Mrs. D)

"I cried a lot, that time, not because this happened, but because of my hairs. My hairs were very long, I knew that when chemo is given, hairs would be lost, so I used to worry a lot for my hairs, used to cry a lot because of it. I was like what I will do if my hairs are gone, how will I come to the office? The doctor even told me to remove one breast, and I was like if you will remove, how will I go to the office like that? It looks so bad" (Ms. E)

"My sister and my sister in law after that (after cancer being detected) feels scared every day, they are like "wouldn't I be suffering from disease too?" Like that. Both of them showed to the doctors, my sister also did go for mammography but still, it is was not getting out of her head, she is like will I also suffer from this?". (Ms. E)

Motivators & Demotivators

The theme reflects on what motivates the participants to start and adhere to treatment, and what setbacks them for the same. Need a life was a major motivator factor which demonstrated will power along with extrinsic motivators like support system where support from family members, society, workplace, and doctors were included. Apart from these, demoral society was a major roadblock.

"dr. xxx told me not to lose hope and not to cry, and told me, see I am a doctor and my real sister in law has been diagnosed with cancer. See others in the hospital, so many people come, every day around 500 people come of cancer in an xxx hospital in Gandhidham. They are strong. There are 500 patients, and when we see them, we feel we are like them only" (Mrs. D).

"I am very much strong in this, I am like what has happened, has happened, now I need to face it and nobody is there to take my sorrow. Everyone says that in this disease if you have a strong will power, then only you can live your life further otherwise every day you will feel that if it will reoccur? If it will reoccur, then what? and going on thinking like this, death comes. To accept what has happened and live your life more happily" (Ms. E)

"At first I am like I don't want to live but when I see my long life back, I am like I need to live, live the days I have with me." (Mrs. D)

Despite the above motivators, different other factors also played its part as being a motivator like parenting concern, spirituality, faith, fear of recurrence along with being good exemplars.

"When we know that after so many years, the baby was born, after 18years at the xxx hospital. When the kid was small & this disease came, then we need to raise him, I need a life." (Mrs. A)

"whatever the doctor said, we have done everything. My husband says that this treatment we need to do only. I am taking treatment from past 5yrs so that it won't be occurring again" (Mrs. B)

Some participants also reported a demoral society as a demotivating factor. The majority of participants were not concerned about what society thinks.

"they (society) only say that cancer is not curable, they say only this, it constantly runs in my head that will it not be cured ever? which makes us more depressed, due to this I wasn't able to say to anybody, and used to keep inside only." (Mrs. B)

"See in society, people says everything, some wishes good whereas some bad. If I say it is good if others it is bad, but none should be taken seriously. We have to see our god, family members and then spent our life, right or not? Should we care about society? Will society earn bread and butter for us? Will, they will raise our kids? What will they do?" (Mrs. D).

Inspiration Even after going tough time, the participants never fail to be exemplars for others to come from the house and go for a check-up and if needed go for treatment for the same.

"Nothing happens in breast cancer. If nothing happened to me, what will happen to you?" (Mrs. A)

"I say that you go for treatment, everything will be good, I say my treatment is going on, in Ahmedabad and it is going good. Anybody is there, I say you will be fine and you should also go for treatment" (Mrs. B).

Discussion

This study explores various determinants and psychosocial dilemmas in the process of decision making for therapeutic mastectomy. From the analysis, it emerged that in the majority, men along with family members played an active role in decision making, commencing from the disclosure of information regarding having the disease to where to seek treatment from. Though the major decisions regarding surgical treatment were always backed by physician's advice, whereas women's role in decision making was found mainly passive. The findings coincided with 'paternalistic model', where the decision was either physician-led or men led, though the surgical decision was mostly physician paternalistic which was also reported by Beaver et al., 1999, Butow et al, 1997, Sekimoto et al., 2004, and Yusuf et al., 2013. [10][11][12][8] Health professionals' credibility was a driving factor to trust in the decision of the physician and even leaving decision completely onto them, congruent with Lauren, 2017 and Shariff et al., 2008. In some cases, the shared model was present, where the decision was taken collectively by the physician, family, and patients. [13][7] It also supports the view of Williamson that for seriously ill disease, patients do prefer paternalism as initial shock and distress condition lowers the coping mechanism for pessimistic information or decision.[11] The qualitative design was not meant to explore the relationship between the sociodemographic profile and role in decision making, but it is found in several studies that less educated patients are mostly passive in decision making. [7, 11, 12] The study also revealed different information needs during treatment. Friends, family, known doctors played the primary source of

informers which showed the relevance to interpersonal communication networks. Other than this, different sources of media also acted its part as informers. A review of literature by Ankem, 2005 on seeking information by cancer patients, revealed that disease-related information like diagnosis, chances of cure, reoccurrence, etc. and therapy-related information like options for treatment, side-effects, etc. were indicated as most important to cancer patients. [14] However, priorities for the types of information might also depend on various factors such as age, time since diagnosis, patients' fondness for a role in decision making, knowledge, and gender. [14]

The treatment decision completely relied on physician's advice, no other option for a therapeutic mastectomy was sought for, when faced with a potentially fatal alternative. However, there was a distinction in making a decision and then living with it, while the latter being more emotionally challenging, and was more like a burden which was needed to be shovel off. Though studies confided with the findings of initial despair or emotional breakdown at the time of diagnosis being experienced by patients [7], there was a grave concern about being the loss of femininity. Hairs and breasts which were metaphorized as a symbol of femininity, indicating womanhood, this scar of being was forever itched in mind of patients, along with scar of surgery. The perception of participants is being influenced by societal objectification of breasts with sexuality, femininity, and eroticism. [13] Though this emotional fragility didn't concern in delaying the treatment, or opting for other options of treatment, as to get cured was of prime importance. But still, this fear leads to the ignition of social fear followed by exclusion. These findings were also documented by Saxena et al, 2018, whereas Storm-Dickerson et al., 2018 documented that retaining attractiveness, breast and feminity was not a concerning factor at the time of deciding the treatment, which was also reported in the present study. [2,15]

From the time of diagnosis to coping with stressful conditions, a strong support system was standing hand in hand with the patients. According to Janis and Mann (1977), two factors were identified for influencing decision making, internal factors and external factors. [7] The reported internal factors which were also motivators were a strong will power, urge to live a long and healthy life and fear of reoccurrence. The main external factor as a motivator was support from friends, family, physicians, and society. The studies have suggested that a good and strong support system is a strong motivator factor in enduring support from the initial diagnosis phase, confirmation of it, adhering to the treatment till completion of it. [2,8,13,16] Though society has a dual role, in a positive one, they motivate participants by setting good exemplars whereas in other it causes unwanted stress by spreading misconception and misguidance about disease. But most of the participants were not showing any concern much during the treatment phase. Despite this, participants never fail to be good exemplars themselves and indeed encouraged other women to seek consultation and go for treatment if required.

The study was an extensive exploration of the determinants for undertaking surgical decisions of breast cancer patients. To the best of knowledge, it is the first of its kind in the country, where the decision-making process was looked at with a psychosocial lens. With a small size of five participants, the results can't be generalized. The study location was a tertiary care hospital, where all the cancer patients were not managed, which also halted the generalizability of the results. One of the participants wasn't aware of the disease, which led to under exploration of the patient's emotional dilemma during the treatment. Nevertheless, more research is still required in this arena for further implications in the decision-making process for cancer patients.

Conclusion:

The study gives a prominent and complex view on determinants of undertaking surgical decisions. The current study highlighted the passivity of women as decision-makers even while taking the wrath of treatment affecting her mentally more than physically or biologically. Hence a patient-centered approach should be utilized to discuss and acknowledge the women's preferences in the decision-making process. It can be through the early use of appropriate psychometric measures to gain an initial understanding of how an individual might be conceptualizing the experience. The findings from the study would contribute to better strategizing the management of patients in the local context from all aspects and not just from the clinical lens. The participants were taking treatment from a hospital having a counselor, which many facilities don't have. [2] So along with strategies like having breast cancer education programs for patients and their family, and improving the interaction between the patients and healthcare providers, counseling services would address the emotional context of the treatment.

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