

CHALLENGES AND BARRIERS IN BREAST CANCER DIAGNOSIS AND TREATMENT IN PAKISTAN

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Abstract

Background: Breast cancer is the most frequently diagnosed female cancer globally, with Pakistan holding the highest incidence rate in Asia. Despite the critical importance of early diagnosis and treatment, Pakistani women often seek medical help at advanced stages due to various socio-economic and cultural barriers.

Objectives: This study aims to explore the individual, socio-cultural, and structural barriers that hinder timely breast cancer diagnosis and treatment in Punjab, Pakistan.

Methodology: Employing a qualitative methodology, the research involved in-depth interviews with 45 breast cancer patients. The study focused on identifying key obstacles such as lack of awareness, reliance on spiritual healing, feminine sensitivity, stigmatization, aversion to male doctors, economic limitations, and inadequate medical services.

Results: The findings highlight significant barriers to early diagnosis and treatment, including socio-cultural factors like stigmatization and feminine sensitivity, individual factors such as lack of awareness and reliance on spiritual healing, and structural barriers like economic limitations and inadequate medical services. These barriers contribute to delayed medical intervention and increased mortality and morbidity rates.

INTRODUCTION

Breast cancer is the most frequently diagnosed female cancer in the world and the second most frequent cancer in general, after lung cancer.¹ The rate of incidence of breast cancer is also greater in Western European nations than in Eastern Asian and African nations.² Still survival is much more common in Western European nations than in low and middle income nations.³ This is largely attributed to the much superior screening and treatment centers found in high-income nations. Greater awareness of early mammography screening

in these nations has also led to a reduction in breast cancer death rates over the last four decades.⁴

Pakistan holds the highest rate of breast cancer in Asia⁵ and most recent demographic trends indicate that this rate is likely to continue growing in the next few years.⁶ Early diagnosis of breast cancer is vital to decreasing both mortality and morbidity. Moreover, mammographic screening is subject to a range of socio-cultural as well as economic factors.⁷ Yet, Pakistani women tend to visit medical facilities at the terminal stage of cancer because of various socio-economic and cultural reasons. They are age, work

status, unawareness, fear of surgery, and dependency on traditional therapy and spiritual healing.⁸

In Pakistan, 89% of breast cancers are diagnosed at an advanced stage, and 59% are at an advanced stage, mostly because of unawareness.⁹ The fear of stigmatization and feminine sensitivity limits treatment options and delays the early detection of breast cancer in low- and middle-income countries.¹⁰

Also, physical barriers cause psychosocial stress because patients fear going through the tiring screening and treatment process.¹¹ In Pakistan, there are very few studies that have looked into the causes of delay in cancer screening and treatment, and awareness has been a major cause of delay.¹² Other risk factors include low socioeconomic status, unavailability and affordability of cancer drugs, and exposure to toxic industrial chemicals.¹³

No study has been conducted on the role of socio-cultural beliefs in delayed breast cancer treatment and screening in Pakistan. Nonetheless, some research has been conducted on patients' knowledge regarding breast cancer in Punjab,¹⁴ which has investigated the role of social support in breast cancer coping, how to manage the illness, and the causes of delayed diagnosis and treatment.¹⁵ In addition, Banning et al. (2010) also carried out a qualitative study that was predominantly centered on the cultural background of breast cancer experiences.¹⁶

By contrast, the current research uses a qualitative methodology to explore breast cancer diagnosis and treatment fears as well as barriers. One of the unique features of this study is its detailed investigation of individual, socio-cultural, and structural barriers that prevent women from availing themselves of timely diagnosis and treatment in Punjab. It also explores facets of the experience of breast cancer that are not well covered in current literature.

Literature Review

Khan MA, Shafique S, Khan MT, Shahzad MF, Iqbal S, et al., (17) conducted a study in which they examine the problematic issue of delay in diagnosis in late-stage breast cancer and the implications thereof for patient survival. It draws attention to the fact that delays in treatment arising most often because of unawareness, social stigmatization, economic hardships, and inappropriate medical

facilities, reduce survival prospects profoundly. Research concludes that three-to-six-month delays can enhance disease progression possibilities while diminishing possibilities for recovery. The paper highlights the critical necessity for early detection schemes, enhanced healthcare accessibility, and awareness campaigns to increase breast cancer survival rates in Pakistan.¹⁷

Majeed I, Rana A, Rafique M, Anwar AW, Mahmood F, et al., (18) conducted a study in which they examine the cancer diagnosis and treatment delays in Lahore, Pakistan, and its environs with the objective of determining causes of the delays and how they can be minimized. The study entailed an in-depth study between 2016 and 2017 using questionnaires and interviews among 673 patients to assess several elements of delay time across various phases of cancer care. The research examined six intervals: patient delay, referral delay, oncologist delay, treatment delay, system delay, and overall delay, to identify the determinants for the overall delay in cancer treatment.¹⁸

Agha N, Tarar MG, Rind RD, et al., (19) conducted a study in which they experience of Struggle against Socio-Economic and Geographical Barriers in Rural Pakistan," presents information about struggles experienced by Breast Cancer (BC) patients from poorer rural Pakistan. The study involved interviews with 42 BC survivors of northern Sindh in southern Pakistan. The study was set to explore and analyze socio-economic, geographical, and financial barriers, and their intersection and complexification of the lives of BC patients. The findings reported that most of the women were poor and that their socio-economic background informed their health-seeking behavior. Their knowledge about the disease was also poor, leading to delay in symptom assessment and proper treatment.¹⁹

Raza S, Sajun SZ, Selhorst CC, et al., (20) conducted a study identifying Local Beliefs and Knowledge," was designed to evaluate the attitudes of general practitioners (GPs) and women in Karachi, Pakistan, toward breast cancer, mammographic screening, and barriers to breast health care. The study included surveys of 200 women and 100 GPs, using questionnaires and cellular phones to gather data. The results indicated that women's knowledge of breast cancer was correlated with their education,

and although most GPs were aware of significant risk factors, a few held misconceptions about the illness. The study concluded by pointing out specific areas for targeted educational and early detection programs, noting the necessity of heightened awareness and access to care by women and additional education for GPs.²⁰

Material and methods

This research used the descriptive exploratory qualitative study research design to find out the phobias and hindrances around breast cancer diagnosis and treatment among people in Punjab. This method allows respondents' perceptions, assumptions, and action to be described in depth. To realize this, extensive in-depth interviews with breast cancer-affected women were carried out with the objective to identify the reasons behind the late diagnosis and treatment of breast cancer. The

investigation was conducted within Punjab, Pakistan's most populated province, wherein over 70% of Punjabi people belong to this territory. Punjabis form most of an ethnic group whose population exceeds over 45% of the Pakistani population of 220 million people. There are seven specialized hospitals in Punjab for cancer care. For this research, Faisalabad's Punjab Institute of Nuclear Medicine (PINUM) Hospital was chosen purposefully as it is easily accessible to patients. The hospital caters to 14 million people from five surrounding districts. Permission to collect the data was obtained by a written application, together with a proposal for research to be submitted to the Director of PINUM. The Director asked a female doctor from the hospital to introduce the researchers to potential study participants to facilitate rapport-building with the patients.



Table 1: Socio-demographic characteristics of study participants (n=45)

Variable	Category	Frequency (n=45)	Percentage (%)
Age Range (Years)	19-23	06	13.3
	24-28	06	13.3
	29-33	05	11.1
	34-38	10	22.2
	39-43	09	20.0
	44-48	07	15.6
	49-53	02	4.5
Residence	Rural	22	48.9
	Urban	23	51.1
Marital Status	Married	30	66.7
	Single	10	22.2
	Widow/Divorced	05	11.1
Monthly Income (PKR)	Up to 30,000	12	26.7
	31,000-60,000	21	46.7
	61,000 & above	12	26.6
Education	Up to Middle (8th)	05	11.1
	Matric to Graduation	33	73.3
	Masters & above	07	15.6
Diagnosis History	Up to 1.5 years	10	22.2
	1.6-3.5 years	28	62.2
	3.6 years & above	07	15.6

Study participants

A breast cancer patient between the ages of 18- and 50-years undergoing treatment in the hospital constituted the study group. The socio-demographic backgrounds of the patients, such as age, locality, marital status, income level, education level and diagnostic history, are presented in Table 1. A purposive sampling technique was employed to recruit 45 women with breast cancer. Nevertheless, three participants withdrew from the study after initiating the interview because they lacked interest, and their responses were not included. The sample size was calculated based on the saturation principle, whereby data collection was halted once no new themes or information was gathered. Patients coming to the hospital only for screening were excluded

following consultation with a doctor. Interviews were conducted only with those under active treatment.

Data collection

The research employed semi-structured interviews to investigate obstacles to breast cancer diagnosis and treatment. The interview guide was created following a literature review and piloted with medical specialists, medical sociologists, and a social psychologist. It was pilot tested among five patients and iteratively refined during the study. Female research assistants trained in interviewing approached participants in waiting rooms at hospitals, screened them for eligibility, and received consent. The lead researcher, with four years of experience in qualitative research, interviewed

participants privately. Participant consent was received for digital recordings and detailed notes. There were two interviews with each participant. The briefing and consent session came first, and the second was a recorded interview. Interviews lasted between 14 and 47 minutes, for which 45 participants had a total of 1,337 minutes recorded. All interviews took place in Punjabi from January 22 to April 30, 2018. The researchers conducted debriefing sessions after every session to review the responses.

Data analysis

Data for this research were analyzed employing an inductive strategy. All interviews, as recorded, were transcribed word-for-word from Punjabi to English. The transcripts were thoroughly reviewed, and notes were recorded for data accuracy. Analysis blended predetermined as well as emerging themes based on field observations and ward discussions with patients, attendants and physicians. Themes and sub-themes were determined collectively by the research team through a rigorous review of field notes, transcripts, and recordings. A coding book was designed and reviewed every now and then to make modifications in categories. The themes were classified into three levels: individual, socio-cultural and structural barriers, and were represented utilizing the socioecological model.

Results

The present investigation identified some breast cancer screening and treatment barriers divided into three groups: individual, socio-cultural, and structural. Individual barriers cover a lack of awareness of breast cancer, hesitance for social support seeking, and reliance on spiritual healing. Socio-cultural challenges majorly cover feminine sensitivity, stigmatization, and aversion to male doctors. Additionally, structural barriers including economic limitations and poor medical services were discovered to hamper the access of women to diagnosis and treatment. Socioeconomic and demographic information of the study population is shown in Table 1.

1. Individual barriers

This theme identifies individual-level barriers to breast cancer diagnosis and treatment. It is organized around three main sub-themes.

● Lack of awareness:

Breasts in Pakistan are mostly considered sexual organs, and it is not easy for women to talk about breast cancer in public. Social norms hinder women from sharing information about their bodies, making awareness of possible health conditions low. Therefore, women's knowledge about breast cancer screening is still inadequate, and they have never learned how to do breast self-examinations. Such a lack of awareness prevents them from identifying lumps or other symptoms. In this research, most of the participants conveyed that women as a whole are not well informed about breast cancer, screening, and medical intervention. Many also conveyed that they felt shocked upon the diagnosis. One 47-year-old woman conveyed her reaction when she was told about her status:

“Oh! It was a very difficult time in my life. My mind was empty, unable to think of what to do. Poor women like me do not know how and where to get the screening and treatment. No one in my surroundings could guide me about it”. (Age range 44-48, Rural, Married).

● Spiritual healing:

Religious beliefs are commonly perceived as a source of support and a way to deal with life-threatening illnesses. Religious myths, social pressure, and misinformation contribute to low rates of breast cancer screening and late medical consultation among Pakistani women. Most of the participants expressed overall ignorance about the disease and its treatment, prompting them to look for alternative remedies that were not always effective. As a patient said:

“When it happened to me, I didn't know why a lump appeared in my body. I shared it with my sisters and cousins. They shared a few stories of women with the same symptoms and suggested to visit spiritual healers who had reportedly healed those women. I visited those healers for more than 6 months, but the lump got more swollen and that scared me further”. (Age range 34-38, Urban, Married).

● Hesitance in accepting social support

They found that breast cancer women experience shortage of social and emotional support from family and other relationships. Because of the perceived insensitive behavior of individuals, patients shun encounters with friends and neighbors. Patients feel that their social body is not sufficient for public sphere. As a result, breast cancer patients prefer to spend more time alone since they do not want to confront people. Patients would rather have social isolation than available social support to escape negative body image evaluation of their bodies.

"I face some strange behaviors from my relatives and friends who often avoid me. They think that they will get affected by my disease. Even when some of them want to spend time with me, I simply avoid them because I feel that my relatives stare at my head, eyebrows and chest constantly". (Age range 39-43, Rural, Married).

2. Socio-cultural factors

This theme covers social and cultural factors that pose barriers to individual agency of women suffering from breast cancer. Three sub-themes have been discussed under this theme.

● Feminine sensitivity

Women linked breast cancer to a broken body image and loss of femininity. This was because they felt that the disease affects a body organ that symbolizes femininity and motherhood. Additionally, cancer treatment can cause skin coloration, hair loss, loss of eyelashes and eyebrows, all of which disrupt the body image. A participant shared her fear of the treatment. "One day I came to the hospital for chemotherapy, and I was told that my hairs were going to be removed. At that time, I wanted to run away from the hospital. When my hair was removed, I cried a lot. My next fear was that they would cut off my breast. Breasts are the sign of completeness for women. I feel scared when I think about a mastectomy". (Age range 39-43, Urban, Married).

● Stigmatization

Members explained that family members and neighbors started avoiding them after they came to know about their breast cancer. Due to this, breast cancer patients faced severe discrimination as their

bodies were negatively labeled and viewed as unclean. A woman shared her experience to reveal her disease in community:

"I never hid my disease and that was my biggest mistake. Women come to see me, but their conversation made me feel guilt and shame. I feel that God gave me this disease because I am a very bad woman. Now I do not go to my husband and children because my in-laws think that they will suffer because of me. I feel pain, sad and cry when some people avoid me and reject me". (Age range 34-38, Urban, Married).

● Aversion to male doctors

Our interviews indicated that women were hesitant to go to male physicians for treatment because they did not wish to expose their breasts for examination and treatment to male physicians. Religious beliefs and cultural values restrict women to undergo breast cancer treatment and consultation from male physician. In addition, husbands and relatives also disapprove of seeking treatment from male physician. Therefore, most women postponed treatment due to the distress felt on speaking of a breast-related issue to a male doctor. They believed that a pious and righteous woman should not reveal her body to any man other than her husband.

"When I was directed to a male doctor and he asked me about my disease, it was very embarrassing for me to discuss my breasts with him. It was worse when he asked me to show the tumor. As a Muslim female, I could not imagine that I can ever show my breasts to an unknown male, but when I had no choice, I had to do so". (Age range 34-38, Urban, Married).

3. Structural barriers

The accounts of breast cancer patients suggest that there are a few macro-level institutional factors hindering screening and treatment. Two sub-themes have emerged under this theme.

● Lack of financial resources

The majority of the patients interviewed were of lower socioeconomic status and could not afford health care expenses. Financial constraint is a main deterrent against breast cancer treatment. Women do not wish to be an addition to their family's expenses as treatment for cancer is very costly and generally lower-middle income groups cannot afford

the cost. Therefore, patients do not undertake treatment and conceal pain. This is illustrated in the account below:

“When I came to know about the disease, I thought my treatment expenditures will be a financial burden for my family. I belong to a poor family; if my family spends money on my treatment then they would not have enough for their livelihood. (Age range 24-28, Rural, Married)

In Pakistan, health insurance is not common and most of women remain economically dependent on their husbands. Moreover, they are conscious about meeting the needs of their children and other family members and often neglect their own health.

● Apathetic medical services

A considerable portion of cancer patients find it difficult to access treatment centers, including pain relief for incurable cancer. In hospitals, most patients are turned away because there is no inpatient space and no oncologists available. Most primary healthcare centers and hospitals also do not have appropriate cancer screening centers. Even among those hospitals that provide cancer treatment, the care given to patients falls short. One participant told us about her experience:

“Initially, I faced a terrible experience when I visited a renowned hospital. The hospital administration refused to provide in-patient care because they felt I was too old. They made me feel like a burden and I realized that old people are not needed by society. I visited the hospital for treatment and their (physicians’) attitude made my sickness worst.” (Age range 44-48, Urban, Married)

Discussion

The interviews uncovered the diverse obstacles to diagnosis and treatment of breast cancer in Pakistan. Interviews indicated that women are reluctant to reveal breast cancer in early stage and generally believe breast to be a sexual organ. Awareness of breast cancer screening is highest and women were lacking awareness about breast screenings, self-examination, treatment centers when they first noticed lump in their bodies. Different studies from Muslim majority nations have also indicated that absence of awareness regarding the disease results in

delay in the screening and treatment of breast cancer.²¹

Lack of information regarding proper breast cancer screening and treatment may result in adverse perceptions and their unrealistic dependence on spiritual and traditional treatment. It can lead women to embrace spiritual and traditional healing. Additionally, in cultures where individuals believe in religious beliefs, they tend to attribute calamities and affections to the will of God and assume that supernatural interventions will heal the disease. In this study, some of the participants reported that they were unaware of the causes of their disease and felt that only God could heal them. This response is like reports from both African American and Asian American women who believed that their future was in God’s hands as God has more control over the development of cancer. Consequently, consulting spiritual and traditional healers can lead to delays in treatment.²²

Conclusions and implications

In this research, various barriers to diagnosis and treatment of breast cancer, which are individual, socio-cultural, and structural in nature, were identified. These individual barriers encompass a lack of awareness, dependency on spiritual healing, and aversion to social support seeking. Socio-cultural barriers in the form of feminine sensitivity, stigma, and uncomfortableness with male physicians further deter women from accessing healthcare services. Economic hardships and an inefficient healthcare system also act as structural barriers. To deal with these problems, an overall strategy aiming at psychological, socio-cultural, and structural barriers is required. Due to limited resources in Pakistan and the high percentage of illiteracy among women, women afflicted by breast cancer are severely handicapped. Hence, education plays a key role in increasing awareness about the disease. Breast health programs must be initiated at the community level to minimize the death rate. Policy makers, healthcare professionals, and researchers need to adopt culturally appropriate interventions to improve breast cancer diagnosis and treatment in Pakistan.

Limitations of study

The current study has two principal limitations. The sample of this study was comprised of women from Punjab which is a large province with diverse sociocultural settings making it difficult to reflect the findings at border level. Furthermore, data were collected from only one hospital that may have potential bias from the participants' views.

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