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# Experiences of the Breast Cancer Patients Undergoing Radiotherapy at a Public Hospital Peshawar Pakistan

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## ABSTRACT

**Objective:** This study aimed to explore the experiences of female breast cancer patients undergoing radiotherapy (RT) in a public hospital in Peshawar, Pakistan. **Methods:** This study employed a descriptive exploratory method. A purposive sample of 14 breast cancer women undergoing RT was selected for this study. Data were collected over the period of 5 months, using a semi-structured interview guide and conducting in-depth face-to-face interviews. These interviews were audio taped and transcribed by a bilingual transcriber. The translated version of the interview was coded, and the analysis was done manually. **Results:** Four main categories emerged from data analysis, which

were: feelings and perceptions of the patients, their challenges, coping strategies, and teaching and informational needs. **Conclusions:** Women undergoing RT in this culture experience more intense psychological effects, as compared to the physical effects. Keeping in mind, the magnitude of the emotional stress experienced by the participants, recommendations for policy reforms, and training for female RT staff are suggested based on findings of this research.

**Key words:** Breast cancer, experiences/problems/issue/ challenges, radiotherapy/radiation therapy

## Introduction

Globally, breast cancer is the most common cancer among women, and also a leading cause of cancer-related deaths in this gender.<sup>[1]</sup> It accounts for 23% of all cancer cases worldwide.<sup>[2]</sup> The incidence of breast cancer has been

increasing rapidly in the developing countries.<sup>[3]</sup> Among the Asian countries, Pakistan has the highest prevalence of breast cancer, where one in every nine women is at risk

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of developing breast cancer.<sup>[4-6]</sup> In western countries, breast cancer is prevalent among women aged 60 years and above, whereas, in Asian countries, including Pakistan, it occurs during the reproductive age between 30 and 50 years.<sup>[6-8]</sup> Hence, women with breast cancer, in Pakistan, may face more challenges due to household and child-rearing responsibilities, as compared to those living in the western countries.

According to the American Society for Radiation Oncology, radiotherapy (RT) is a common treatment modality for cancer which is prescribed to about two-thirds of the cancer patients, either before or after surgery (as cited in Berkey).<sup>[9]</sup> In breast-conserving surgery, RT reduces the chances of recurrence as well as the risk of metastasis and death from breast cancer.<sup>[10]</sup>

Despite the wide use of RT and its significant role in cancer treatment, the experiences of patients undergoing RT remain under-investigated. Only a few international studies have reported that women undergoing RT experienced undesirable side effects.<sup>[11-22]</sup>

### Literature review

Existing literature report that RT exerts multiple overwhelming physical side effects, including skin toxicity, fatigue, cosmetic changes, fibrosis and damage to underlying normal structures, pain, and swelling gastrointestinal problems.<sup>[10,17,23-27]</sup> The psychological effects of RT are also extensive, including, fear of RT, stress, anxiety, and depressive symptoms.<sup>[27-30]</sup>

Fatigue is also a commonly reported symptom of RT. Fatigue and local breast skin problems are strong factor that can adversely affect the quality of life in breast cancer patients.<sup>[15]</sup> Moreover, Wratten *et al.*<sup>[21]</sup> found that patients developed fatigue gradually during RT. In their study, the participants began to feel fatigue at the 2<sup>nd</sup> week, which reached its peak in the 4<sup>th</sup> week. Similarly, Lavdaniti *et al.*<sup>[14]</sup> found that fatigue level increased significantly during the first 2 days of RT. Stone *et al.*<sup>[27]</sup> found that 69% of patients reported an increase in their fatigue at the end of the RT in addition to pain, gastrointestinal problems, and insomnia that affected their role performance.

Sundaresan *et al.*<sup>[18]</sup> identified that 45% of patients undergoing RT experienced pain along with dermatitis, difficulty in sleeping, fatigue, depression, and anxiety. Likewise, Schnur *et al.*<sup>[16]</sup> also reported a range of skin problems, including pain, discomfort, irritation, swelling, and soreness. In addition, feelings of burning, itching, heaviness, and roughness of the treated area were also reported. Schnur *et al.*<sup>[31]</sup> also affirmed that physical side effects of RT led to psychological effects such as low self-esteem and fear of rejection. In addition, Webber *et al.*<sup>[19]</sup> showed that 50% of the participants' sexual performance

was significantly undermined after RT. Furthermore, Dhruva *et al.*<sup>[11]</sup> reported changes in sleep patterns among 50% of the participants at the initiation of RT, among those 19% ended up with insomnia.

Based on literature review, Rose.<sup>[26]</sup> highlighted that almost all women undergoing RT experience fear of RT machines and potential side effects of RT. Similarly, Halkett *et al.*<sup>[12]</sup> explained that, before, and at the start of the RT, patients experienced fear of getting burnt, damaging internal body parts, and feeling tiredness. The researchers asserted that these kinds of fears may have a negative impact on treatment compliance. Therefore, most of the patients need psychosocial support at the start and the end of RT.<sup>[32]</sup>

Considering the psychological and physiological effects of RT, several studies signify the role of patient education in RT. Halkett *et al.*<sup>[33]</sup> found that for most of the patients, their informational needs were unmet. Likewise, Hendry,<sup>[13]</sup> revealed that the clients asserted a dire need of information about RT. The findings also showed that the staff was not good at communicating information clearly, which provoked patients' anxiety. In addition, participants were also apprehensive due to the presence of male staff in the RT room. Zeguers *et al.*<sup>[22]</sup> identified that 76% patients wanted to know whether they could be cured with this therapy, while 72% were interested in prognosis-related information and 71% wanted to know if there was any other treatment modality after RT. Wong *et al.*<sup>[20]</sup> also reported that older women also have unmet information needs related to treatment choices, investigative tests, chances of relapse, and cancer prognosis. In their study, Sherminie and Cottrell.<sup>[17]</sup> also identified that the informational needs of the patients were unmet. This study also reported that some patients felt uncomfortable and stressful in the presence of male staff members in the RT units.

However, most of the studies that have reported ill effects of RT have been conducted in western countries, having different sociocultural and economic background than the eastern countries. There is only one study conducted on Sri Lankan women, undergoing RT by Sherminie and Cottrell 2014.<sup>[17]</sup> Participants in this study were apprehensive due to machines, and fear of the RT side effects and also because of the presence of male staff members in the RT units. Women anxiety due to exposure to male staff is very relevant to the Pakistani culture, especially from conservative cultures such as Khyber Pakhtunkhwa (KP) province, where a majority of the women strictly observe Purdah – concealing body from unknown people by wearing an additional big cloth or abaya over the clothes. Women may find it disconcerting to expose the intimate parts of their body in front of health-care providers (HCPs) of the opposite gender. Thus, exploration of women's experiences

undergoing RT was considered important, so that their needs can be identified and health-care professionals can support them through their trajectory of breast cancer.

### Purpose of the study

This study aimed to explore the experiences of women with breast cancer undergoing RT at a public hospital, Peshawar.

### Study questions

1. What are the perceptions of the women with breast cancer undergoing radiation in a Purdah observing culture
2. What kind of teaching or information is provided to patients before, during, and after the RT
3. What are the different types of challenges faced by women undergoing RT
4. What strategies and support system do they use to cope with these challenging/experiences?

## Methods

The study employed a qualitative, descriptive exploratory study design. The study setting was the RT unit of a public hospital in KP, Peshawar. There are four radiation machines in the hospital, which are operated by qualified male technicians.

Using a purposive sampling strategy, 14 adult female breast cancer patients were selected for this study with variations in their age, educational level, socioeconomic status, and number of exposures to RT.

After obtaining permission from the head of the institute, approval for this study was sought from the University Ethical Review Committee (3356-SON-ERC-14). Participants who gave informed consent were recruited for this study with the help of the staff, while they were waiting for their turn to receive RT. Participants were explained the voluntary participation, potential risk and benefits, confidentiality of information, and right to withdraw from the study. Pseudonyms were assigned to ensure anonymity.

### Data collection and analysis

Data were collected through the recording of the face-to-face in-depth interviews, using a semi-structured interview guide. The average duration of interview was 26.17 min. The interviews were conducted in Pashto and Urdu language, based on client's preferences. Moreover, reflections and field notes were also written to identify nonverbal gestures or the key features of the interview. The interviews were transcribed and translated into English by a bilingual transcriptionist.

The transcribed data were organized by collating all the responses of the participants against each study question for

manual content analysis. The research read the narratives line by line to gain insight of the data, and coded similar data together.<sup>[34]</sup> Words phrases and sentences were coded based on their explicit and implicit meanings. Further reflection on the codes led to the formation of categories and subcategories.

As shown in Table 1, rigor in the study was ensured in accordance with Lincoln and Guba's criteria of trustworthiness.<sup>[35]</sup> (p584).

## Results

As depicted in Table 2, a total of 14 female breast cancer patients participated in this study. Their age ranged between 20 and 60 years, with an average of 35 years. Majority (79%) of them were married. About 50% of them were illiterate, whereas 43% were matriculate. All of them were Muslims and of Pathan ethnicity. Before RT, all of them had mastectomy of the affected breast, followed by chemotherapy.

Analysis of the interviews data led to four categories with 2–4 subcategories [Table 3]. Each category and its subcategories are described below with some excerpts from the participants' narratives.

### Feelings and perceptions

The participants verbalized various feeling while reflecting on their experience of RT, such as grief and sorrow, shame and guilt, fear and anxiety, and uncertainty about the disease and its treatment.

#### Grief and sorrow

Most of the participants shared intense feelings of grief and sorrow, due to loss of womanhood related to mastectomy and alopecia. In relation to RT, the main cause of their grief and sorrow was losing their honor and dignity due to exposing themselves in front of male staff, which they considered as an invasion of their purdah. The extent of grief and sorrow was apparent in various analogies which they shared in their narratives. For example, Naina said that "It is very difficult to expose yourself in front of unrelated men (*gair mard*). It is the most agonizing moment for us because we are poor and the only thing we have is our dignity. Our purdah is our wealth and if that too is lost we are left with nothing."

Another participant expressed;

"Exposing my breast in front of the doctor was the most traumatic experience for me (*Dair afsos khabara da*)... I was distressed at having to endure this intense suffering. When my tumor was removed I was relieved of my physical ailment, but the agony of losing my honor and dignity will stay with me" (Rozi).

The participants also experienced grief and sorrow when they had to expose themselves in front of their male

**Table 1: Lincoln and Guba's criteria of trustworthiness**

Criterion	Description	Implementation in the study
Credibility	Credibility involves confidence in truthfulness in the interpretation of data	This was maintained by audio recording of the interviews, transcribing, and checking for its accuracy Member check during the interview was ascertained through deliberate probing to get deeper insight Data collection continued till saturation Field notes to note the nonverbal gesture and reflections soon after interview were written to validate the researcher's subjective impressions of each interview
Dependability	Dependability is stability of the findings and yielding similar results if the study is replicated in a similar context and population	To fulfill this criterion, interviews were repeatedly listened and validated Detailed information regarding research methodology has been provided for future researchers to repeat the study if needed
Confirmability	Confirmability is about the objectivity of the data and the accuracy of its meanings with minimum researcher's biases	Confirmability was enhanced through integrity of the findings, all the data analysis processes was discussed with the committee members and the supervisor The researcher's analysis and commentary is supported by relevant excerpts from the narratives of the participants
Transferability	Transferability refers to the ability of the findings being applicable in another setting	Transferability is facilitated by presenting detailed information of the research process for the readers to enable them to evaluate the applicability of the findings to other settings

**Table 2: Demographic characteristics of participants**

Variables	Frequency (%)
Age (years)	
20-29	5 (35.71)
30-39	4 (28.57)
40-49	4 (28.57)
50-60	1 (7.14)
Marital status	
Married	11 (78.57)
Unmarried	2 (14.29)
Widowed/divorced	1 (7.14)
Educational status	
Illiterate	7 (50.00)
≤10 <sup>th</sup> grade	6 (42.86)
>10 <sup>th</sup> grade	1 (7.14)
Social status	
Homemakers	13 (92.86)
Working woman	1 (7.14)

**Table 3: Categories and subcategories of the findings**

Categories	Subcategories
Feelings and perceptions	Grief and sorrow Shame and guilt Fear and anxiety Uncertainty of treatment
Challenges faced by women	Role performance Emotional instability Access and affordability of treatment Faith and prayers
Coping strategies	Family support Mind diversion
Teaching and informational needs	Source of information Quality of information

family members, on the 1<sup>st</sup> day, when their chest was being marked for the radiation site. Marking procedure required a male family member be present with them. In most of the cases, they were accompanied by their husband, brother, or father. However, when they had to expose themselves

in front of an unrelated male technician in the presence of their male family members, the experience was even more traumatic. As Rozi stated "When I came here to this room for marking, the doctor said, 'take off your shirt.' My husband was very saddened and dismayed and I felt it through his deep sigh"... He remained upset even after going home. Likewise, Sajida, an unmarried woman, who had brought up her siblings like a mother, recalled:

"During the marking my brother was standing beside me, and I felt extreme grief and shame at that time. I thought that I have spent my entire life in a respectful manner ... but due to my misfortune now my younger brother is seeing me naked and I was extremely upset for this reason."

For most women, their grief was related to the fact that this disease involved a private part of their body. For instance, Hina expressed,

"When I realized that a male technician would do my radiation, I became very upset and I questioned the Almighty 'O' Allah what have you done to me." O' Allah, it is not the disease but the site of the disease, which is so private, that is painful for me. It would have been better if it involved my hand or feet instead, which is not so private."

The participants were sharing feelings of helplessness because they had to take RT, otherwise, they may experience relapse of the disease. As Fozia mentioned, "I have to expose my body to unknown male staff. This is shameful, but I have no choice."

### **Shame and guilt**

Nearly, all of the participants expressed feelings of embarrassment when they were asked to remove their shirts in front of strangers. A young client exemplified the intensity of her feelings by saying,

"I felt very much ashamed on the 1<sup>st</sup> day, even when I got dressed (after the RT) and was going home. I felt

as if I was still naked (said loudly), I felt like all the men on the road are looking at me (pause) and I am naked (crying)” (Hina).

Describing almost similar feelings, another participant stated,

“When I was asked to take off my shirt for X-ray and skin markings, I felt an extreme degree of humiliation.... I cried a lot that day.... as we are Pathans and it sounded very bad to me.... I cried a lot and thought how embarrassing this life is (*sharmindgi wali zindgi*). Why did I become a victim of a disease that crushed my dignity and modesty” (Naina).

Many participants emphasized that it would have been more comfortable for them if they were dealt by the female staff members during RT. As, Hina, verbalized that “My purdah was compromised but the women in future should not be made to suffer like me.” Shameem added that, “When women can fly airplanes why can’t they operate this radiation machine, they can handle it as well.”

#### **Fear and anxiety**

Almost all of the participants described feelings of fear and anxiety before their first exposure to RT. Their fears were related to the terminology used for radiation, unknown treatment, cultural stigmatization, and the machine itself. The word “shot” was being for RT at this local setting. Almost all of the participants, irrespective of their educational status, dreaded this terminology. They misperceived the word “shot” as an electric current. Shameem said that she was really scared when she heard the word “shot” because she perceived it as an electric shock. She pointed out that “they (staff) did not refer to it as radiation (*shoan*). Likewise, Tahira expressed, “I was terrified by the word ‘shot’ before I experienced it ... however, it was just like an X-ray.”

In addition, being scared of the terminology several participants also expressed that they found the RT machine itself very intimidating. As Sajida expressed,

“On the 1<sup>st</sup> day, when I was in the waiting area and he [technician] called my name for radiation, I felt terrified and panicked. I was unable to stay still; I felt tremors in my whole body and experienced a severe headache. My throat and mouth became dry... I was thinking of what this machine will do to me?”

Similarly, Hina stated “When I stepped inside, and saw the machine, it looked like a monster (*bala*), so I got scared of it.” Likewise, Shamsa said, “I was afraid... as to what the machine will do to me, will it press my chest?... my wound... will it hurt me or not?”. The participants’ fears related to machine, subsided after having the first exposure to the radiation. Some participants also expressed that they were fearful of cultural stigmatization. They shared that they hid

the fact from their family that they were being attended by male staff for the radiations. Shameem disclosed,

“I have just mentioned that inside the radiation room there is female staff.... Because my sisters-in-law are illiterate, and they may pass sarcastic comments on me that unknown men see me undressed. In Pathan culture, quarrels and fights run in our families... So, if they know the reality, they will taunt me for the rest of my life.”

#### **Uncertainty of treatment**

Many participants were worried about the prognosis of their disease and the effectiveness of the RT, as it was communicated to them at the beginning that RT was the last treatment modality, after surgery and chemotherapy. They reported that the connotation of the phrase “last treatment” bothered them, as reflected in Tahira’s statement:

“I am just worried about what will happen after this therapy. Will I get better or not, I have this worry that this is the last treatment, and after that what is next?... they say it is a last treatment... what is next?”

#### **Challenges faced by women**

This category talks about the challenges faced by women during RT treatment. Most of the participants reported that RT affected their life. During the trajectory of this treatment, they experienced physical, psychological, and financial challenges. Physically, fatigue, body aches, and pains were their major challenges. Some participants reported symptoms such as itching, discoloration of skin, swelling of the radiation area, numbness, tingling and a burning sensation. The challenges perceived by women are subcategorized in 3, including role performance, emotional instability, and access and affordability.

#### **Role performance**

A majority of the participants experienced inability to perform their role during RT towards their family and society, due to fatigue and pain. As Maria said,

“Due to this pain in my hand and fatigue I cannot do any work at my home. My children are very young so, looking after them and washing their clothes daily becomes very difficult.... I can hardly take care of myself, then how can I take care of my children... So this is a great stress for me.”

Similarly, Naina shared her helplessness that she comes for radiations daily and leaves her kids at home; when she goes back in the evening, she finds them hungry and unkempt. She described that her children and husband also suffer a lot when she comes for RT.

Similarly, Asiya expressed:

“There is no one at home; I have to leave my children with the neighbors.... Children get affected more than me... My younger daughter has become very sensitive.

I think, as a mother, I have not taken care of her, that's why she has become agitated and irritable."

Many of them revealed that due to fatigue they were unable to have sex. Maria, explained "It requires strength and health to maintain a sexual relationship. When one is unwell, engaging in sex becomes difficult; therefore, I avoid him (husband)... Likewise, Tahira, mentioned, "I do not attend any event, I have difficulty in walking. Even if I walk slowly, my feet hurt too much, so I quit socialization."

#### **Emotional instability**

Most of the participants shared that they experienced anger, agitation, and depression as a result of radiation. Several of them were aware of their emotion of reactions, but they had no control over them. Their experiences are illustrated through the following excerpts:

"I do not want to get involved in any discussion.... I was not like this before...now I get angry and shout at my kids; I even slap or hit my kids ... I just cry for no reason or sometimes for very minor reasons. Even if someone says something good or bad" (Meena).

Similarly, Naina expressed, that, "I just want to lie down in some corner and want that nobody should talk to me. I do not care about my meals and other needs; I just don't want people to talk to me."

#### **Access and affordability**

For many participants, accessibility and affordability of the RT was a big challenge. Due to limited beds, clients had to come from far off areas, and live in hotels or with their relatives so they could arrive on time for treatment. Most women expressed that as a cultural norm, female has to accompany by a male family member while they were coming for RT. Due to which their male members' job also got affected and added to their financial burden, as evident in the following excerpt:

"We have come from a far off area, and have been staying in hotels... we did not get a bed in this hospital, so even from the hotel I have to come daily and I have to pay Rupees 200-400 for traveling... My husband and sister-in-law accompany me... He cannot leave me alone...as women cannot travel alone; one needs a man for going here and there. My poor husband was working in a foreign country he came because of my treatment and now he is jobless over here. Whatever he earned is finished; now we are taking loans" (Maria).

Hina described that she lives at her mother's place for 5 days in a week, during her radiation days, and she goes home on Saturdays and Sundays. Two of her school-going children also come with her and their schooling has got affected, which is the biggest problem for her besides her home being disturbed.

Most of the women reported that they belonged to the low-income families. They are unable to meet their routine

household expenses and the cost of their treatment. Almost all the participants shared that they had to borrow money for their treatment and due to the financial problems, their families are suffering too as Maria shared:

"I feel very weak, as one need to eat a healthy diet, but, we are poor, we are just concerned about the disease, we cannot afford a healthy diet along with the treatment. It is very difficult for us and we are just surviving."

Shamsa elaborated "We are extremely poor. My father has a low income; which hardly covers household expenses, rent, electricity and gas bills. The expenses of RT are huge so my brother took a loan to pay this fee."

#### **Coping strategies**

This category includes findings about the participants' coping strategies which consisted of, faith and prayers, family support, and mind diversion.

##### **Faith and prayers**

Almost all participants in the study showed a strong belief in God and fate. All of them believed that their suffering is a will of Almighty Allah. They used different expressions such as, "Allah will give me strength," "it is from Allah's side," "this was part of my destiny," "Allah is there," and "Allah will help" as Hina reflected:

"I pray and cry in front of Allah, that O' Allah this disease is from your side and You can cure me from this disease, and help us in getting this treatment.... I even recite holy verses quietly in the van, while I come here. I drink holy water and it makes me feel better."

Fari shared "I recite the holy verses, 'Astagfirullah' and the holy Quran. I offer my prayers and I also offer midnight prayers," which makes me peaceful and relaxed.

##### **Family support**

The family appeared to be the main support system for all of the participants. They shared that their family provided them, physical, psychological, and financial support during the trajectory of their disease and treatment. A participant Meena mentioned "Now they know that I am not healthy like before, so they help me a lot in all the household chores." Likewise, Fari expressed, "My sisters-in-law do not allow me to do any household task; they say that it will affect my treatment... when I go back home from here, they make my bed and bring me milk and medicine." Almost every participant shared that their family comforted them during their stress and despair. As Hina shared:

"He (husband) made me realized that I am valuable for him; I was concerned about the treatment expenses, but he consoled me and said that he can return the loan later on, but my life is very precious for him; he does not want any compromise in my treatment."

The majority of the participants reported that their relationship with their family improved during this disease

and its treatment and the bond of love strengthened when they became victims of this disease. Like Fozia shared “Initially, my relationship with my family members was not that good however, after I was diagnosed with this disease, they have changed, and now they care for me... my treatment is going on because of their support.”

Almost all of the participants shared that their families invested enormously in their treatment management, despite being very poor. For instance, Fari reflected on the sacrifices of her family, “My husband works on weekends to earn extra money for my treatment. He skips lunch to save money his parents also advise him to take care of my treatment only, and not to contribute money in other family expenditures.”

#### **Mind diversion**

Findings indicated different ways of mind diversion used by clients. Most women had strong bonding with their families; and this gave them the strength to cope with their worries, distress, and different challenges. For a majority of the participants, being with the family was their mind diversion strategy. The narratives of several participants illustrate these sentiments. For instance, Fari shared “When I have my kids and my husband around me I talk to them and my mind remains diverted and I feel relaxed.” Another participant Meena shared how she diverts her mind through socialization. She shared, “I visit the sick and go to celebrations and ceremonies. My children ask me to avoid going, but I say, no, let me go to people... I ventilate there and my mind gets diverted.”

Some of the participants also shared that they divert their mind by masking their worries, and by behaving as a normal person. Asiya shared, “When I go from here, I feel upset, so I wear beautiful clothes to look nice, I don’t want to look ill. I try to involve myself in household activities I don’t want anyone to say ‘she is ill’.” Similarly, Shameem reported:

“If I lie down on the bed, people around me will think that I am going through this problem or they will say ‘look poor girl is ill’. I never ever sat down. I just know that, I must keep on doing something so that I look normal, not ill.”

#### **Teaching and informational needs**

This category includes findings about teaching and informational needs and describes the concerns related to sources and quality of information.

##### **Source of information**

For nearly all of the participants, the key source of information was other patients coming for radiations. If they had any question or fear related to therapy, they used to seek information from clients sitting there. When inquired about why they did not seek information from

the HCPs, Sajida expressed that she is thankful to the women who gave her some information. She stated, “The hospital staff did not say anything about this... they have no time for these things.” Interestingly, another client Meena shared, that her husband inquired from his friends all the necessary information, about the machines and the process of radiation before coming for radiation; therefore, it was not a very fearful experience for her. She expressed, “My husband briefed me in advance that nothing happens initially; however, later some complications may occur. So from the start, I knew everything about the machine and the process. And I did not feel any fear or tension.”

##### **Quality of information**

Findings reveal that the informational needs of the patients were either minimally met or completely ignored. Majority of the participants reported that they had multiple queries related to RT, but they were not provided with any teaching or information by the HCPs.

As Maria described “Doctors and nurses do not take the time to explain these things to make us understand.” Few participants said that they were provided with very limited information when they requested for it. For instance, Naina shared that the doctor briefed her, that due to RT “the skin area will turn black. You may develop some cardiac problem, but radiations do not hurt. He did not tell me about the process, which I wanted to know, nor he consoled me that I should not worry.”

These findings indicate that almost all participants were minimally informed during RT, which affected their treatment. Nearly, all of the participants showed concerns regarding the markings drawn on their skin, for the identification of the radiation area. Most of them shared that they were asked not to erase these marks but were not educated as to how they could care for that part and maintain their hygiene.

Nighat expressed, “they (staff) told me that, I should not take a bath because the skin markings will wash off. I should not let it get wet. So, I have not taken a bath since 3 weeks.”

Some of the participants raised another concern that even if they had no problem in getting involved in sexual activity, but due to the religious obligation of taking a bath after sexual intercourse, they avoided sexual activity. Naina explained the effects of the markings on her sexuality by saying, “I do not go near my husband for any sexual activity because these markings will be erased with bathing... as one needs to take bath after sex.” Likewise, Shameem also shared, “they told me, that these marks should not be erased, so I stay away from my husband, because these markings will go away with bathing.”

A majority of the participants had misconceptions about radiation. Since they were not getting any information from



the HCPs, they were relying on information received from other patients, which most often created misconceptions among them. The following narratives depict as Sajida recalled:

“When I came here... a woman was discussing that it is like an electric shock...they hold an electric wire on the wound. Her son told her that you are weak that is why you had such feelings. Then I asked her, ‘does it hurt?’ She said ‘yes, it does’. That made me panic (*war me khata sho*) and I was extremely depressed for 2 days. I assumed from her discussion that it would be an electric shock.”

Likewise, Asiya explained,

“A newcomer woman told me that ‘there may be nails in the machine and that will pull out flesh (*gosht nikalen ge*) from our breasts’ she scared me so much that... I used to ask everyone how will it be? And what will happen after this therapy. So some people gave reassurance... and some made me more fearful... different people give different information, which confused and petrified me.”

The above findings indicate that accurate and complete information was not available to the patients and the information highly depended on the informant’s own experience and effects of RT.

## Discussion

The participants experienced shame and guilt as a result of being exposed to male staff during RT. Earlier studies<sup>[13,17]</sup> had also reported that women felt very uncomfortable and stressed due to the presence of male staff members in the RT units. However, the intensity of their feelings was not as strong as noted in the current study. The participants in this study also experienced intense feelings of grief and sorrow which is not found in the previous literature. The difference in the feelings could be related to their sociocultural background, and religious believes. As participants in the current study were Muslims and belonged to Pathan families, whose women strictly observe purdah. Revealing one’s body to unrelated men is forbidden in Islam, and a breach in purdah is considered a violation of their religious and cultural norms. It is important to consider that, for any female who belongs to the eastern culture being made to undress in front of a nonrelated male is an awkward situation, especially, exposing the body part which is of intimate nature and has been pointed out in the Holy Quran as a private part of the women’s body, “And tell the believing women... protect their private parts. (Soorah Al-Ahzab: 59).”

A study in New York, Schnur *et al.*<sup>[31]</sup> reported that women felt uncomfortable about exposing their breast in front of other HCPs because they did not want to expose themselves

in an unattractive state. As – “I felt uncomfortable having my breast exposed to another male technician. Feelings of not being attractive as a woman,” (p672). The difference in reasons of discomfort among women while exposing their breasts during RT clearly necessitates the importance of cultural awareness among HCPs while caring for these women.

Similar to the findings in the existing literature,<sup>[12,17,26]</sup> participants in the current study also experienced fear and anxiety before their RT. However, unlike the existing literature, their fear and anxiety was related to the use of terminology by the HCPs. For instance, the term “shot” was used to denote RT which in the local language, refers to an electric shock. However, the participants were terrified as they envisaged having electrical current and its consequences. The HCPs were using this term without realizing its negative consequences on the patients. Likewise, HCPs were referring to RT as last treatment, which, in their view was the last step in treatment, but the Pashto speaking women understood it as the last resort. Therefore, several of them were worried about their disease prognosis. These findings suggest that HCPs should be careful when translating western terminology into the local language; they should ensure that words chosen from the local language are nonthreatening and do not create any misconceptions and misunderstanding among the patients. As reported in literature,<sup>[12,17,18,31,36]</sup> the participants in the current study also expressed the feelings of uncertainty regarding the prognosis and effectiveness of the treatment.

Similar to the existing literature,<sup>[16-18,31,37]</sup> participants in the current study also reported experiencing numerous physical side effects of RT, for example, itching and discoloration of the skin, swelling of the radiation area, numbness, and sensation of tingling and burning. However, unlike the participants in other studies, these participants were not primarily concerned about the other physical effects, except fatigue, and body aches, because these symptoms greatly affected their role performance which is also reported by other studies.<sup>[27,31,38]</sup> Since most of the participants were of a younger age group, married, and mainly responsible for household tasks, inability to perform their household chores was a disappointment for them.

One of the major challenges mentioned by all of the participants was the affordability of RT. Most of them shared that their families took a loan to pay for the expenses of their treatment. These findings affirm the findings of previous studies in Pakistan.<sup>[39,40]</sup> This finding is not surprising, considering that the low socioeconomic condition of the people in Pakistan, high cost of cancer treatment, and out-of-pocket payment posed a heavy financial burden on them. Although some of the participants were supported

by the hospital welfare system for their RT, they were still required to bear other expenses, such as, traveling and food, etc. Moreover, as a cultural norm, a male family member had to accompany the female for traveling to the hospital. Hence, one should have to take off from work and compromising their sources of income, which further aggravated their financial crises. This became an even bigger issue for those who had young children and came from far-flung areas to the hospital. They had to reside in hotels along with two or more family members.

Almost all participants acknowledged the sacrifices made by their families; which also became one of the causes of their desperation. In the cultural context of Pakistan, women are the ones who make sacrifices for their family needs, but in their cases, families had to make sacrifices. When the participants found out that all the family resources had been depleted because of them, it caused them extreme distress. Temporary migration to other cities for treatment not only complicated their financial issues but also led to psychological distress. There were several other reasons for their desperation too, for instance, separation from their children and family upset them. In some cases, if they brought their children with them, their schooling got compromised; if they left them at home, their care related issues became a cause of concern for these women. All these issues resulted in their desperation.

Consistent with other studies,<sup>[31,38,41]</sup> participants in this study too revealed that women experienced distress, anger and agitation after going through RT. They disclosed that they displace their anger on children in a state of anger and agitation, depicting vulnerability to mental health issues in these women. This may be the consequence of a series of challenges that these women confronted during the trajectory of their disease and previous treatment, for example, surgery and chemotherapy. When they reached the final stage of treatment, which is RT their psychological problems were at their peak. Another reason for this could be the fact that they were unaware about the positive anger management techniques and they were displaying their anger in a wrong manner. It is important for the HCPs working in the RT department to be aware of these issues and conduct timely assessment and interventions to help these patients.

In terms of coping strategies, almost all the participants of this study displayed an accepting attitude as they had a strong belief in God and believed that the suffering was sent to them by the will of Almighty Allah and He alone would resolve it. They also used prayers, and recitation of the Holy Quran and Holy Verses, as their coping strategies. These findings concur with other studies reporting spirituality and religious practices as coping strategies.<sup>[42-45]</sup>

Although less frequently noted in the existing literature, the participants of this study used recitation of Holy verses as their spiritual strength to cope with the psychological stress experienced during RT, especially when they were lying with their chests exposed, in the presence of male staff members. Knowing that prayers are strong coping strategies for these patients, HCPs working in the RT department can support and encourage their patients to utilize their coping system more effectively. This healthy coping mechanism could also be utilized while teaching anger and stress management techniques.

As reported in the study by Hendry,<sup>[13]</sup> the participants of this study also acknowledged that the family was the biggest support system that offered them physical, emotional, psychological, and financial support to cope with the disease and its treatment-related issues. Participants highlighted that their family members became more sympathetic during their disease, and perhaps this attitude of family members was due to the cultural and religious belief that caring and helping a person in illness is as an act of goodness that promises rewards in the hereafter.

Similar to the study by Halkett *et al.*<sup>[12]</sup> the participants in this study also emphasized the need for adequate support by the hospital staff to make patients feel more comfortable during RT. Despite receiving substantial support from their families, they felt the need to talk to HCPs about their treatment, its side effects, and precautions.

Several authors,<sup>[20,22,33]</sup> reported that informational needs of the participants were not fulfilled by the hospital staff. Due to which patients felt overwhelmed, fearful and anxious before RT; though these studies were conducted in settings where patient teachings were a part of the practice. However, in the current study, participants reported that they received almost no information from HCPs and had to rely on the information shared by the other patients. This reliance on information from other patients, who were also not educated, usually offered little help; in fact, it increased their fear and misconceptions.

Unlike the findings of Halkett *et al.*<sup>[12]</sup> whereby participants also obtained information from other patients, in addition to the information provided by the radiation oncologists and the available printed material, in the current study, no teaching was provided by the staff, nor was any printed material available for patients. Moreover, in the present study, participants were not educated enough to retrieve information using the informational technology. Thus, keeping in mind the issue of illiteracy in Pakistan, HCPs should be even more cognizant of the patients' informational needs.

It is disconcerting to know that the area for RT was marked with ordinary ink and patients were told not to

take a bath as this could have negative consequences for them. Considering the compromised immunity of these patients, due to cancer, and chemotherapeutic effects, maintenance of hygiene is highly significant. Moreover, all the participants were Muslims, and taking a bath after sexual intercourse is a religious obligation, which meant that they also had to suppress their sexual needs. The lack of undesirable practices highlighted above may be attributed to the workload of the nursing staff, lack of awareness, and competence of staff to provide complete and accurate information, and lack of institutional policies and standards on the importance of health teaching for clients.

## Conclusion

Findings of this study provided rich information about the experiences of the women with breast cancer while receiving RT. It assists nurses to understand the unique experiences, feelings, perceptions and informational needs of women undergoing RT. These women experience adverse physical effects, they suffer from grief, sorrow, shame, and guilt more as a result of various psychological effects related to the violation of sociocultural norms. Since the provision of the RT appears a technical nature of task and duration of an RT session is short, especially deployment of male technician is considered appropriate. However, findings of this study suggest that this practice should be changed. Properly trained female radiotherapists, technicians, and nurses in the RT department must be deployed to provide comfort, privacy, and culturally sensitive care and reduce these patients additional RT-related stress. In addition, HCPs should provide teaching and information in adequate and timely manner to every patient, before, during, and at the completion of RT, about the effects, precautions, adverse effects, symptoms management, hygiene care, and other healthy practices.

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## Conflicts of interest

There are no conflicts of interest.

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