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Exploring Breast Cancer Patients’ Experiences of Struggle against Socio-Economic and Geographical Barriers in Rural Pakistan

By Nadia Agha¹, Maliha Gull Tarar², Rahim Dad Rind³

Abstract

This study offers insights into the barriers experienced by Breast Cancer (BC) patients from less privileged rural areas of Pakistan. We conducted in-depth interviews with 42 BC survivors, from the northern Sindh in southern Pakistan, to explore and analyse knowledge, geographical and financial barriers and how these barriers intersect and complicate BC patients’ lives. Results indicate that most of the women in this study were poor and their families’ health seeking behaviour was influenced by their socio-economic background; their knowledge about the disease was limited and they were unable to appropriately assess the symptoms for months, which caused delay. Based on the results, we underscore the need for increasing health education as who had a sound academic background, awareness about health as well as better social standing, accessed the treatment facility in time, approached quality healthcare services and were in a better position to cope with the aftermath of cancer. Extending the fold of quality healthcare services to less privileged areas and enabling women easy and inexpensive access to healthcare services will help in early diagnosis when treatment is affordable and chances of survival are better.

Keywords: Pakistan, Breast cancer, Poverty, Patriarchy, Women

Introduction

Breast Cancer (BC) is the second most frequent cause of cancer-induced mortality among women worldwide. According to WHO (2018), 2.1 million women suffer from BC every year. Not all cases of BC are fatal, but several are: approximately 627,000 deaths in 2018 were caused by BC worldwide. The remedy of BC is possible if it is diagnosed at an early stage when the treatment is less complex and more affordable and can save the lives of many women (WHO, 2017). Early detection is one of the key global concerns which can be addressed with public

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awareness and public education. Early detection is not possible unless people are aware about this fatal disease (Yip et al., 2008). However, accessibility and affordability are matters of great concern for less privileged people, particularly in developing countries where women are less advantaged in terms of equal access to timely and quality BC treatment (Shulman et al., 2010).

There are some common models for the inspection of BC such as Clinical Breast Cancer Examination (CBE), Breast Self-Examination (BSE) and mammography screening. The most viable method is mammography screening, but unfortunately these facilities are not available in low-income countries, like Pakistan, at the gross root level. Pakistan is the country where premature deaths from BC are on the rise (The Express Tribune, 2018). In Asia, Pakistan has the largest occurrence of BC; over 90,000 cases of BC are reported annually and approximately 40,000 women die every year. A great number of these cases are diagnosed when the cancer is at the advanced stage (Dawn, 2017). Approximately, one out of every nine women in Pakistan is likely to be the victim of BC (Malik et al., 2016; The Nation, 2017).

Globally, women face various difficulties in seeking BC treatment pertaining to knowledge, finances and their location. These barriers intersect with each other and further complicate the situation of BC patients. Unlike literate individuals who are determined, motivated and feel confident to have a clinical examination of BC, women with low literacy particularly from rural and less developed areas have limited knowledge about BC without the information of appropriate venues for treatment. For example, the majority of rural women in India do not know about BC, the mammography process or where to go for screening (Tripathi et al., 2018).

This study in an extension of our previous research in which we explored the extent to which families support BC patients (Agha & Tarar, 2019) and the prevalent beliefs and perceptions about BC in less privileged areas of Pakistan (Agha & Rind, 2021). This paper further extends knowledge about the hurdles that bar BC patients from accessing the treatment and how patients and their families negotiate with the barriers led by BC. By taking into account three barriers i.e., knowledge, financial and geographical, we argue that the level of health literacy, distance to quality healthcare facilities and financial constraints are associated with BC detection and treatment, and how these barriers affect primary prevention of BC among rural populations.

**Barriers to the Diagnosis of BC in the Context of Rural Pakistan**

There are multiple barriers such as socio-cultural, knowledge, economic and geographical to early diagnosis and treatment of BC. However, this study is designed to focus on three major barriers which impede early detection of BC and its treatment among rural Pakistani women i.e. knowledge, geographical and financial barriers. Knowledge about the disease is crucial for early diagnosis of cancer. A few factors are identified as obstacles of women’s access to BC treatment: first, knowledge deficiency is of the core importance because it impacts health seeking behaviour of individuals (Islam et al., 2017; Ersin & Polat, 2016). The majority of the population in Pakistan lives in rural areas with limited opportunities and less access to quality healthcare facilities. Lack of knowledge about available diagnosis and treatment facilities is another barrier to BC treatment (Khan et al., 2017; Akinyemiju, 2012).

Most of the women in Pakistan are unfamiliar with BC; Naz et al. (2016) explored poor knowledge of cancer among the women where three out of seven women had no idea about BC before the diagnosis. Siddiqui et al. (2016) found in their study that majority of women had a lack of basic knowledge with regard to early symptoms of BC, screening, breast self-examination, risk factors and its occurrence in Pakistan and about 84.2 percent women had no idea about BC.
diagnoses method and mammography. Lack of knowledge about BC is central to late detection. This has been borne in several recent studies in Pakistan. For example, Gulzar (2018) reports that poor knowledge and illiteracy led towards reduced survival rate of BC patients in Pakistan. This lack of knowledge also has its consequences on women; for example, a study on BC patients posits that more than 50 percent of women were presented for screening at an advanced stage of BC (Khokher et al., 2016). Secondly, geographical barriers are also the prime barriers in seeking timely health solutions. Women living in less privileged and remote areas face great difficulty in accessing healthcare services. Poor road structure, limited transportation and restricted access to BC specialists are key issues in the way of early diagnoses (Ponce et al., 2018). Inadequate transportation restricts women’s ability to find treatment, and also affects their health seeking attitudes. Larger distance, difficulties in accessing treatment facilities, living in remote areas perpetuate great difficulties for women to have access to BC screening and treatment (See: Akuoko et al., 2017). To attend a physician on a regular basis, conveyance is a big challenge for rural women in Pakistan. In this context, a free mobile mammography screening campaign was launched in 2013 by the Pink Ribbon Pakistan in an attempt to provide door to door service to the rural women in Pakistan (Pakistan Today, 2013).

A recent report of the World Bank has highlighted that rural areas of Pakistan have been the most underprivileged in terms of provision of services. These are the areas where most of the poor people in Pakistan (about 80%) live (World Bank, 2018). In urban settings, women have better opportunities and face no such demographic variations to approach health practitioners. However, women from less developed areas face pervasive socio-economic and geographical discrepancies in accessing clinical facilities (Baade et al., 2016). Rural Pakistani women cope with many difficulties to receive mammography screening on a regular basis, they have to travel many miles to reach hospitals (Pakistan Today, 2013) because tertiary level facilities are available in big cities.

Thirdly, financial barriers greatly discourage women from poor families from receiving BC treatment. Poverty and unavailability of resources are major hurdles to have a mammography screening test (Okoronkwo et al., 2015). BC diagnosis is followed by economic implications in terms of cost as it includes clinical diagnoses procedures such as mammogram, magnetic resonance imaging, biopsies and so on, which all are costly. Besides, BC treatment like mastectomy, chemotherapy and radiotherapy interventions are expensive and exist only in a few government hospitals. This high cost of treatment has a serious impact on people with constrained economic status; they are compelled to sell their property for the treatment of BC (Saeed et al., 2019).

Research indicates that BC patients have a better survival rate in developed countries because cancer is diagnosed and treated timeously. In developing countries, like Pakistan, most of the population cannot afford expensive diagnostic procedures and treatment of BC due to their low socio-economic status (Gulshan et al., 2018; Talpur et al., 2011), which has also been identified as a main barrier towards decreased survival rate of BC patients (Gulzar, 2018). Pakistan has a poor cure rate of cancer patients as the majority of the patients do not receive optimal treatment because of poverty (Aziz & Sana, 2002). For example, a cross-sectional study in Pakistan found that the mean cost of cancer care was 1,093USD, more than the monthly income and anticipated cost by the patients (See: Zaidi et al., 2012).

Poverty is a major barrier to the treatment of BC. More than half of the population in Pakistan have low socio-economic status and are unable to afford food three times a day for the family. The affordability issues make it quite difficult for women to access healthcare centres.
Gender discrimination and gender insensitiveness in receiving health facilities further deteriorate poor women’s conditions in Pakistan. The majority of women are not in any formal employment; they are given a handful amount at the beginning of every month and are warned not to ask for anything further until the end of the month. Therefore, they prefer to spend available money on children and family members by ignoring their health complications (Gulshan at el., 2018). Male family members are usually owners of wealth and property. In such a situation, poor women are not allowed to make independent decisions about their health (WHO, 2017).

Women having no reliable BC information or timely healthcare professional support may be more susceptible to emotional barriers such as discomfort, apprehension and fear. Women with lack of ability to find, understand and assess health information may be more vulnerable to knowledge related barriers whereby women with low social support or skill to steer healthcare services may be more likely to face structural barriers to diagnosis (O’Hara et al., 2018). This delay further worsens the lives of children and family members. Apart from this, Pakistan is a less developed country where clinical facilities for early detection are inadequately managed and poorly distributed. In this situation, the poor victims of BC reach healthcare centres when the symptoms have already grown and spread (WHO, 2017).

Methods

This study dealt with the women’s experiences of different barriers to BC treatment. Therefore, all three authors, belonging to the field of sociology and social work, chose a qualitative research design for data collection. A cross-sectional survey was employed as data for this qualitative study was collected from different parts of the northern Sindh, Pakistan. We used purposive and snowball sampling techniques to choose the participants as Cohen, Manion & Morrison (2013) suggest that sampling technique, representativeness and access to the participants must be taken into account while making a sampling decision. Purposive sampling is part of qualitative research and is often used to identify certain cases or individuals who meet a particular standard. The research questions guide who to sample for the study thus helping in selection of the participants in a strategic way and fulfilling the research goals (Bryman, 2012). Therefore, we purposively selected 42 women who suffered from BC during past five years and belonged to rural or less privileged areas of Sindh province.

Table 1: Age of the Women

<table>
<thead>
<tr>
<th>Age (in years)</th>
<th>No. of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-22</td>
<td>02</td>
</tr>
<tr>
<td>23-27</td>
<td>02</td>
</tr>
<tr>
<td>28-32</td>
<td>05</td>
</tr>
<tr>
<td>33-37</td>
<td>04</td>
</tr>
<tr>
<td>38-42</td>
<td>07</td>
</tr>
<tr>
<td>43-47</td>
<td>05</td>
</tr>
<tr>
<td>48-52</td>
<td>10</td>
</tr>
<tr>
<td>53-57</td>
<td>04</td>
</tr>
<tr>
<td>58-62</td>
<td>03</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
</tr>
</tbody>
</table>
We adopted a qualitative research design for three reasons: one, we wanted to record women’s experiences from various areas in the rural northern Sindh. These women belonged to marginalised areas with limited socio-economic opportunities. Research studies on such population are limited and do not highlight women’s plight and their struggle in their own voice. Recording their voices would contribute to understanding the conditions in rural areas, generally in low-income countries and specifically in Pakistan. Among the many reasons, the first-hand information gained through these women would be significant in understanding geographical variations and financial constraints that families face in marginalised areas. Second, qualitative methodology enabled us to understand the problem deeper and better. Three, the research question we wanted to answer, how less privileged families negotiate with the barriers led by BC, was adequately addressed by in-depth interviewing which also guided our investigation further.

Semi-structured in-depth interviews were conducted by using an interview guide. The interview guide was designed in a way to cover knowledge, financial and demographic barriers faced by the participants in gaining access to diagnosis and treatment facilities. For example, the interview guide contained the questions about: what were the initial symptoms of BC, how were those symptoms assessed, when and how did the women seek medical help, what role did the family members play in facilitating the women, how did the women’s location complicate their access to the treatment of BC, what difficulties did the women face in accessing diagnostic and treatment facilities, and how did the women and their families address financial constraints?

Table 2: Literacy Level of the Women

<table>
<thead>
<tr>
<th>Years of formal education</th>
<th>No. of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>10</td>
</tr>
<tr>
<td>Primary (5 years)</td>
<td>11</td>
</tr>
<tr>
<td>Secondary (8 years)</td>
<td>05</td>
</tr>
<tr>
<td>Higher Secondary/Metric (10 years)</td>
<td>06</td>
</tr>
<tr>
<td>Intermediate (12 years)</td>
<td>00</td>
</tr>
<tr>
<td>Graduate</td>
<td>03</td>
</tr>
<tr>
<td>M.A</td>
<td>06</td>
</tr>
<tr>
<td>MBBS/M.Phil</td>
<td>01</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
</tr>
</tbody>
</table>

The issue, however, was sensitive in nature and required prior measures to build trust and rapport with the participants. It was difficult in the beginning to approach the participants, in particular those from the villages where women’s lives were constrained by patriarchy. Thus, we did not access the participants directly and used intermediaries instead. These were the people who either knew the women or were among their relatives or friends. Participants’ fear to disclose their disease due to social stigma and social alienation was another challenge. Therefore, using intermediaries helped to develop trust because the intermediaries were trusted by local people. For building rapport, we initiated each interview asking the women about their lives, education, how they start their day and discussed their daily routine and social life at length.

To address gender and ethical concerns, women researchers conducted interviews with the women. This gave a degree of comfort to the participants in sharing details about their disease, treatment experiences and barriers. However, because of indigenous culture and notions of honour, initially, a few respondents were reluctant to talk about breast related issues and disease. In this
connection, some ethics of participation were ensured during the process of conducting interviews such as anonymity, confidentiality, and voluntary participation. If any participant refused to record her voice in an audio device, her verbatim consent was taken as a main factor of her participation. The interviews were conducted in Urdu and Sindhi languages and later translated and transcribed in English. In this study, we thematically analysed collected data as suggested by Braun & Clarke (2006). We followed the six-step model for analysing the data: we familiarised ourselves with the data by listening to the recorded interviews and then transcribing them. We then generated codes, developed themes and then reviewed the themes. After defining and naming the themes, the report was finally written.

Findings and Discussion

In this section, we discuss the main obstacles that bar women from assessing symptoms of BC and prevent them and their families from approaching the appropriate treatment facility, which causes further delay. We have divided these barriers into three categories, namely knowledge, geographical and financial. Although these barriers look general from names, when studied and analysed in detail, they demonstrate to be strong hurdles affecting patients and their families greatly.

Knowledge Barrier

Of all the women in our sample, none had prior knowledge of the signs or risk factors of BC. They were asked about the initial symptoms and all of them said that a lump or cyst had appeared either under the armpit or in one of the breasts. The women waited for it to be healed on its own as none of them had any idea about BC unless diagnosed and explained by their doctors. In other words, these women did not have an understanding of what the lump or cyst in the breast could mean. Although many of them had heard of cancer and some of them in fact knew that it is a life-threatening disease, the knowledge barrier barred them from assessing the symptoms accurately. This barrier was not only central in preventing the women from timely calculating the risks, but also contributed to wasting time. For example, 42-year-old Mansoora, who ignored the reoccurring dark circles around her breasts and shared it with her husband after several months, told:

*I felt a little lump inside my breast in the beginning, but ignored it for several months. One day, I observed a small red circle and a small lump within that dark circle. It was very small and still I kept ignoring it as most of the people do in rural areas. I noticed the dark circle again when it grew to the size of a coin. I was still taking it normally but discussed it with my husband. He advised me to discuss it with the doctor. I visited a private hospital in our city after a few days. The doctor suggested the surgery to remove that lump. Actually, I felt no pain in the lump, but the doctor was somehow sure that it could possibly be cancer. It was a huge shock for me because it is believed that there is no remedy for such disease, it is fatal.*

In traditional South Asian settings, women usually feel comfortable sharing their gynaecological issues only with female doctors (See Burnett, 2015). In contrast, most of the women in this study shared the signs of BC initially with their husbands and later discussed the issue with a female elder in the family. Only two women disclosed their condition to the mother-
in-law. This is despite the fact that Pakistan is a conservative society, yet the first point of approach was the husband.

The barrier of knowledge was not limited to women only, it had also influenced men’s understanding about their wives’ health condition. The women’s families, and most importantly husbands, were unaware of the signs or risk factors of BC. The husband’s level of understanding of the situation and assessment of the signs were correlated with his own educational background and exposure. This played an important role in accessing the healthcare facility; those who had limited literacy or were not able to evaluate the wife’s symptoms of BC made delays in taking the wife to the doctor. They considered these signs to be some infection or allergy that could be healed on its own. They only took the patient to a healthcare provider upon ongoing requests of pain and discomfort and that too for some medicines for this infection or allergy, as in the case of 39-year-old Nazia. She told us:

I felt a lump in one side of the breast, change in size and shape of the breast. There was an unusual pain that did not go away. I discussed this with my husband. Although he is a doctor, he ignored it. He told me that everything should be normal and that I should not overreact on such little things. I then took antibiotics and painkillers to get some relief, but pain became unbearable. I then went to see a physician. He advised me to go for tests and reports from a cancer hospital. Only then my husband became serious and took me to the cancer hospital.

Quality healthcare services in remote areas were almost non-existent. Local clinics were providing treatment for routine illnesses such as flu, fever, viral infections or at the most diabetes and blood pressure. These women as well as their families did not know beyond these routine illnesses, which influenced their understanding about major and serious health problems they could be exposed to. Therefore, they saw the symptoms of BC in relation to common health problems. However, there were a few women who still managed to break the barrier of knowledge and strategized to enlighten themselves about their bodies. With all obstacles, lack of access to information and ignorance prevalent in these areas, these few women seemed to make attempts to reach out to the venues they thought could help them gain effective knowledge. For example, 40-year-old Rukhsana did not wait for a moment to consult with important persons as soon as she realised that the symptoms appearing on her body could be a sign of a potential danger to her life. She shared:

I felt something like tumour in my right breast and started gaining weight quickly. I became worried because being a lady health worker I had some knowledge about cancer and one lady is a patient of BC in my relatives. I met my sister first and shared my problem, she asked me to see a doctor. I then thought of meeting the lady with BC considering that she might be helpful. She was under treatment. She educated me a lot about the signs and symptoms of the disease. She underwent mastectomy and treatment from the best hospital in the country. She advised me to consult the doctor, and only then I consulted the doctor.

Knowledge barriers diminish the chances of survivorship and are likely to increase BC fatality. Individuals with deficient knowledge are less likely to participate in screening test trials. A large proportion of people in rural areas are ignorant of the importance of mammography
screening and possess fatalist beliefs about BC. Lack of knowledge and poor awareness inhibits treatment seeking attitudes of individuals. Although Rukhsana did not have adequate knowledge about BC, she had experience of a relative who had suffered from this disease. Being a lady health worker, she sensed something wrong from the signs on her body. These experiences proved to be lifesaving knowhow for her. Some women in our sample also had a prior BC patient in the family. They, however, remained unsuccessful in utilizing that experience effectively in relation to understanding their own symptoms. Rukhsana’s experience of a family relative coupled with her job in the health department had enabled her to further organize her knowledge and overcome the knowledge barrier. Another woman (50-year-old Shehrbano) had also managed her disease effectively. She was an MBBS doctor and had knowledge about BC. She went for her routine mammography, without having any clear sign or symptom of BC, where a tumour in her breast was detected.

This is not to deny the importance of health education in women’s as well as men’s lives. Those having knowledge and training of health manage to access the venues useful for them. Knowledge barriers such as poor health information and misunderstanding about BC to be an incurable disease is one of the factors discouraging people from seeking treatment. According to the US Department of Health and Human Services (2010), health literacy means “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Lack of knowledge limits the ability and motivation of individuals to gain information regarding BC treatment (WHO, 2013). Women with low level of education have negative behaviour about mammography screening and consider this malignancy painful, harmful and leading to the loss of a breast (Mamdouh et al., 2014). Those who possess knowledge of BC screening are susceptible to emotional hurdles such as fear, embarrassment, discomfort and anxiety (O’Hara et al., 2018). In our study, Rukhsana and Shehrbano remained successful in accessing timely and quality care for their treatment because they had avenues and the ability to access the venues of knowledge, others did not. Other evidence points that literate individuals are determined, motivated and feel confident to have a clinical examination of BC. Women with more education are less likely to be vulnerable to morbidity and mortality from BC than those who have lower education (Mamdouh et al., 2014). Shehrbano and Rukhsana in this study were less vulnerable than other women. Their exposure, job, and training in health had enriched their knowledge, to some limit in Rukhsana’s case.

Geographical Barriers

All the women we interviewed lived in villages or less developed areas with no quality healthcare or diagnostic services available for serious health problems e.g. cancer. People requiring any scans, X-rays, or blood tests for common diseases usually travel to nearby cities for these services, but they have to travel even farther for cancer related screening, detection and treatment. In this study, distance to the adjacent facility has been evaluated to find out the degree of accessibility. Two hospitals existed in rural Sindh which deal with the diagnosis and treatment of cancer i.e. Larkana Institute of Nuclear Medicine and Radiotherapy (LINAR) and Nuclear Medicine Oncology and Radiotherapy Institute Nawabshah (NORIN). However, both of these hospitals do not cater for the proper treatment of BC. LINAR in Larkana is the only cancer treatment facility in the northern Sindh. It was established in 1978 by the Pakistan Atomic Energy Commission (Medical Review, 2016). In 2016, Scotland donated five BC screening units, but the Sindh government has been unable to make them functional and the units of worth one billion rupees are rusting (Kunbhar, 2017).
The women we interviewed usually visited Larkana for BC diagnosis. During the interviews, they said that LINAR was not up to the mark in terms of BC treatment. They further added that doctors at LINAR often recommend BC patients to visit Karachi – the capital of Sindh – for proper treatment. Karachi is located around 450-500 kilometre away from the villages and towns where these women lived. This longer distance caused serious demographic concerns because the women were poor and less autonomous to make health decisions. They did not have money to afford expensive treatment, transport and living expenses. Consequently, longer distance adversely affected the attitude of women’s families to go to Karachi for treatment.

Similarly, the women’s location in the villages without adequate healthcare facilities affected the early detection process even if some women suspected that the symptoms were dangerous. Lack of cancer related specialists in these areas further worsened the problem; many practitioners in the locality, where the women lived, did not have relevant speciality of BC. This further delayed the diagnosis and added more pain to the patient’s life. 47-year-old Akhtiar shared her experience:

*My cancer was not diagnosed at first because each doctor was identifying my disease as something else except cancer. It was a very irritating experience for me moving from one hospital to another. We travelled to various nearby cities to treat my disease, but all in vain. We then travelled to Karachi and BC was finally identified by the doctors of a cancer hospital.*

The fact that cancer related diagnosis and treatment can be sought only in big cities has impacted the access of families in remote areas. The distance of Karachi, which is the capital of Sindh and where all tertiary level quality care is available, was a problem for poor families. This added travel, accommodation and maintenance expenses, which could have been reduced if treatment facilities were available in or close to their own villages and towns. Some of the families had to move to Karachi to overcome the distance constraint and avoid frequent travel, as in the case of 30-year-old Falak. She narrated:

*I have been to LINAR for almost 5 months then my family suggested a hospital in Karachi, and till date I am following my treatment there. Initially it was a major problem while travelling around 450 kilometres to Karachi, but later we shifted our half family to Karachi and rented a house. Now I only travel for my treatment twice a week and visit my home town once in two months.*

The geographical barrier not only intersected with the knowledge barrier but also impacted the patients’ timely access to the city where appropriate and quality cancer treatment was available. For example, 45-year-old Sadia lived about 550 kilometres away from Karachi. She first consulted her gynaecologist to discuss the signs on one of her breasts which she herself failed to assess. Unfortunately, the gynaecologist could not assess the symptoms accurately and regarded these signs as normal. Sadia then travelled to a bigger city to consult a surgeon who told her that she was at the risk of BC. Her husband then took her to Karachi where her treatment started immediately.

Geographical concerns have been identified to have caused reluctance among women in seeking treatment. Health facility’s location at a longer distance has a significant impact on women’s health seeking behaviour (See: Abu-Shammala & Abed 2015; Onitilo et al., 2014). These
barriers not only discourage women, but also cause delay in accessing timely treatment. Women living in less privileged areas in Pakistan commonly experience geographical barriers, which ultimately makes their access to the BC treatment difficult and delayed.

Financial Barriers

Most of the women in this study had poor socioeconomic background. They and their families had limited resources to survive on. They lived in remote areas and this geographical barrier further increased the financial burden on them to manage the expenditure, if any of the family members was diagnosed with any disease. Financial barriers also appeared as determining factors in the women’s treatment process. Cancer related screening and treatment is expensive and there are no such financial assistance programs to help the needy. The situation is even worse if a woman’s husband has no source of earning or is involved in drug addiction.

Treatment cost for BC varies from hospital to hospital and the stage of cancer. On average, the women’s families spent $10,000 to $15,000 on the treatment. This cost went even higher for the patients who were treated at private hospitals. Some families were not able to arrange the required money which forced them to sell their valuables such as property or business. For example, 50-year-old Rabia had to visit Karachi frequently for her treatment. Her husband was unable to meet the cost of the treatment. Thus, he had to sell his agricultural land, which was the family’s only source of income.

Some families, however, managed to arrange money while others waited for any external help in the shape of loans. Husbands of the poor women in our sample tried their best in the beginning to arrange some money in order to seek treatment for the wife. This was apparent in the case of Falak and Naheed. Falak’s husband was not earning thus the father-in-law supported her financially. She also received her share in the property from her natal family which was also used for her treatment. In Naheed’s case, the family first tried to seek loans from relatives, but it was not sufficient for the treatment. They then sought a loan from a bank. Others, who did not have any property, had to leave the patient at the mercy of god. Many survivors in our study said that their husbands and in-laws showed less willingness to initiate the treatment of BC because of unaffordability. In this situation, women had to look to their natal families for support. Many women in our sample sought the financial help of their fathers and brothers after their husbands did not initiate the treatment process, such as 37-year-old Ruhi:

I had been facing tremendous financial constraints while having treatment of this disease. My husband left me at the mercy of my fate. He said that he had no penny to pay for incurable disease. I was greatly upset. My father demonstrated full support to me. My parents were not rich, but they still assured me of their help. My brothers also came to the forefront to support me. They arranged money and decided to get my treatment done from a good hospital in Karachi.

Low income and illiteracy are largely associated with poor access to screening services, delayed diagnosis and late follow-up (See: Okoronkwo et al., 2015; Akuoko et al., 2017). Those with high status and income are more likely to access healthcare than those with lower status and income (Sharrocks et al., 2014). In this way, the affordability issue is an added hurdle in the way of marginalized women to receive timely BC treatment or its detection. Families’ support and the treatment process were greatly influenced by their socioeconomic conditions in most of the cases in our sample. The women whose families had better economic positions accessed quality
treatment facilities. They did not encounter the issue of affordability or accessibility as compared to the women who belonged to lower classes. For example, 45-year-old Sadia whose husband had a private job at a multinational company which provided medical coverage for the family. Most of her treatment cost was covered by the company her husband worked for. This enabled her to be treated at the best private hospital. She regularly had her follow-up check-ups during the time of her interview. 54-year-old Rani had a similar experience: she belonged to a well-do-family and her husband and two children were doctors. Thus, she was immediately taken to a quality hospital for her treatment. This not only enhanced her chances of survival, but also enabled her family to meet the cost of cancer treatment because of their strong socio-economic position in the society.

BC can be cured with a minimum amount and the patient has greater chances of survival when the signs and symptoms are detected early (The Pan American Health organization PAHO, 2017). This study has identified some areas to prevent delays and ease BC patients’ lives in Pakistan. First, women who live in less privileged areas do not know that the treatment of this disease is possible, and such a notion has further worsened the lives of the women. Due to the limited access to information, education and awareness about BC, most of the women could not assess the symptoms and signs of BC. They did not know where exactly they had to go for diagnosis. The lack of knowledge about the process of initial screening led the patients to experience several challenges, sometimes more serious than expected.

Based on the findings of this study, it is suggested that there must be focus on cancer prevention instead of treatment for combating the disease. The situation of BC patients in rural areas needs immediate attention and intervention by the state: introducing health literacy and embedding it to the curriculum can be effective in tackling the knowledge barrier. Health workers from the government departments can also be taken on board in educating families about BC. Besides, media, community or religious leaders, survivors of BC should also be included in awareness programs. It is important to develop a mass awareness campaign about this disease in local languages in order to avoid unnecessary delay. In this regard, health practitioners and media can play a vital role, since the participants in this study, who were health professionals, managed their ordeal in a systematic way and can be a source of inspiration for the rest of the BC patients in Pakistan. These steps can be effective in early detection where treatment is less complicated and expensive.

Secondly, governments of all provinces should ensure that diagnostic facilities of BC are provided at all district level hospitals so that people from remote areas do not have to travel to big cities where tertiary level health facilities are available. This will augment the community's access to BC screening at the convenient location. This significant component of health system can expand BC screening coverage, through mobile mammography services, to less privileged areas where women lack BC knowledge and resources. This will help in addressing the geographical barrier.

Thirdly, easy and inexpensive access to BC treatment can reduce the agony of the patients. The research findings revealed that cancer related screening and treatment is expensive and there are no such financial assistance programs to help the needy; some families borrowed money from banks or relatives or were even forced to sell their valuable assets for expensive BC treatment. Introducing a well-integrated health insurance system, provision of free transportation cards and subsidized cancer treatment can play a central role in reducing the pain of BC patients and their families. The study has demonstrated that rural women’s lives are complicated by several barriers, if decision makers take into account these barriers before forming interventions, it can be helpful in early diagnosis where survival is possible.
The insights gained through this research are the life stories of some women who have successfully coped with a life-threatening disease. This was a small study to explore difficulties faced by BC patients in which barriers of knowledge, locality and finances were analysed. More research should be done to explore the situation of BC patients in other provinces. Other barriers, along with the three examined in this study, should also be assessed to provide an overall situation of BC in the country.

Conclusion

Pakistan has a high prevalence of BC, which poses many risks to women’s health and well-being. Women in rural areas of Pakistan experience a number of hurdles in seeking BC treatment. This is despite the fact that the disease is increasing in the country at an alarming rate. The present study was carried out to examine knowledge, geographical and economic barriers to cancer detection and treatment. The interview responses provided detailed information about three major barriers to BC diagnosis and treatment.

Findings indicate that the dilemma of families living in rural and remote areas is even worse as these families live in underprivileged conditions and their attitude and access towards cancer treatment is influenced by the three barriers i.e. knowledge, geographical and financial. These three barriers intersect with each other and further complicate the situation of BC patients in Pakistan. The results offer insights to understand the barriers associated with early diagnosis and cure of BC. These also present various real life stories, miseries and complaints of BC patients from underprivileged areas of Pakistan. Besides, the study also provides recommendations and solutions to the government, stakeholders, NGOs and policy makers which are specifically working for women's healthcare services. Currently, there is a dire need to expand the fold of health education including BC. Lack of knowledge and limited information about cancer treatment prevents early diagnosis and treatment of BC in Pakistan. Considering the high prevalence of BC in Pakistan, provision of quality healthcare services is mandatory, and it is severely needed to start education and awareness programs in local/regional languages to minimize delay in treatment. This study specifically focused on three explicit barriers. There may be other multiple barriers in the way of timely diagnosis and treatment of BC that need to be explored and analysed in future research.
References


