

Social And Psychological Issues Experienced By Women Suffering From Breast Cancer

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Abstract

Breast cancer is becoming a worldwide concern with a significant increase in the number of cases every year. Women suffering from breast cancer face several issues in their personal and social life. It also harms their emotional and psychological well-being. This study was conducted with the goal in mind to figure out psychological and social problems faced by women suffering from breast cancer. Additionally, it also sheds light on how these women deal with issues brought about by cancer in their lives. To get an in-depth knowledge of all this, one on one deep and personal interviews were held with patients in their native language. Eleven patients were chosen at random from each of the two government hospitals, Jinnah Hospital Lahore and Mayo Hospital Lahore, making a total of twenty-two participants. Research showed that most of these patients complained about financial and transportation issues. A lot of these patients talked about how they had to sell their belongings and take loans to pay for the continuation of treatment. Physical symptoms like fatigue and chronic pain were a huge hurdle in performing their daily routine tasks. Most of these patients talked about feeling alone, depressed, angry, and envious. Almost all of them suffered from depression and anxiety. All of them feared relapse and death. Many patients reported suffering from side effects of chemotherapy like insomnia, weight loss, loss of hair and appetite. Young patients were mostly worried about infertility and change in physical appearance. The majority of respondents said that they get social and emotional support from their blood relations. Male family members helped by contributing financially and female members helped by giving a helping hand with household chores. Few of them said that their friends and neighbors were helping them in fighting cancer too. Contrarily, most of the participants were worried about treatment facilities and the ill-mannered behavior of medical staff and said that they don't receive any support or empathy from medical staff. The majority of them coped with the issues by turning to religion and spirituality. Most of the patients talked about how praying and visiting shrines helped them deal with their anxieties. Accepting the fact that the disease is a form of test from God and believing that He can make it easy for them soothed a lot of patients in this study.

Keywords: Breast malignancy, Breast cancer, Social issues, Psychological issues.

Introduction

Background

The female breast has been associated with beauty, femininity, and being fertile. Its malignancy, however, has proven to be a challenge for doctors for ages. It is a disease that is not limited to any culture, religion, social status, or financial status. Researches show that there are more than 1,050,000 new cases of breast

cancer every year (Stewart et.al, 2003). The etiology of breast cancer is very complicated and can depend on various factors like genetics, dietary habits, natural factors, and artificial substances. The increased number of breast cancer cases is very frightening.

Place and Duration: This study was conducted in Jinnah hospital and mayo Hospital from 2017 to 2019.

National perspective

In Asia, Pakistan has the highest incidence of breast cancer, and it's increasing at an alarming rate. Among all the diseases females are suffering in Pakistan, breast cancer is growing at a rate of 40 percent making it the fastest-growing illness in females. Breast cancer is more fatal in Pakistan as compared to developed countries due to the following reasons; poor literacy rate, malnutrition, poor health facilities, and late diagnosis making it scarier than it has to be. Early diagnosis can help with a relatively good prognosis.

Psychosocial Aspects of Breast Cancer

Patients suffering from breast cancer are more prone to many psychological issues. Roughly one-third of patients suffering from breast cancer experience impediments. Side effects of chemotherapy continue for a decade or two after discontinuation of treatment. It is also frequently accompanied by psychological disorders like altered sensorium, depression, anxiety, and forgetfulness which can lead to drug abuse (Coyne et. al,2004; Luecken and Compas, 2002). Women who undergo mastectomy develop body image issues and cosmetic insecurities, which makes them unsocial and more inclined towards depression and other psychological issues. While women in later stages of cancer suffer from generalized depression and hopelessness.

Breast Cancer Statistics

Breast cancer is the most common malignancy in women all over the world. It is the second most common cause of cancer-related deaths after Lung cancer. Breast cancer is the second most documented disease in women and men around the sphere. In 2012, breast cancer was recorded to be about 15 percent of all new malignant cases and one-fourth of all diseases in females. Since 2008, the breast cancer growth rate has increased by 25 percent. According to the latest research, the 5-year survival rate of women with breast cancer is very close to hundred percent, the 10-year survival rate is 85 percent, and the 15-year survival rate is 80 percent. On the other hand, the 5-year survival rate for local infections is 85 percent, and 25 percent for end-stage diseases.

(American Cancer Society, Cancer Facts and Figures 2017-18) Genetic mutations, ecological factors, and lifestyles have put every ninth woman in Pakistan at risk of having breast cancer.

Significance of the Study

Women above the age of 50 years are more likely to have breast cancer, but young females can have a cancerous growth too. There are many psychosocial issues related to this disease other than financial loss. Infertility in young females which is a side effect of chemotherapy produces a strain on marital affairs. Social stigma and shame revolving around this disease makes its early-stage diagnosis difficult. And women get scared once diagnosed due to lack of information and proper knowledge on this topic.

Objectives

To figure out the social repulsion and shame surrounding breast cancer in women.

To find out the social and economic issues faced by breast cancer patients.

To point out the psychological and emotional difficulties related to breast cancer.

To investigate how breast cancer patients deal with their disease and side effects of its treatment.

Literature Review

Epidemiology of Breast Cancer

Breast cancer is most vigorously studied diseases worldwide. Breast malignancy is the second most common cause of cancer related deaths in females (Cancer Research UK, 2011). Breast cancer screening programs in UK have considerably reduced the death rate due to breast cancer but the frequency of disease has increased. Research shows that most women affected with breast cancer are older than 50 years of age (Cancer Research UK, 2011). Hormones like estrogen and progesterone and their intricate balance plays an important role in the course and outcome of disease.

Psychosocial Impact of Breast Cancer

Chemotherapy as a treatment for breast cancer can be very challenging in itself. Depression in cancer patients can be reduced by social and moral support. Proper education about different treatment options like total or subtotal mastectomy, lumpectomy, breast reduction, and breast reconstruction can help patients in selecting the best suitable option for their physical and mental health as well as their relationship with their partner (Harmer, 2006). Fears and concerns related to relapse, change in femininity, sexuality, and reaction of their partner to disease and changes in the body can cause psychological issues even in the long run (DH et al, 2006).

Shock of Diagnoses

Diagnosis of breast cancer can agitate feelings of helplessness and despair. The year following the diagnosis, women show feelings of denial, apathy, grief, and anxiety. These challenges not only affect the patient and their partner's life but also their families are affected. People start distancing themselves from the patient in consecutive years after diagnosis which leaves the patient more helpless and alone (Northouse et al., 2000). Shock and fear are typical responses to diagnosis for many women. It can elicit feelings of discomfort, emotional turmoil, nervousness, and the inevitable fear of death (Perreault & Bourbonnais, 2005).

Treatment and Limitations

Chemotherapy leaves women weak, lethargic, and unable to take care of themselves or their families. Almost all the complaints these women have were noticed to be a side effect of cancer treatment they were undergoing (Fobair et al, 2006). Women intent on getting breast cancer treatment are forced to compromise between many vexing treatment options. Most women have to decide between complete or incomplete removal of breast followed by chemo and/or radiations. Factors like suffering from a critical illness, excruciating medications, and not being able to work or perform daily life tasks are the reasons for psychological problems in these women. Not being able to afford expensive medical treatment is also a cause of mental stress for these patients. Trying to manage the negative

side effects of cancer treatment on fertility and conception was a huge concern of younger females.

Body Image Concerns

Following the surgeries for breast cancer, giving up a piece of your body changes how you view yourself. Especially a part that's given so much value and importance in Western culture. Understandably, women suffering from breast cancer suffer from low self-esteem and body issues. Such surgeries impact all parts of a woman's life and bring changes in their psychosocial relations, their personality, sexuality, views, their idea of beauty, and personal relations. The research found that strenuous physical labor during cancer treatment leads to emaciation. Women have a very intricate relationship with their hair, long and thick hair being a symbol of beauty almost everywhere in the world. Alopecia being a side effect of chemotherapy had a very deep impact on the psychological health of patients. Some might even lose their personality and self-confidence in this heart-wrenching journey of cancer treatment (Boehmke and Dickenson, 2005).

Sexual Functioning

Results of numerous studies show that women have an abundance of sexual difficulties and that these difficulties become worse for younger women (Ganz et al., 2003). Even five to ten years after their recovery, women continued to suffer from sexual difficulties such as vaginal dryness, decreased sexual recurrence, and decreased bosom affectability, according to a large study of healthy people who had conquered breast malignant development. According to one study, the majority of women with malignant growth experienced sex problems in the year following therapy. Nevertheless, research suggests that when relationships are strong before the development of breast cancer, the illness does not often disrupt the relationship and may even lead to a much-improved quality of life. (Oktay and Walter, 1991). Although it is important to make women and their partners aware of these difficulties, the stress that results from doing could lead some couples to avoid sex altogether or to experience discomfort while having sex.

Fear of Reoccurrence

However, the mental condition that follows anxiety is probably easy to distinguish from stress since it includes the fear of illness recurrence (FCR), which is a symptom of anxiety. FCR entails persistently worrying that the cancerous tumor will come back. Thewes et al. (2013) discovered that FCR negatively affects a young lady's state of mind, ability to achieve goals, and capacity to prepare for the future. Young women with breast malignant growth have consistently been shown to be at a higher risk of struggling with depression about illness recurrence. When a woman has breast cancer, it often gives her the strength to fight against feelings of vulnerability, fear, and—most terrifying of all—the prospect of death. These challenges pose a number of existential questions, such as "What is important in my life?"

Cultural Taboos

Often, women were reluctant to disclose their condition to even close family members, neighbors, and friends due to the social stigma associated with a diagnosis of breast disease. The child might subsequently have cancerous breast growth. According to this belief, mastectomy is the primary treatment option for breast cancer since it removes the illness from the breast; however, it carries a stigma in society. Many women sought advice from neighboring homoeopaths when they discovered a protuberance in their breasts for advice on treatments or used friends (otherworldly researchers) for insightful advice and support. Exactly Four of the women we met were hiding their protrusions from other relatives. This result is consistent with widely reported findings from other countries in Asia.

Life Post Cancer

Many women found passionate support from spouses, children, and other female relatives in their family circle. Even in the context of generally appealing relationships, many women with breast cancer find their interactions with their partners to be frustrating. Patients frequently

state that they are not ready to communicate with their partners and family members as openly as they would like to. Breast malignant development can cause people to constructively reevaluate their lives, mindsets, and practices, resulting in a positive psychosocial acclimation to sickness (Andrykowski et al., 1993). Younger women discussed the limitations they felt in their careers and manner of life.

The overall quality of life

Surveys showed that women with breast cancer suffered from a decreased quality of life especially during the first few months after being diagnosed (Glanz and Lerman, 1992). Results of many similar studies emphasized the relation between decreased quality of life and grievous manifestations of breast cancer treatment. Whenever a patient display sign of depression it automatically means decreased quality of life. This could happen at the beginning or towards the end of treatment, but it remains inevitable. It needs to be understood that breast cancer survivors have distinct physical, psychological, social, and educational needs.

Role of Religion and Spirituality

Religion and spirituality also play an important role in the fight against breast cancer. The concept of Higher power provides a blanket of comfort. It is shown that spirituality can bring physical and psychological well-being (Oxman, Freeman, and Manheimer, 1995), and it can also bring positive results (Levin, 1994). Levin (1994) surveys showed favorable results for religion and spirituality. Since breast cancer patients are facing innumerable stressors, this could provide much-needed support against some of these challenges.

Research Methodology

To get a deeper understanding of the psychosocial issues of patients suffering from breast cancer, qualitative methods were used. Researchers conducted a study at Jinnah Hospital and Mayo Hospital Lahore. Both hospitals have a distinct Oncology ward. The researcher used a non-probability study design. In it, the researcher used selective sampling to explore the

psychosocial issues of breast cancer patients. Sampling did not finish until the researcher reached saturation point which is why the number of participants varies and the researcher may not know the accurate number of respondents in a qualitative study. This study was conducted on twenty-two participants, who were interviewed in depth. Follow-up questions were asked to make sure all aspects were covered in the interviews.

Results

According to data from this study, patients with breast cancer have come to terms with socioeconomic barriers to their treatment, such as the cost of care, transportation problems, a lack of understanding about the disease, and low health literacy. Participants mentioned worry about the financial issues they had while receiving therapy. 63% of the study's participants experienced financial troubles. Some people had to sell their possessions and valuables in order to pay for therapy. Participants also described borrowing money to pay for their medical care. According to Baird (2014), given financial constraints, a patient's domiciliary could try to subsist with this peak of medical debt by consuming fewer other goods and services.

Selling assets and taking out loans are two other ways to cope for therapy. Numerous respondents highlighted how this illness has drastically changed the structure of their homes. Their kids had to stop going to school. Due to her husband's unable to pay for the therapy, one respondent filed for divorce. Due to the fact that they frequently lack a stable source of income, divorced and widowed individuals often have additional challenges with their finances. According to a study, people who are getting cancer frequently struggle with money issues (Ward et al., 2008). Data This study showed that financial crises, which can cause pain and a host of psychological problems, are the largest difficulty affecting the majority of breast cancer patients.

Data from the questionnaire also showed that lack of transit was one of the primary issues that many participants (32%) opposed. Numerous informants claimed that experiencing financial difficulties made it difficult to access pleasant transportation options. Some of them suffer from

additional medical conditions like motion sickness, claustrophobia, and spinal obstacles. The study found that some patients would neglect necessary care due to transportation concerns. According to patients who were believed to be credible, obstacles including extensive distances, access to transportation options, and the availability of certain drivers who could take them to treatment facilities were potentially serious issues (Guidry et al., 1997).

This study additionally demonstrated that certain participants' transport issues were more pressing, particularly for those patients who were underprivileged or had a long commute to the treatment clinic. Travel lengths are a concern because patients may not have access to nearby services or may forego local options if they are not satisfied with their quality, the study revealed (Bewdley et al., 2008). When such patients have these concerns, they frequently stop receiving therapy and begin to experience a variety of additional physical and mental health problems. Participants (9%) discuss the intimidation they experienced from male passengers and bus workers. The patient also brought up the uncouth conduct of male passengers and bus employees. Extreme stress, varicose veins, and other unpleasant emotional and bodily concerns emerge in breast cancer patients as a result of prolong waiting at bus stops and standing while travel.

Lack of information and not enough health literacy were two additional issues mentioned by several participants (27%) in the survey. The respondents specifically described the issues they experienced as a result of their low health literacy. Patients frequently had issues with their understanding of medical terminology, their conception of medicine's time and schedule, their ability to properly communicate with medical personnel, their difficulty orienting themselves during hospital visits when trying to find the rooms and labs, and their wrong interpretation of the treatment and follow-up schedule. Previous studies showed that variations in health literacy may further cause health inequalities.

(Bennett et al., 2009; Curtis et al., 2012). The survey also revealed that there was a disparity in language between patients and doctors. The results of this investigation showed how many cancer patients knowingly worsen their condition

by ignoring the early signs of the disease because they lack consciousness about it. Health literacy has an impact on health outcomes and healthcare costs, according to Murray et al. (2009).

Data from the current study revealed that just one of the 22 respondents discussed any complaint. Nearly all respondents claimed that they never kept their illness a secret from others and instead discuss it freely with others in their social circle. Nobody who responded said that people associate their illness with bad things. Similarly, not a single respondent mentioned that their daughters' breast cancer affected their weddings to be postponed.

None of the participants complained of rejection by people around them. People thought of it as just another illness and hoped that it will be treated like any other disease. On the contrary shame and stigma surrounding breast cancer were also reported (Neal, Beckjord & Rechis, 2014). Im et al., (2002) showed that the discrimination women faced forced them to hide their diagnosis from their peers. Cancer and its treatment present a great impediment to performing motherly responsibilities. Breast not only affects the person suffering from it but also negatively affects their families (Osborn, 2007). It also has a dreadful effect on their work lives. Less than 15 percent of participants reported that constant distress and anxiety compromise their work life. Even if it doesn't affect the profession of all patients, it definitely changes their ambition Stewart et al. (2001).

Depending on the treatment option, women experienced various side effects. Lethargy due to chemotherapy was not the kind that will go away after getting enough sleep and giving yourself some rest (Carroll et al., 2007). One-fourth of the participants complained that continual painful treatment negatively affected their quality of life and proved to be a hindrance in performing daily life chores. One-fourth of the respondents talked about infertility as a consequence of chemotherapy. The probability of irreversible menopause, and ovarian repression were reported as major concerns (Baum & Shaughnessy, 2002). Less than 15 percent of respondents reported a decrease in libido after cancer treatment. Patients that underwent mastectomy reported a massive reduction in libido as compared to their pre-operative patterns (Aerts et al., 2014). One-fourth

of the participants voiced their concerns about cancer treatment negatively affecting their body image. Alopecia, emaciation, and removal of breasts changed the appearance of women and how they view themselves. Negative changes in body image can lead to lower self-confidence and ultimately poor life quality. Self-perception is actually how people think, act, and feel about their outer appearance (Dohnt et al., 2006). Negative changes in outer appearance led to feeling insecure and introverted, which results in feeling alone and isolated. Less than ten percent of women reported social dysfunction which leads to depression and other mental issues. Three participants in the study received massive emotional support from people around them which positively affected their outcome. Contrarily, participants who did not receive any social support had worse mental health (Hammoudeh et al., 2017). Research showed that spouses were considered the main support system during the diagnosis and treatment (Hammoudeh et al., 2017). Unmarried females relied on their friends and family for emotional support. Females living in combined families received support from some and were neglected by others. About twenty percent of women receive social support from other females (Alqaisi & Dickerson, 2010). Two of the respondents said they did not receive any support from anyone in their lives. Most of the participants complained about a lack of empathy from doctors and paramedical staff. Breast cancer diagnosis is the hardest time in anyone's life, and has a massive impact on their physical and psychological health (Hewitt, Herdman, & Holland, 2004). Thirty percent of participants showed distress about the future. Parents of young children were worried about the future of their children too. Few women worried about their spouses. Fear of relapse is a common issue among these patients which leads to anxiety and mental stress. Most cancer survivors dreaded relapse (Bloom et al., 2004) Some patients reported insomnia, which is a side effect of some drugs, and constant unease about future. Insomnia was more commonly reported in patients with end-stage cancer (Collie & Batiuchok., 2007). Thirty percent of patients reported anxiety during various stages of treatment. This anxiety leads to insomnia, nausea, and vomiting. There's a higher incidence of

depression in cancer patients as compared to the general population (Massie, 2004). Some of the patients expressed how they were scared that they will never recover from cancer. Most cancer patients feel alone and isolated because of their inability to perform any social activity, bed riddance, and discontinuation of work. Some were isolated because people abandoned them. And some isolated themselves because of low esteem due to changes in physical appearance.

Research showed feelings of anger, annoyance, and envy in these patients. Participants also talked about feelings of despair after diagnosis. Fear of speedy death after diagnosis elicited feelings of anxiety, hopelessness, and agony. How these patients cope with these feelings was a huge part of this research. Religion, spirituality, and belief in divine power were some of the major coping mechanisms. Faith in Higher power provided the internal support needed to fight this battle (Gall et al., 2002). Respondents said they managed their fear and anxiety through prayers. Spirituality and belief in the divine were found to be directly proportional to personal well-being (Levine et al., 2001). Spirituality and faith play a pragmatic role in the fight against cancer (Matthews, 1997). Most of the respondents believed that they were people of God chosen to fight the hardest battles. This helped them cope and manage their anxieties and affected their quality of life in a beneficial way.

Limitations

This study was limited to two public hospitals in Lahore, Jinnah Hospital and Mayo Hospital, so further studies should be conducted on other public and private hospitals in other areas.

The numbers of patients interviewed were limited so the results of this study are specific to this sample and cannot be generalized to larger populations.

This study was completed in a limited time frame with limited financial resources. As this topic is very vast, it should be studied in detail within a relatively large time frame and using more resources.

Conclusion

In conclusion, after diagnosis patients suffered a variety of psychological and social issues. Patients had to sell their belongings and take loans to continue the treatment. Only a few hospitals had cancer treatment facilities so many patients had to travel long distances. Patients often felt feelings of envy, anger, frustration low self-esteem, and isolation due to side effects of treatment which are loss of hair, loss of weight, and changes in physical appearance. Young patients showed great concern about fertility and sexual issues. Fear of death, depression, and anxiety were common in most cancer patients. Most of the participants relied on their spouse and immediate family for support. Male figures supported financially while female figures supported emotionally. Unfortunately, some of the patients had little to no support from anyone in their life. It was found that hospitals lacked facilities and medical staff lacked empathy. The major coping mechanism for most patients was religion and spirituality. Belief in a Divine power helped people manage their anxieties and fight against cancer, as concluded by the research.

Recommendations

- Cancer treatment is very expensive and not everyone can afford it. Government should make cancer treatment free or at least provide loans through banks or NGOs so that everyone has access to treatment.
- There are only limited cancer facilities and not enough to cover a large population. So there's a need to develop more facilities so people don't have to travel long distances to get treatment.
- Families of cancer patients should be consulted to provide maximum emotional support to patients. Also, psychological help should be offered by professionals to minimize psychological issues experienced by cancer patients and survivors.
- Physical side effects like hair loss and loss of femineity are a huge cause of distress in patients. Therefore, wigs and breast reconstruction surgeries should be offered to these patients to deal with body image issues.

- Negative body image forces these patients into isolation. So immense support from friends and family is required to prevent this issue.
- Healthcare professionals dealing with cancer patients should be provided with the latest information so they can offer the best possible care to these patients.
- Paramedical staff should also be given appropriate training on how to deal with already grieved cancer patients and policies should be made to ensure its implementation.
- There's a massive need to raise awareness about breast cancer through infomercials, symposiums, and social media to detect and manage cancer at its earliest stages.
- Studies showed that many people relied on exorcists to get rid of cancer and don't seek medical help until it's too late. Proper education is necessary to avoid this issue.
- Due to increasing incidences of cancer in young patients, screening tests should be performed in colleges, universities, and job centers. Young females should also be educated about and encouraged to perform self-examination.
- Gynecological and psychological help should be made part of the oncologists' team to deal with reproductive and psychological issues faced by breast cancer patients.
- Breast cancer insurance policies should be introduced by the government and NGOs.
- Cancer treatment requires a long time, due to which most women lose their jobs during this phase. Paid leaves and job security should be provided to these women and implementation should be made sure by higher authorities.
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