BATTLING BREAST CANCER: WOMEN’S NARRATIVES OF STRUGGLE, FAMILY SUPPORT AND SURVIVAL FROM RURAL SINDH, PAKISTAN

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Abstract

Breast cancer poses a major health risk to Pakistani women causing 40,000 deaths annually in Pakistan (Pink Ribbon 2019). Based on 40 in-depth interviews with women who have been treated for breast cancer from rural Sindh, this study explores the extent to which families, living in rural and less developed areas with poor socio-economic conditions, provide support to the patients. The results show that women as well as their husbands’ level of education and awareness is correlated to delayed access to medical services. Our findings show that husband’s support and empathy has a therapeutic effect on cancer patients. Women’s well-being and self-esteem was strongly associated with how men saw and dealt with their disease. Based on the findings, we recommend introducing awareness raising programmes and a well-integrated social support system to help the patients and particularly men who control women’s lives.

Keywords
Breast cancer, family support, Pakistan, patriarchy, rural Sindh
Introduction

Throughout the world, breast cancer is the most frequent form of cancer among women and poses a major health risk to them (Bray et al. 2013; Jemal et al. 2011; Hunter 2000). Globally speaking, breast cancer is detected among more than one million women every year and most of them succumb to it. The situation is even worse in low-income countries where women have limited treatment and screening facilities, low awareness level, financial constraints and cultural barriers to access the available treatment options (Coughlin & Ekwueme 2009; Porter 2008). Because of these constraints in low-income countries, breast cancer is usually detected when the patient is in the later stages. Breast cancer patients in these countries also have limited access to adequate treatment services because of major mobility related restrictions. In such circumstances, women’s education and awareness is crucial for effective clinical examination, screening methods, mammography and removal of individual and structural barriers (Crawford et al. 2016; Paskett & Stark 2000).

Pakistan is known for the highest incidence rate of breast cancer among the Asian countries (Begum, 2018). Because of the staggering unofficial statistics, Begum (2018) rightfully identifies breast cancer in Pakistan as a looming epidemic. Scarcity of data on breast cancer prevalence, early detection, treatment and follow-up on patients further aggravates the trauma of the patients and of their families. It is significant to note here that the stepping-stone in the provision of a healthcare system is the presence of a well-integrated social security system to protect poor people from social and economic vulnerabilities. Sadly, this basic requirement is nonexistent in Pakistan, thereby causing worsening effects on the health status of low-income and poverty-affected people (Syed 2004; Gazdar 2011).

Although the Constitution of Pakistan guarantees that provision of health services is the State's primary responsibility (Zaidi et al. 2019; Nishtar et al. 2013), Pakistan shows a poor record in the fulfilment of its responsibilities. Lack of funds, widespread corruption, and bad governance has caused low budgetary allocations for the health sector, which is merely 2.6 per cent of GDP. Natural disasters, political, administrative and institutional changes are also responsible for the unsatisfactory performance of the country’s health sector (Khaliq & Ahmed 2018). Moreover, the World Health Organization (2017) reports that Pakistan has failed to achieve the Millennium Development Goal Targets related to the provision of quality healthcare. Despite the fact that most of the people in Pakistan need social protection from the state to reduce poverty and vulnerability and to enhance their capacity to deal with financial and health risks, the absence of social protection services is highly likely to affect poor families, particularly those having patients with chronic and life threatening diseases.
In the case of women of Pakistan, the general negligence of health needs is worse. Patriarchy, the number one culprit harming women, is the norm of Pakistani society and affects these institution (Gazdar, 2008). The World Health Ranking (2018) places Pakistan at the eighth position, having the highest number of breast cancer patients in Asia, with ninety thousand annually reported cases and more than forty thousand deaths (Agha 2016, 2018; Ilyas 2017).

In view of these alarming statistics, breast cancer needs special attention. Research studies have reported that Pakistani families face severe social and financial problems related to cancer (Naqvi et al. 2018). A major portion of Pakistan's population, which lives in rural areas remains deprived of basic amenities of life. Despite the guarantees enshrined in the Constitution of Pakistan, vide Article 38, which stipulates that the State shall provide necessities of life, including medical relief to all citizens, rural areas do not have even minimal formal healthcare infrastructure and social protection services. Consequent to this neglect of and apathy towards citizens’ welfare, women who are already the most vulnerable segment of the society, despite being more than fifty percent of the national population, remain at high risk in terms of detection, diagnosis and treatment of life threatening diseases. Even if rudimentary facilities exist, rural women are prevented by truncated social norms and gender-based discriminatory practices to access medical facilities (Sohail & Alam 2007).

This deplorable situation is exemplified by a research study published in 2012 on 200 breast cancer cases. Patients in Karachi report that very few women had ever undergone clinical breast examinations (16%) or mammography (9%). The study shows that women need more awareness and access to routine screening for mammography (Raza, et al. 2012). Unavailability of tertiary level healthcare services exacerbates women’s situation because these hospitals are not within the reach of poor rural people. Although when compared to previous decades, understanding about the disease has notably risen and demand for treatment and diagnostic services has surfaced (Pakistan Today 2017), socio-cultural barriers still hamper women’s access to diagnosis and treatment services. For example, Khan (2018) reports that Pakistani women are reluctant to go for any kind of breast examination because of shyness and lack of awareness. Thus, many women are unable to share their health issues specifically related to breast and reproductive health.

This reluctance, embedded in religious-cultural norms, emphasises the importance of female physicians for female patients. Studies have demonstrated that Muslim women prefer to be examined by female physicians, especially when it comes to examining their private body parts or pregnancy related checkups because of embarrassment that they experience with male physicians (Amir et al. 2012). Despite this fact, the government has done little to address women’s preference for the gender of healthcare providers,
particularly in rural areas where literacy is less prevalent and women have constrained lives. Although there is no exact data about practicing women doctors in Pakistan, the statistics of the Pakistan Medical and Dental Association (2019) reveal that 64,320 doctors were registered up to 31st December 2018 in Sindh, and of them 33,816 were women. However, Masood (2017) reports that official statistics do not present a real picture as the majority of women doctors do not work and leave their careers for family life.

Women’s mobility is another issue, which influences their access to healthcare services. In the context of Pakistan, women’s mobility is restricted by various factors such as age, marital status, and codes of honour (Mumtaz & Salway 2005; Sathar & Kazi 2000) which pose serious hurdles in seeking healthcare. Younger women have more restricted mobility than older women do, (Saeed 2012). Since women’s unchaperoned and free mobility is socially condemned, strictly prohibited and discouraged, their access to healthcare or other social services becomes conditional upon the willingness and availability of male family members, particularly husbands. Such restrictions on mobility have serious health implications for women; not only do they discourage and bar them from participating in the socio-economic mainstream, but also prevent them from living a healthy life (Maqsood 2007).

Cancer and role of family support

Cancer patients have complex needs related to personal care, emotional support, medication administration, symptom management and treatment monitoring. For daily care of cancer patients, dependency on family involvement has increased since the 1980s when the healthcare system transferred in-patient arenas to ambulatory and home settings in the USA. In such a situation, well-prepared and educated family caregivers can bring positive outcomes in the cancer healthcare system (Given et al. 2001; Arno et al., 1999; Lobchuk et al. 1997; Given & Given 1994).

Fear of cancer diagnosis, lack of knowledge about the association of age with the risk of breast cancer and issues of privacy and modesty are the main cultural factors, which affect breast cancer screening. However, support networks can enhance well-being and positive health outcomes by helping the patients to cope with the disease as well as stressful events (Katapodi et al. 2002; Facione & Katapodi 2000; Molinari et al. 1998). A study of older women with breast cancer explored the relationship between support networks and patients’ mental health. The study reported that adult children, partners and other family members were the key source of support for breast cancer patients and had mental health impacts (Maly et al. 2005). These results, however, reveal ethnic and racial diversities. The extent of family support determines a patient’s level of stress and fear of cancer.
For example, a longitudinal study on white well-educated women undergoing breast cancer treatment in the United States found their anxiety co-related with their partner’s anxiety. A partner’s anxiety also influenced women’s well-being regarding management of symptoms, fatigue and depression. Thus, it is essential for partners to manage their own stress because breast cancer patients have to deal with their own stress and treatment of the disease (Sergin et al. 2007). In our study, similarly, we attempted to examine how couples with low-income, and living in underprivileged conditions, manage the challenges of cancer and what role their relationship plays in supporting the patient. We also want to explore the extent to which men can provide care giving and relief to their wives.

Family caregivers have played an imperative role in cancer care, but as patients’ functional status declines, perceived burdens and depression among the caregivers increase (Grunfeld et al. 2004). Previous studies have indicated that a wife’s breast cancer not only affects the woman but also her spouse because both – husband and wife – have to face consequences related to household and personal disruptions due to the unpredictable nature of the disease, including problems with sexual intimacy and other unbearable symptoms. Because of this, cancer may be called ‘the couple’s illness’. In breast cancer treatment, the role of caregivers, specifically of the spouse, is of core importance. A husband’s capacity to help his breast cancer-afflicted wife wavers because of his fear of losing the wife and because of his lack of information and training in care giving. For successful treatment and care giving, therefore, understanding of the psycho-social needs of caregivers, especially of the spouses cannot be overlooked (Zahlis & Lewis 2010; Lewis et al. 2008; Lethborg et al. 2003; Skerrett 2003; Ben-Zur et al. 200; Hilton et al. 2000).

Psychosocial, religious and cultural impacts of breast cancer are not recognized in Pakistan even though family and spiritual support is crucial for the patients' treatment in order for them to cope with issues of anger, aggression and isolation (Banning et al. 2009). Social support props breast cancer survivors’ coping strategies. It can influence their positive reframing and psychological well-being (Kim et al. 2010). Thus, Malik (2002) notes that families in Pakistan usually believe that a patient’s physical and psychological well-being will be adversely influenced by his/her awareness of diagnosis of cancer.

In a patriarchal society such as Pakistan is, women’s autonomy, empowerment, and access to social space is strongly associated with men (Tarar & Pulla 2014). In this subordinated position, women suffering from breast cancer are more vulnerable as compared to healthy women. Breast cancer-afflicted women are often victims of harsh treatment by the family and by society. We attempt to highlight rural Pakistani women’s struggles through the process of breast cancer treatment, and record to what extent family, in particular husbands, can support women in the battle against breast cancer.
analyse how men strategize to support their wives and what impact this support leaves on women.

Research methods

For this sociological qualitative study, we conducted in-depth interviews with 40 women who had either undergone breast cancer treatment during the last five years or were undergoing treatment during the time of the fieldwork for this study. The fieldwork was carried out between March – August, 2018 in various parts of northern Sindh. Over the span of 6 months, we looked for cancer survivors and patients living in villages and towns of different districts, namely, Jacobabad, Shikarpur, Qamber Shahdadkot, Larkana, Sukkur, Ghotki and Khairpur. We used intermediaries to access the respondents. Those intermediaries included doctors, neighbours or relatives of women patients. The intermediaries were contacted through the persons we knew. Women interviewed for this study belonged to different age groups; for example, the youngest survivor was a 19-year old, whereas the oldest one was aged 60 years. The table below shows the age group of the respondents.

Table 1: Age of the respondents

| Age (in years) | No. of women |
|----------------|--------------|
| 18-22          | 02           |
| 23-27          | 02           |
| 28-32          | 05           |
| 33-37          | 04           |
| 38-42          | 05           |
| 43-47          | 05           |
| 48-52          | 10           |
| 53-57          | 04           |
| 58-62          | 03           |
| Total          | 40           |

Family support

In each interview, participants were asked how their families dealt with their situation. For instance, who accompanied them to the doctor, how often they visited the clinic, who looked after the children when they were being treated, and how their children reacted to the mother’s condition. The length of each interview varied depending upon how willing the participant was and to what extent she was prepared to share her personal life with us. On average, each interview lasted for an hour in which the participants also spoke about
how they felt once they knew the diagnosis of breast cancer and how they coped with the
after effects of chemotherapy.

**Depression and cancer related stigma**

The main aim of this research was to find out how women battled the deadly disease and
to what extent their families, particularly husbands, helped and supported them. Since this
was a sensitive topic, the discussion of depression or stigma was evident. While sharing
how they faced these circumstances, many women had tears in their eyes. Some of them
told us how some of their community members treated their disease as an epidemic.
Nevertheless, the majority of the women were brave enough to defeat cancer despite all
odds.

**Ethical concerns**

Our study of breast cancer involved several ethical concerns because of the sensitivity and
nature of the problem. The women’s educational level and their cultural and economic
backgrounds further complicated the situation. We, therefore, had to take extra measures
to contact the respondents and take their consent for interviews. We reached out to all the
women through intermediaries we already knew. These intermediaries either had some
relations with the women or knew them through some other source. Once the woman
showed her willingness to be interviewed, only then we approached her and scheduled the
interview. Since most of our respondents were either uneducated or had limited education,
we verbally assured them of keeping their identity confidential and then recorded their
verbal consent. Before we began asking questions, the purpose of the research was
thoroughly explained to each participant. In so doing, we did not jump to any tough
question; rather we began with discussing their daily life routine and their family
engagement.

**Results and discussion**

The women we interviewed belonged to either rural or less developed areas of the Sindh
province in Pakistan. The female literacy rate in the rural areas of Sindh is very low.
According to the Pakistan Economic Survey (Government of Pakistan 2018), the female
literacy rate stood at 65% in urban areas and 19% in rural Sindh in 2015-16. Our data
confirms the low literacy level of women. The majority of our respondents had never
attended a school and could hardly read or write. Surprisingly, six respondents had studied
up to Masters' level and one had done MPhil.
Physicians with speciality in cancer treatment were almost non-existent in the areas where we carried out the fieldwork. Presence of fake and fraudulent medical practitioners further aggravates the situation as most patients of low-income groups often are trapped by the low fee charged by such quacks. Nevertheless, not all qualified women physicians in the towns or cities had adequate or specialised knowledge about breast cancer, its signs and symptoms. For example, 47-year-old Akhtiar approached two qualified women physicians in two different cities who could not diagnose her problem; she then had to go to Karachi where her cancer was identified. Thus, the absence of qualified women physicians having expertise in breast cancer is a matter of great concern.

| Years of formal education       | No. of women |
|---------------------------------|--------------|
| None                            | 10           |
| Primary (5 years)               | 11           |
| Secondary (8 years)             | 03           |
| Higher secondary/Metric (10 years) | 06         |
| Intermediate (12 years)         | None         |
| Graduate                        | 03           |
| M.A                             | 06           |
| MPhil                           | 01           |
| Total                           | 40           |

Subsequent to the 18th Constitutional Amendment, provision of health services is a provincial matter. Sindh's health system is comprised of the public and private services. Divided into three categories, Primary, Secondary and Tertiary level healthcare facilities in Sindh are provided by the Department of Health, the Government of Sindh under a public-private partnership. Primary healthcare services, including primary healthcare units, dispensaries, rural health centres, mother and child health centres, are expanded to rural and remote areas, whereas the fold of secondary level healthcare facilities is limited to district and taluka headquarters. However, tertiary level services are limited in number and are located only in big cities (Health Department, Government of Sindh). In this study, the Larkana Institute of Nuclear Medicine & Radiotherapy (LINAR) was the only hospital located in northern Sindh (in Larkana) where diagnostic and treatment facilities for breast cancer were available. In this hospital, there was no qualified female cancer specialist doctor; a female gynaecologist was checking the patients to assess the signs and symptoms of cancer. Women respondents in this study were not satisfied with the treatment facilities at LINAR and many of them moved to better hospitals in Karachi.

Most of the women in this study lived under severe economic conditions; poverty was the major barrier preventing them and their families from accessing an appropriate
healthcare facility. Usually, they lived far from tertiary level healthcare facilities. Thus, many of the families had to take loans or sell their valuables to make travel arrangements and treatment possible.

The treatment of breast cancer patients in Pakistan is affected by several factors, such as lack of social acceptance of cancer, unawareness, limited access to medical care, and fear of the disease and its association with death (Malik 2002). Similarly, low socio-economic status and limited literacy, coupled with restricted exposure to the social world, has a considerable impact on women’s understanding of breast cancer. This fact was visible among the women we interviewed. Most of the women in our sample lacked basic awareness of the disease. It was commonly found that the initial signs of breast cancer were perceived as a pimple or swelling because of some infection. Some of them who experienced pain in their breasts ignored it, expecting it to heal by itself. These women were taken to the doctor only when pain intensified and they were unable to tolerate it any longer.

Primarily, women are barred from the public sphere, their mobility is restricted, and they can only go out with a male family member. Those who somehow manage to access healthcare services also do not fare better as the service providers have limited knowledge about breast cancer. Our data evidences that delay in diagnosis and treatment could have been prevented if the healthcare provider had dealt with the matter professionally; in many cases, the lump was considered a pimple and pain as normal. Another significant health deterrent in rural areas is the presence of fake healthcare providers that goes unchecked. Therefore, lack of any specialist in the area resulted not only in further delay in accessing appropriate diagnosis and treatment for these women but led them into the trap of these fraudulent health practitioners. Shockingly, the local doctors considered women's initial reports of pain usual and prescribed painkillers. For example, 36-year old Rasheeda, with a primary level of education, narrated the following to us:

I had a lump in my breast then pain developed. I consulted with a local doctor who considered it normal and gave me painkiller. When I had my second baby, I had serious problems and pain in breastfeeding. I then consulted with a woman doctor who asked me to get tests done and go to Karachi for treatment.

This lack of proper diagnostic facilities and dearth of specialists in the area worsened the problem and caused further delay. This delay proved fatal in Rasheeda’s case because by the time she could manage to reach Karachi, her situation had gotten worse.

Other women, who went through terrible pain and discomfort and kept on asking their husbands for relief, narrated similar stories. These symptoms went on for several
I felt pain in my breast for many months; I suspected something serious and shared this with my husband. We consulted with a local doctor who failed to diagnose the actual problem. Pain kept intensifying. My husband started asking his relatives about a relevant doctor. He then took me to a specialist who successfully diagnosed the problem and informed me that the disease was at initial stage. I had a mastectomy, where my surgeon found a hidden, malignant tumour, and further testing showed my left breast had a number of pre-cancerous cells developing. Next step was eight rounds of chemotherapy.

The outcome of lack of awareness, coupled with delay, proves lethal for these women. Many of the women in our sample reached the appropriate diagnostic and treatment facility when it was too late; one such woman, 28-year-old Hajra, reached the cancer hospital at the last stage when there was no treatment possible. She died within two weeks of her interview. In such a situation, women had only one person who could enable them to access and avail appropriate treatment – the husband. However, the husbands in our study also faced barriers imposed by their socio-economic status. Husbands' lack of education and absence of information about breast cancer significantly aggravates breast cancer patients' condition.

**The Extent to which husbands supported their wives**

Research data indicates that depression and anxiety is a usual phenomenon among breast cancer patients, and even after treatment a clear majority experiences psychosocial morbidity. Thus, those going through the situation need longer-term supportive care (Bozo et al. 2009; Reich et al. 2008; Zabora et al. 2001). In a society where men dominate and control women’s lives, as it is in Pakistan, the husband’s role becomes crucial in dealing with the situation women face. It is important to note that women’s health status after the diagnosis is correlated with how breast cancer is perceived by others, particularly by their family members and most importantly by their husbands. All of the women in our sample discussed the symptoms of breast cancer with their husbands first. In the majority of cases, the husband was the first person with whom the woman shared her situation. However, husbands’ levels of awareness about the disease were directly proportional to a future strategy. Many men lacked basic knowledge about breast cancer; they relied on information transferred to them either through relatives or quack doctors who lacked expertise. Fifty-two year old Naseem, whose husband had a high-school level education, encountered a similar situation. She told us, I would often have abdominal pain and I told my husband
about it. He first ignored considering it a usual thing but later, he took me to the doctor for check-up. The doctor told us it is a routine thing and I will be all right soon, but my husband was not satisfied because my condition did not improve. He kept taking me for check-up to different places. We then contacted our family doctor and got final check-up from him. A soft lump had appeared on my breast by that time and two other lumps under my armpit, my stomach was upset. The doctor then told me about the disease, although hesitantly.

Our findings show that men with an enhanced level of education strategized to deal with the situation differently and were able to take their wives to the specialist in time. Their strategies to support their wives and prevent any potential traumatic situation differed, such as the case of 54-year-old Rehana whose husband, as well as two of their children, were doctors. Rehana’s family members had initially dealt with her case in secrecy; they hid the diseases from her and revealed the truth only after the danger to her life was over. Her family went through immense pain, but they did not disclose this to the patient and extended their unconditional support in her crucial time. Sharing her story, this is what she told us,

A large egg-sized lump in my armpit compelled me to discuss about it with my husband who is a doctor and that is why my treatment started on time. I am fortunate enough to have a loving and caring family, particularly my husband. This is the main reason for my survival. He took me to a renowned gynaecologist of the city, who after a check-up told my husband that there are evident symptoms of breast cancer. He then quickly took me to the best cancer hospital in the country. The surgeon, after all tests and diagnosis, operated me and removed my tumour at once. But till that time, I was not told by my family about my disease, instead I was told that I have a small gland, which needs to be removed urgently. I was convinced by my family that I should not worry. Even though, I had an idea that there is something wrong. Slowly and gradually, I was told during my second surgery that I have breast cancer, and that the only reason for hiding this disease was to keep me away from any trauma.

Contentment and a feeling of relief were apparent on Rehana’s face. She was thankful to her family; particularly her husband whom she thought was a protagonist in this story. Her husband had also suffered with her but did not lack the courage to console his wife. This response played a constructive role in Rehana’s life as she was already going through the treatment and it was the psychological and moral support that she needed the most during that time. She continued:
One of the main reasons of my survival is the exceeding support of my family members who were with me during my treatment. When my son brought my first reports of breast cancer diagnosis, he also brought cake and drinks to show me that my report is normal and there is nothing to be worried.

It is evident that cancer changes family life, responsibilities and roles as it may affect activities related to homemaking, family care, childcare, and bread earning. Families can cause anxiety and depression or can provide strength and comfort to a person diagnosed with cancer. Good communication and family sharing can help patients cope with the disease and avoid misunderstandings, frustration and isolation (Cancer Support Community, 2018). Along with the moral support that gave courage and hope to women with breast cancer in the rural areas of Sindh, communication played a significant role in reducing stress and trauma. In a few cases, women’s husbands used communication as a strategy to relieve the wife: the husband would discuss her reports with the wife and express his feelings. The discussion would comprise possible treatment and its effectiveness to eliminate cancer from the body. This conversation reduced the degree of shame and shyness among women and enhanced their level of confidence in what they were experiencing.

Most women who participated in this study lived in extended families with their in-laws. This setup provided them with assistance in terms of childcare when they were being treated. However, the children’s well-being was affected by the mother’s illness and by the family's perception of the disease. Some women in our sample highlighted the psychological conditions of their children when the reaction of others scared them. For example, 30-year-old Nazia’s son, who overheard a conversation about his mother, asked her innocently, ‘Mama! Will you die?’ These children were terrified of the fact that cancer is incurable and that their mother would leave them soon. Some of the patients’ children were traumatised and went into isolation during their mother’s treatment process.

In some cases, children were also taken on board and were told about their mother’s disease so that they could also understand their mother’s condition, as in the case of 50-year old Saira, whose husband, a graduate, would discuss her reports in front of their kids. She told us,

My husband remained supportive through the process of diagnosis and treatment of breast cancer; he would discuss my reports and complications with me. He would sometime discuss it in front of our kids. With the courage the doctor and my husband gave me, I did not find it difficult to talk about it; I became very courageous. I was shattered in the beginning, but he supported me and held me
strong. He told me if I look at the hospitals, there are hundreds of women who face this disease, which is curable.

The kind of words men used as a reaction to the wife's illness had a huge impact on these women. Those who consoled their wives and told them not to worry about cancer infused a ray of hope in them which they lived on. The hope given to the women was the only spiritual source which helped them fight with the deadly disease and defeat it. However, those who remained unsuccessful in receiving such care faced the situation with agony and pain.

**Unsupportive role of husband**

Social support acts as a force of resistance among persons suffering from traumatic situations (Bloom & Spiegel, 1984). Social support is multidimensional and family support influences patients' well-being; it also improves their social functioning as well as opportunities for social exchange. However, families also find it difficult to provide support through the entire process of treatment, and the degree of care decreases with the passage of time. For example, Arora et al. (2007) in their study found differences in effective family support between the initial and post diagnosis and treatment period of breast cancer patients; it fell drastically low within the first year of diagnosis and treatments compared to the initial period.

Despite the fact that social and emotional support for breast cancer patients is required throughout the process of treatment, not all women in the study were able to gain family care in their difficult and stressful times. A few factors such as the number of years of marriage, the presence of adult children in the family, husband's level of education and awareness, husband's socio-economic status and the degree of empathy with the wife, played a positive role in many women's lives. Those whose husbands had sound economic status and were well educated provided immediate support to their wives. Wives of such men also performed better and lived with self-esteem during and after the treatment (as in the case of 54-year old Rehana whose husband and two children were doctors). Those who did not have these variables or had a disturbed marriage, suffered immensely; they struggled to gain support from the family and the husband and remained vulnerable throughout the treatment process.

For example, in the case of 28-year old Hajra whose husband had limited literacy and a humble job, she had only one young child from the marriage, which did not work well, and was divorced after her breast cancer was diagnosed. She was at the last stage of breast cancer when we met her for the interview. She shared her painful story in these words:
My husband had a humble job in Saudi Arabia. He would rarely contact me, so I shared my symptoms with my mother-in-law who was the sole decision maker of the family. Instead of any sympathy, she deliberately neglected everything and said that I was making lame excuses to avoid household work. To avoid divorce, I gave up all confrontations, continued to work as an unpaid maid, and experienced verbal and psychological abuse on minor issues. No one in my family showed mercy towards me except my parents. My illness was perceived as an epidemic disease and my only baby was separated from me. Later, I was divorced and sent back to my parents’ home. I realized my worth; I was an object of lust and care giving for my husband, and an unpaid maid for his family. My father sold his shop for my treatment. Even though he had little hope for my recovery, he tried to relieve my pain and suffering as much as possible through treatment, comfort and consoling.

Hajra was not the only woman in our sample who suffered negligence, maltreatment and injustice because of her disease. Thirty-seven year old Ruhi went through a similar situation; her husband turned a deaf ear when she told him about the symptoms of breast cancer. When cancer was finally diagnosed, her husband abandoned her. In a society where women’s well-being depends on men, a troublesome marriage or lack of empathy from the husband are often lethal. Such women are forced to live in isolation where death becomes inevitable. Hajra died two weeks after her interview with us, whereas Ruhi was living in isolation at her parents’ house; her husband had disowned her, believing that her disease was infectious and would affect him.

Cancer care involves a complex structure of care and coordination, especially among patients with advanced stages of disease who need more time and effort to manage aggressive therapy-related side effects. This need makes family caregivers more vulnerable. Moreover, family caregivers also have to manage patients’ transportation, comfort and care, and equipment care as well as financial concerns (Given et al. 2001; Given & Given 1994; Kaye & Gracely 1993). In advanced level breast cancer cases, coping becomes immensely challenging for family, caregivers and patients (Kershaw et al. 2004). Family care in our study proved phenomenal in enhancing self-esteem and level of confidence among the women. Family care also helped in reducing the level of shame and fear of death among the women. Every kind word and every gesture of care and concern worked wonders in the lives of these devastated women, as in the case of 50-year old Rehana who battled breast cancer and defeated it with all the courage and self-esteem she received from her family. She summed up:

My psychological battle against breast cancer will haunt me forever. I was not ready to face this unbelievable and scary situation. I felt devastated but the support from
my family helped me face this difficult time, which I could not have been able to do alone. Their smiling faces, warm hugs, kind and caring words made a huge impact on my life. I faced the hardest times of my life only with their support. I cannot express how grateful I am to them, and especially to my husband.

Conclusions

Based on the findings of this study, it is suggested that we introduce a nationwide programme on breast cancer awareness and implement interventions at the local level with a special focus on rural and remote areas. People living in these areas experience several hindrances, financial and social, in accessing a proper cure for a life-threatening disease. An extension of well-integrated healthcare services, with a special focus on women’s health will integrate more people, specifically families, in awareness raising campaigns and prevention programmes and initiatives. Moreover, the importance of support networks in these areas cannot be denied. These support networks can be phenomenal particularly for the women who are deprived of family care and attention (Agha 2018). As time passes, patients’ counselling becomes essential because families are likely to decrease their support with the passage of time and as the disease debilitates the quality of life. Therefore, these networks on a local level can enable women to cope with trauma and fight the disease. The well-being of breast cancer patients can only be ensured if there are trained and educated families or personnel for patients’ counselling.

This study analysed the extent of family support of breast cancer patients and survivors from the rural and less developed areas of Sindh. Findings indicate that social and emotional support for patients of breast cancer is essential through the process of treatment and the women’s well-being. Women who were loved and cared for by their husbands during this health crisis coped well with the trauma. Marital harmony, care for each other, and respect for human rights are some of the factors that ease the pain of breast cancer patients. The presence of adult children and the husband’s socio-economic status also contribute to minimising pain. Women with disturbed marriages had to suffer doubly; they struggled to gain support from the family and husband who already were estranged and suffered immensely as they felt lonely and abandoned. To ameliorate the sufferings of breast cancer patients, some of them terminally affected, civil society must move ahead by creating cancer patients’ support-groups. In this connection, institutions of higher learning, particularly medical colleges, need to revise their curricula to include the needs of breast cancer patients.
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