

The impact of culture, sociological and psychological issues on Muslim breast cancer patients in Pakistan.

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Abstract: Breast cancer is the most common form of cancer in Muslim women in Pakistan. The impact of the initial diagnosis, culture, religion and psychosocial and psychological aspects of the disease are not well established. This qualitative study examined the experience and coping strategies employed by breast cancer patients in relation to its impact on their physical, mental health, religious and family issues. Thirty breast cancer patients were interviewed. Data was analysed using thematic analysis. The patient experience of breast cancer focused on the range of emotions felt throughout the illness trajectory, the importance of religion and family support on coping strategies employed to manage the side effects of chemotherapy and also financial concerns. This is the first study to examine Pakistani Muslim women's views on the lived experience of breast cancer. This paper provides clarification of the voiced experiences of women with breast cancer. The data highlight the role of religion and family support as essential coping strategies, but also emphasize the issues of isolation, aggression and anger as common responses to chemotherapy. Unique features of this study are women's need to seek spiritual support for their illness and the overriding innate characteristic of maternal responsibility. These cultural features require further analysis and research.

Key words: Breast cancer, Pakistani Muslim women, culture, religion, family support, maternal responsibility.

Breast cancer is a global concern. It is a disease that is not restricted by culture, religious belief, social class or economic status. Global estimates suggest that on an annual basis there are more than 1,050,000 reported new cases of breast cancer.¹ Among Asian countries, Pakistan has the highest rate of breast cancer. Evidence from the Karachi cancer registry indicates that the age standardized annual rate of breast cancer is 69.1 per 100,000. This figure is equivalent to European and North American rates.² In Lahore, Pakistan, over a period of 8 years there were 3,338 cases of breast cancer presented at Shaukat Khanum hospital.³ Current figures indicate that in Pakistan breast cancer affects both young and middle aged women and can affect women as young as 20 years of age. The aetiology of breast cancer is complex and can involve numerous indicative factors such as genetics, diet, chemicals and environmental factors. In Pakistan, it is estimated that germ line mutations in the BRCA1 and BRCA2 genes account for account for 5% of breast cancer cases.⁴ Recently it was shown that in Pakistani families with multiple cases of breast cancer the prevalence of BRCA1 or BRCA2 mutations was 42.8% and 11.9% for single cases of breast cancer.⁴ Thus, Pakistani women who carry either of these deleterious mutations face a lifetime risk of developing early onset breast cancer.

There is no cure for breast cancer, even after surgical, chemotherapy and radiation treatment there is the constant fear of recurrence and uncertainty.^{5,6} There is no universal experience of living with breast cancer, only individuals that have the experience can relate to it.⁷ Every woman's interpretation of living with the illness will be subjective and influenced by their social and cultural life context, sense of well being as well as religious beliefs.^{8,9} These factors may underpin the types of suffering they endure.^{10,11} Women with breast cancer experience suffering related to life dimensions: physical pain, spiritual, emotional,

psychological and social forms of suffering.⁶ This experience can have an impact on how they cope with their illness.

Coping strategies can be influenced by how women view their illness.^{12,13,14} Illness representations may be presented according to symptom perception/cultural beliefs; perceptions of the chronicity of the illness; the physical and emotional influences of the illness; cause and effect perceptions; and potential for cure. Misconceived beliefs about causation may adversely alter coping strategies and can have an impact on the outcome of the disease and quality of life of the individual suffering from the disease.¹⁵

In Pakistan even though breast cancer is the most common form of cancer in women, the experiences of patients and suffering they endure is relatively unknown. This is the first study to examine the lived experience of breast cancer in Pakistani Muslim women.

The aim of the study is twofold: (a) to examine women's experiences of breast cancer and the coping strategies that they utilized to manage the illness and (b) to investigate whether there are any cultural, socio-psychological or religious factors that influenced Pakistani Muslim women's views or experience of managing their illness.

Methods

This qualitative study used semi structured interviews to explore the views of women in relation to breast cancer, experiences of living with the disease; from early diagnosis onwards, coping strategies employed, and possible impact of cultural, socio-psychological or

religious factors that may influence women's views on how they manage their illness. The interview questions were developed from the available, relevant breast health literature.

Sample selection and procedure

A purposive sample of 30 female breast cancer patients were recruited from a regional cancer hospital in Lahore, Pakistan. Selection criteria included; a confirmed history of breast cancer, age range 22 to 60 years; receiving treatment as a hospital in-patient for breast cancer, of Muslim belief and Pakistani origin. This sample selection and size permitted the exploration of the diversity of views from women in relation to the study aims. It is important that the design of the interview questions specifically addressed the cultural sensitivity of the women involved. To achieve this, the co-investigator in Pakistan is also a Pakistani involved in the design of the interview questions to ensure that participants were familiar with the phraseology used and could engage with the questions employed.¹⁶ The suitability of the interview questions was tested using three pilot samples and necessary changes to the schedule questions were made.

All researchers in the study were experienced in interviewing techniques. To ensure the consistency of the interview process and to enhance the validity and reliability of the data collected, the principal investigator was involved in all interviews.¹⁶ After informed consent was obtained, interviews were arranged at a convenient time and location in the hospital clinical areas.

Translation and back-translation

Interview schedules were provided in English and then translated into Urdu and back-translated. Interviews were conducted in English and Urdu according to participant's

preferences. Urdu transcripts were analysed and themes and subcategories were translated into English, and then back-translated to Urdu in order to ensure lexical and conceptual equivalence.

Framework for analysis

The information generated from the focus group and semi-structured interviews were analysed using thematic analysis.¹⁷ The approach allowed the development of core categories, concepts, repeating patterns and emerging themes. To enhance the credibility of the thematic coding and its adequacy in representing these data, the researcher's constructions were grounded in the data of the participants. This allowed an evaluation the trustworthiness of reported generalizations.¹⁸ The credibility of the data was enhanced by the exploration of alternative views and the review of the terms of reference with respect to interpretations and their assessment.¹⁹ Findings were verified by crosschecking across the research team and testing explanations for coherence.¹⁷ Reliability was enhanced by analysing and comparing the data reconstructions and results of syntheses according to the developed categories, definitions, defining characteristics used to develop concepts from the data, and by reviewing the research decision trail.²⁰ All researchers participated in data analysis to ensure the consistency of interpretations and the internal validity of the data.

Interview participants received a participant information sheet outlining the following details: the ethics of participation, the study purpose; a statement about the confidentiality of the information given; what is required of them and that participation is voluntary; the number of participants we are seeking to recruit and that the ethics committee has approved the study; availability of the dissemination seminar in accordance with research governance principles.^{21,22} The information was available in English and Urdu and included the contact

details of the researchers. Participants were asked to contact the researcher should they wish to ask further questions and if they were willing to participate in the study.

Findings

In this study, the sample of women varied with regard to marital status, number of siblings and occupation. Three women were single, 2 women were widows, 2 women were living separately from their husbands, 1 women's husband has taken a second wife, and 22 women were living with their husbands and their extended family. Married women had an average of 3 children, with the range from 2 to 5 children. Most women were housewives, 2 women were employed in schools, 2 women earned a living working from home stitching clothes and 1 woman was studying on a full time basis for a post graduate degree.

Eight themes were identified from the data. Shock of diagnosis, concealing the evidence, awareness of breast cancer, family reassurance, coping through prayer, maternal responsibility, feelings of isolation and financial burden of treatment.

The shock of diagnosis

The issue of breast cancer is an emotional one that instigates numerous responses and reactions from women. In this study, women expressed their emotions freely. Women were unequivocal in their response to the onset of cancer, many expressed feelings of distress, shock, disbelief, emotional upset, worry, fear of the diagnosis and its possible outcome. Cancer development is upsetting for women. Many women cried a lot, felt depressed, were scared, worried or terrified at the thought of having to have treatment and the related insecurity associated with the condition. These reactions to the initial diagnosis may have led

to fear and uncertainty of the future. This aspect of the study findings is supported by other published studies.^{5,6}

These sentiments are illustrated in the following excerpt:

My initial reaction was one of distress and apprehension regarding the treatment and also because of lack of facilities. I was worried that I might not be able to get treatment.

When I first heard about the diagnosis I was terrified and I was upset, nobody in my family even had cancer before.

The distress of receiving the diagnosis caused several women to question and ultimately reject their diagnosis. This is a common reaction to breast cancer.^{6,23} This response was often supported by husbands and other family members such as in laws and parents. The lack of acceptance of the diagnosis led many women to refuse treatment for periods of up to two years after the initial location of a lump. This delay often led to a diagnosis of metastatic disease a few years later. In one patient's case, it was only at this advanced stage, when the patient's symptoms became gradually worse that family members realized that she required medical assistance and that she was ill. Reluctance to accept their diagnosis is illustrated in the following excerpt:

My initial reaction was total unacceptance of my diagnosis of breast cancer. I could not accept the fact that I had got breast cancer and that is why I was not willing for treatment at

that time. I felt that I could not tolerate the treatment of the consequences of these treatments, so I opted for non-medical treatment outside the hospital.

Concealing the evidence

The social stigma that is attached to a diagnosis of breast cancer often prevented women from informing relatives, neighbours and friends of their illness. In Pakistani culture, breast cancer is viewed as a proscribed condition which reduces the opportunities for unmarried women with breast cancer to later get married. This is due to the widely held belief that women with breast cancer can spread the cancerous cells to the unborn child. The child may later develop breast cancer. In this belief, the only treatment option for breast cancer patients is mastectomy, as the cancer is extracted/ removed from the body. There is also a social stigma of having a mastectomy. Breast cancer is a source of unhappiness. When finding a lump in their breast many women sought advice from local homeopaths for advice on medicines or used peers (spiritual scholars) for spiritual advice and support. They often suggested that they relied on traditional measures to treat the tumour or may be referred to other hospitals for treatment. Many women had their lumps of up to 2 years before coming to a regional cancer hospital for treatment. In many cases, medical help was only sought due to the insistence of family members. In this study, four of the women interviewed concealed their lump from other family members. This finding concurs with published reports from other Asian cultures.⁸ In Korean society, breast cancer is also tainted by stigma, so it is not unusual for women to hide their diagnosis from their immediate family.⁸

This is illustrated in the following excerpt:

Initially I did not tell anyone when I felt a lump in my breast. I hide it from my family. I did not say anything to anyone about it. I went for spiritual treatment, although I felt better, the lump started increasing in size. When my family came to know about it, they wanted to know why I did not tell them about my illness.

Women's hesitancy to accept their treatment, and undertake a possible mastectomy was expressed continually used the phrase 'I was not ready for that'. One patient expressed this sentiment in the following excerpt:

Two years ago I noticed a lump in my breast and when I noticed it I told my family members. I went to the local practitioners and nobody and any idea of what actually the lump was all about. When I came to know about this disease I was a bit depressed to know that my breast was to be removed and I was pretty hopeful that everything will be fine and I will be treated. The most worry was that about the removal of the breast. I was not ready for that at all.

In a separate interview an unmarried patient expressed her views on mastectomy, she said:

I have sacrificed my hair, I was ready to do that I am just praying that the sacrifice ends here and I won't have to go on and have a mastectomy done. If the cancer was at stage four I will refuse treatment.

Awareness of breast cancer

The term breast cancer was partially understood by many women. Levels of knowledge differed from no knowledge or where they first heard of the condition when they came to

hospital. In other cases women had some awareness either due to other female extended family members developing breast cancer and requiring treatment. Or they had heard about the illness through friends and contacts. A number of patients had heard that breast cancer causes pain and discomfort and is incurable. This increased apprehension amongst women and caused a considerable amount of unrest, fear, tension, worry and apprehensiveness regarding treatment and possible side effects of treatment. For many women, local gossip about treatment reflected the perceived fatality of the condition and the belief that mastectomy is the only way to treat the condition and its symptoms. For this reason, many women kept the news of their breast cancer hidden from the family for considerable periods of time; often years. Only to later require treatment for advanced stage breast cancer. This feature of the data concurs with previous published work.⁸

Only 1 patient identified that that a breast lump could be either benign or malignant. This patient also mentioned that her doctor has said that many cancers are now curable and stated: *it is not such a big deal now.*

Other patients had heard of cancer of the liver, blood cancer and general information about breast cancer and stated that : *I had not heard about its fatality. When I heard that it was an incurable disease I became worried about my health.*

A significant number of women held the belief that breast cancer comes from Allah and by God's grace he will cure them. The development of cancer was a stimulus to strengthen religious beliefs and a coping strategy that the women used for comfort, inner strength support during their troubled time. For the women in this study, the importance of religion

and strength of religious belief and its contribution to coping with the experience of breast cancer equates with previous published reports.⁹ This is illustrated in the following excerpt:

I have a strong faith and when I found out that I had cancer it came to my mind that it is from Allah. My strength in belief is going to make me well again. I pray 5 times per day.

Family reassurance

For many women, the family support that was offered both from immediate and extended family members, husbands and siblings was a positive source of support. In most cases, women praised the support, comfort and hope that they received. Support was used as coping strategy to assist them to overcome the treatment obstacles; both surgery and chemotherapy. The need for support during the illness trajectory is part of an essential coping mechanism.^{6,7}

The following excerpts summarise these points:

: Initially everyone consoled me and everyone was sad at the news but later on they all reassured me that I will get well.

: My family members are really hopeful, they gave me the hope as well. Don't worry everything will be fine.

The alternative position was where the family were reluctant to help. One patient stated: *My family are all very busy with their own lives and they don't really care about me but my daughter helps me out.*

In total 4 women indicated that their husbands and family members were unsupportive which did not help women deal with the diagnosis, its inherent stigma and the numerous treatment cycles.

Coping through prayer

A repeating theme from both young and older women was the importance of praying, having or renewing their faith in Allah and that their future health is dependent solely on Allah's mercy, gracious help, support and Allah's wishes. For many women, their faith and confidence in Allah held the key to future developments, life expectancy, living to see their children mature and ultimately being cured of cancer. Many patients re-affirmed their belief in Allah and with God's help, he can assist them to cope with the stages of the illness trajectory. Namely; related depression; sadness; difficulty in finding happiness in their lives; crying associated with the symptoms of the disease and family pressures. This feature of the data equates with similar studies in Muslim women.⁹ Many women do not seek spiritual guidance from religious scholars but chose to pray independently, and offered prayers up to five times a day if possible. Women also developed strength through reciting surahs (verses) from the holy Koran. Religious beliefs were viewed as a source of strength which has a positive impact on their outlook.⁹ These sentiments are illustrated in the following excerpts:

: When I was told that I needed surgery that's when I became very worried and upset but then I prayed a lot to Allah and I told myself that he is the one who gave me this disease and he is the one who is going to get me out of this disease. Doctors are a source of healing but the healer is God himself.

:As a Muslim we know that every problem is brought on us by God and he is the one who will give us a solution to these problems and the strength to cope with this illness and treatment.

:My faith in God has become stronger and I think that this disease is from Allah and he will cure me.

Maternal responsibility and impact on family life

The majority of women in this study were housewives and therefore the disease had a significant impact on their ability to undertake their household chores, and to attend to their families. For many women, the inability to work efficiently due to physical weakness was a constant reminder of the disease. For women with extended families, other female members of the family, particularly sisters-in-laws, or daughters assisted with the daily chores or recruited the help of servants to complete household chores. A related issue was the future of their children. Many women had young children and were depressed and constantly worried by the uncertainty of treatment outcome and the future of their children. Some older women expressed their emotions in terms of anger and pent up frustration. These sentiments are reflected in the following excerpts:

I was very upset, but then I told myself I have a young daughter and I have to get better for her. If I lose hope what will become of her.

I know that I have to get well for my children and this also gives me strength and the mental strength to get better, to seek treatment and pray for treatment.

I suffer from mental weakness, aggressiveness and get angry easily. I disturb my house, my aggressiveness disturbs my home.

Feelings of isolation

In interviews with both young and older women the issue of isolation was a common theme that appeared to manifest itself 4-5 days after receiving chemotherapy. Women emphasized the need to be alone, preferred not to talk or discuss issues with people and also experienced a dislike of being surrounded by other people. Women expressed that they disliked meeting people and family members and preferred not to attend family functions and weddings. This common problem may be related to the experiences of women in relation to the issue of torture (family members constantly gossiping about them which was a constant reminder of their illness) and issues of extreme discomfort felt by women in relation to relationship with close relatives. These sentiments are reflected in the following excerpts:

: Psychologically, I don't feel like talking to anyone. I think that my appearance has changed drastically, I don't look the same anymore and because of that I don't want to talk to anyone.

: I don't like to meet people. I am usually okay but immediately after my chemo for 4-5 days, I feel sick and I don't want to meet anyone.

I don't feel happy since the moment the disease... there's something going on .I have become extremely sensitive and feeling really low. I don't like to attend functions anymore, I like to stay alone. This item in my life has become very difficult during the time of chemotherapy.

Financial burden of treatment.

A common theme related to the financial implications of treatment. Many patients resourced the treatment themselves. This was very expensive for families, and often led to financial difficulties with many families using all their savings to pay for treatment. This was often related to loss to bread winners and income in the family. For younger, unmarried women, the cost of treating breast cancer meant that families could not offer financial assistance for dowries. In some cases the hospital offered support towards treatment costs. The following excerpts reflect these issues:

: My husband left me six years ago. I don't work so my family support me financially . I also get financial support from the hospital.

:The family have spent so much money on my disease, how can they now prepare a dowry for me. It is not possible to make a dowry and bear the expense of a marriage anymore.

The treatment for this disease is very difficult both financially as well as physically. My brother and my father are both deceased they were the bread winners in the family and now we don't have enough money to pay for the treatment. Everything that we had saved in the bank has now been utilised and we don't know how we are going to go on with the treatment. I just hope that there could be some kind of concession because I am being treated here as a private patient and it is very expensive.

One patient stated that her family were not a source of support:

I am continually upset by the lack of support from my husband and financial issues and that fact that my husband and in-laws blame me for my disease. They say that it is my personal

fault and they are unwilling to spend any more money on me and this blocked access to my treatment.

Discussion

In this study, many women voiced their concerns over the shock they experienced at the time of diagnosis. For many women, shock is a common response to the diagnosis of breast cancer^{6,23} and can petrify a lot of women, leading to turmoil, emotional chaos and the need to re-organise their lives to maintain control.^{6,24} For many women this led to difficulties acknowledging the importance of the diagnosis²³ or failing to 'take much in' at the time of diagnosis. This was followed by the expectation that they were expected to cope with complex treatment cycles that were rapidly implemented. For many Pakistani women there was also the associated fear of possible mastectomy. Although women in this study did not disclose concerns or fear of altered body image, feelings of womanliness or the loss of femininity which may result from having a mastectomy. They did acknowledge that they were emotionally ill prepared for surgery and verbalized their relief that their 'breast was saved'. For these women the journey to diagnosis was a transforming event that can cause many women to develop anxieties about the diagnosis and trepidation about the proposed incurable nature of breast cancer and possible imminent death.²³ This fear was also intertwined with anxieties associated with receiving chemotherapy.²⁵ Fear and a lack of knowledge caused women to hide the breast lump from their husbands and families. In Canada, Asian Canadians have a tendency to assign breast cancer as a low health priority and to not disclose a diagnosis to individuals outside the close knit family, especially as it may impact on their children's future marriage plans.²⁶ Non disclosure of breast cancer is potentially life threatening but may be a reflection of the social stigma that is associated with a diagnosis of breast cancer. This finding concurs with published reports.^{8,26,27} It was

important for women to disclose their illness to partners as they could have offered an enormous amount of support at that time.^{28,29}

Coping strategies

In this study, women employed two main coping strategies; prayer and belief in the almighty power of God and support and continued reassurance from immediate and extended family members. Women used their belief in God to help them cope with the diagnosis and treatment required as breast cancer patients. This is not unusual for Muslim women to gain emotional strength to continue with treatment through prayer, reading verses from the holy Koran, and believing that through prayer they will be cured and regain their health.^{9,30} The need for spiritual support is well established in the literature; irrespective of faith many women recognize the need for spiritual guidance.³¹ Coping through prayer has also been used a source of emotional strength by women from different religious beliefs.^{32,33,34} Religious beliefs are viewed as a source of strength which has a positive impact on their outlook and is viewed positively by women; both young and old. This need for spiritual support is well established in the literature; irrespective of faith many women recognize the importance of God in their lives and the need for spiritual guidance.^{31,32} For women in this study, the diagnosis of breast cancer either strengthened their belief or re-confirmed their belief in God as the ultimate creator and one that will help to cure them. Spirituality was a source of comfort for women, it reduced their fear and uncertainty and gave them the strength to fight the disease, tolerate the treatment and look to the future. This response is similar to reports of both African American and Asian American women who believed that their future was in God's hands.^{26,35} As God has more control over the development of cancer and can alleviate breast cancer symptoms.^{36,37} Many women also sought religious support from religious

scholars such as Imams, from local prayer groups and asking people to pray for them. This concurs with previous studies and reiterates that women used prayers and their religious beliefs to adjust to a diagnosis of breast cancer.^{30,31}

Many women gained emotional support from their immediate family, husbands, children and predominantly female extended family members. The ability to discuss opinions, relate fears and concerns related to their illness is an important aspect of the daily lives of women reported in this study. This was particularly important as their illness had an emotional impact on their children and other members of their extended family.³⁸

The emotional chaos of breast cancer

The majority of women in this study were housewives with children and family responsibilities. Breast cancer treatment left many women feeling too weak, lethargic, and emotionally labile to undertake their household chores or to look after their immediate family. These are common reactions to chemotherapy.³⁹ In this respect, female members of their extended family provided both emotional and social support. Husbands offered extensive emotional and physical support and reassurance which concurs with previous studies.⁴⁰

For many women, the psychological dimension of breast cancer is an important aspect of the disease. As it may not only increase her body consciousness which can result in loss of self-esteem but it can also have an emotional effect. Many women have to cope with disability, the psychological adjustment to the illness, the potential threat of disfigurement^{21,41} and the need to tolerate chemotherapy and often radiotherapy. Although women in this study did not disclose their emotions related to possible disfigurement, or feelings of femininity, many

discussed the pain, fears of uncertainty, possible recurrence⁶ and also the potential sacrifice of losing one's hair and breast due to cancer.⁴² In addition to these, there was also the deep concerns about their maternal responsibilities and who would look after their children. This concern may have been intensified in unfavorable circumstances such as poor relationship with in-laws and husbands or lack of support from families possibly related to blame culture. There is also the issue of denial of the condition, the remarriage of the husband or lack of family support due to family members residing in a different country.

In breast cancer patients, depression is viewed as a common psychological reaction to the illness. The level of depression may vary from moderate to severe^{43,44} and severity may correlate with the stage of the disease at diagnosis.⁴⁵ It is suggested that depression can be assessed using predictors of self-esteem, level of social support and fatigue and can be alleviated through measuring the association between the biological, psychological and social dimensions of experience of breast cancer.⁴⁶ There is also the financial aspects of the illness that need to be considered and their possible impact on depressive illness.

Not all women with breast cancer develop depression.⁴⁷ A woman's ability to cope may be dependent on their psychological status prior to the diagnosis of breast cancer. This is thought to be the best indicator of how women cope with the illness trajectory²⁴ and may be dependent on a fighting spirit, aggressiveness, hostility and emotional anger⁴⁸ as indicated by some women in this study.

In conclusion, although the experience of Pakistani women living with breast cancer may mirror the sociological and psychological adjustments that many breast cancer patients endure and the reliance on religion and spirituality as coping mechanisms which reflect the

findings of African American women and to some extent Persian Muslim women. In addition, there is also the concealment of the illness which is noted in Korean culture. However, seeking spiritual advice rather than medical advice appears to be unique to Pakistani Muslim women. There is also the dominant issue of maternal responsibility which appears to be an innate characteristic of Pakistani Muslim women and one that led to much worry, depressive reactions, emotional chaos and deep concern in women. Many women's initial thoughts were for their children rather than their own lives or the potential impact of their illness on relationships with their husbands. This innate cultural influence needs to be the focus for additional studies. In Pakistan, many women choose to surrender their careers to become housewives and mothers. This was a consistent trait in this study. For this reason, the women in this study appear to have developed a strong bond with their not only their children but their extended family. Families co-habitat and share responsibilities, and many female members possess dominant roles in terms of child care, and family support. Additional studies could examine the impact of breast cancer on women who have dominant roles in extended family networks.

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