

# Barriers to Sexual Health Communication in Breast Cancer Survivors: A Qualitative Study

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## ABSTRACT

**Introduction:** Sexual dysfunction following breast cancer treatment is common. However, it's often been neglected. Patients often have difficulty to talk about sexuality issues with their partner. Health-care providers avoid entering this domain too. Identifying communication barriers around sexuality is important to solve sexual dysfunction in breast cancer survivors.

**Aim:** To diagnose communication barriers regarding sexual health in breast cancer survivors.

**Materials and Methods:** In this qualitative study, 13 breast cancer survivors and 12 key informants were interviewed in semi-structured face to face approach. The participants were

selected through targeted sampling method and data were analysed using conventional content analysis approach by MAXQDA12.0 software.

**Results:** Two main categories including “relationship with partner” and “relationship with health care providers” were extracted from the interviews as barriers. Weakness of sexual discourse was the most important barriers between couples. In terms of patient-providers relationship, the most known barriers were neglecting patients’ sexual concerns and lack of a teamwork approach from the patients and providers point of view respectively.

**Conclusion:** Health provider needs to acquire communication skills and knowledge about managing sexual disorders in breast cancer survivors.

**Keywords:** Breast cancer, Communication, Health care providers, Sexuality, Survivors

## INTRODUCTION

Breast cancer is one of the most common malignancies in women. The incidence rate in Iranian women is 10 years less than the global average. On the other side, survival rate of patients 5 and 10 years after diagnosis is about 88% and 80% respectively [1]. So, the quality of life in these patients is considered and sexual life is one of the most important dimensions of quality of life [2,3]. Breast cancer survivors, experience a range of sexual dysfunctions resulted from decline in sexual intimacy and communication. Sexuality is a complicated issue and is also challenging for health care providers in comprehensive cancer services [4]. Many studies have shown that sexual activity is usually negatively impacted by cancer and its treatment. However, these problems are often neglected [2,5,6]. Communication about sexuality issues is often challenging due to fear and stigma related to cancer, treatment complexities, and uncertainty of the disease process [7]. Among all communication issues between couples, sexual relationship is of particular importance. Many researchers claim that communication in the sexuality field is an essential element to form a satisfying relationship that includes biological, psychological, and social components [2,8]. However, due to inherent vulnerability of this field, a lot of people face relationship problems with their partner [8]. Cancer patients tend to receive sexual health care but they cannot easily talk about it. Health care providers also believe that personal discomfort prevents them from entering this field. Poor relationship between the health care providers and the patient may worsen survivors’ sexual problems [4]. Present studies usually have shown a delicate relationship between cancer treatment and sexual dysfunction. Evidence shows that health care providers seldom care about sexual disorders in their cancer patients, but the reason is still unclear [9]. Therefore, this study was conducted to investigate communication barriers between couples, from the patient and key informant’s viewpoint in the field of sexual dysfunction.

## MATERIALS AND METHODS

### Study Design and Sampling Criteria

The present study is a conventional qualitative content analysis to illustrate unmet communication needs regarding sexuality of breast cancer survivors. The inclusion criteria were, married Iranian women with breast cancer of Stages 1 or 2 who were at least 18 years old and completed the treatment period (at least six months after the last radiation therapy) participated in this study. Individuals with these specialities: radiation oncology, breast surgery, Psychology, Reproductive Health and gynaecology were participants in key informants section. The Exclusion criteria were, patients with stage 3 or 4, metastatic cancer, a history of other physical or mental illness that affects sexual function and disease recurrence were excluded from the study.

### Data Collection

To collect data, a semi-structured in-depth interview with open-ended questions was conducted. Participants were interviewed face to face excepting one key informant who were interviewed by telephone and the other one by using Telegram chat. Each interview lasted 30-45 minutes. All data gathered from February to September 2017. All interviews were conducted by the first author (MM) who is female. She is an academic member and also PhD student in reproductive health with a history of participating in several workshops about qualitative research methodology, the use of qualitative analysis software and courses on sexual function. All steps for data recording and data analysis were conducted under the supervision of the authors (ZK) as productive health specialist (MD and PhD) and (FLK) as a psychology specialist (PhD). Both of them are faculty member with several years’ experience in qualitative studies.

The interviews were conducted in the environments that survivors were easily accessible. So, Cancer Research Centre of Shohada-ye-Tajrish Hospital (cancer referral centre in capital city of Iran) and “knowledge, prevention and combating the Breast Cancer Campaign” considered as

the study environment. Interviews with key informants were performed in their offices. All participants were selected based on purposive sampling method. At first, interviewer introduced research team and explained the purpose of the study to participants. The interview started with this question "What are the effects of cancer diagnosis and its treatment on your sexual function?" and continued with other questions like "To what extent your healthcare specialists talk to you about sexual issues? Have you ever talked openly about influential people around you?" These questions with some changes were applied to get specialists' viewpoints. Interviews continued till data saturation was obtained. A total of 25 individual interviews (13 cancer survivors and 12 key persons) were conducted. To document the data, interviews were first recorded and then transcribed at the right time. Field notes were used as much as possible and non-verbal data such as tone and gestures was also recorded. One case, a 50-year-old survivor didn't allow to record her voice and in another case, the circumstance of interview place, prevent us from recording. These two conversations were written at the time of interview. The stages recommended by Graneheim UH and Lundman B, were used for data analysis [10]. After several times listening to each interview, the texts were transcribed.

**Research ethics:** This research was a part of a reproductive health PhD dissertation from Faculty of Nursing and Midwifery of Shahid Beheshti University of Medical Sciences with the ethical code of IR.SBMU.PHNM.1395.496. Informed consent (written or orally) was taken from participants. In case of participants consent, interviews were recorded. Participants were assured that their audio files will be eliminated after full publication of research results.

## STATISTICAL ANALYSIS

Interviews analysed immediately with MAXQDA 12.0 software. Sentences, or paragraphs with same meaning, were considered as semantic units. Semantic units were summarised as basic codes. Then, these codes were classified based on similarities. In order to estimate validity, reliability, and quality assurance, four criteria of Guba EG and Lincoln YS, including Credibility, Confirmability, Dependability, and Transferability were used [11]. For increasing validity, the research team kept a long-term relationship with the participants (for nine months) and also devoted enough time and cooperation during data analysis process. Yet, the basic codes related to the three interviews were returned to the participants to confirm whether the interview text reflects their experiences or not. To allow other researchers repeat the study, the researchers recorded and reported all the steps carefully.

## RESULTS

Thirteen breast cancer survivors and 12 specialists in related disciplines participated in this study [Table/Fig-1,2]. At the time of cancer diagnosis, average age of patients was  $50.23 \pm 7.90$  (mean $\pm$ SD= $43.54 \pm 8.98$ ). Ten female and two male included four psychologists, four reproductive health specialists, two radiation oncologists, one breast surgeon and one gynaecologist participated as key informant. After continuous analysis, two main categories including relationship with partner (with seven sub-categories) and relationship with therapist (with two sub-categories) were achieved. The description is as shown in [Table/Fig-3].

### Relationship with Partner

Marital relationship quality is one of the most significant predictors of sexual dysfunction in cancer patients.

**P13:** "At that time (before cancer), sexual relationship was very important to me, I was different"

**E6 a Psychologist:** "Since emotional relationship has been destroyed, we cannot build sexual relationship correctly". Most of the participants believed that couples have difficulty to talk about sexuality issues. Couples whose marriage lasted longer, could talk more easily about their sexual concerns.

**P6:** "After my surgery, I said to my husband: "I do not have sexual problem. Just I had breast surgery."

Row	Age (years)	Cancer age (years)	Education	Job
1	56	49	Diploma	Housewife
2	50	35	B.Sc.**	Employee
3	31	29	MSc.***	Employee
4	54	51	Diploma	Housewife
5	48	39	Mid-School	Housewife
6	60	52	Diploma	Housewife
7	56	54	B.Sc.	Retired
8	55	51	B.Sc.	Retired
9	44	42	Upper-diploma	Housewife
10	44	42	Upper-Diploma	Employee
11	57	55	Diploma	Housewife
12	44	35	Mid-School	Employee
13	54	32	Ph.D.	Retired

**[Table/Fig-1]:** Participant's characteristics (individuals with cancer\*\*\*)

\*BSc: Bachelor of sciences; \*\*MSc: Master of sciences; \*\*\*mentioned as [p] in the text

Row	Gender (Male/Female)	Specialty
1	Female	OB/GYN
2	Female	Psychology
3	Female	Breast fellowship
4	Female	Psychology
5	Male	Psychology
6	Female	Psychology
7	Female	Reproductive Health
8	Female	Radiation Oncology
9	Female	Reproductive Health
10	Male	Radiation Oncology
11	Female	Reproductive Health
12	Female	Reproductive Health

**[Table/Fig-2]:** Participant's profile (Experts\*\*) in research.

\*Ob/Gyn: Obstetrics/Gynaecology; \*\*mentioned as [E] in the text

Categories	Subcategories
Relationship with partner	Marital conflicts
	Weakness of sexual discourse
	Reflection of the disease in sexual relationship
	Loss of intimacy
	Mismatched sexual needs
	Partner's viewpoint toward the disease
	Partner physical and sexual problems
Provider-patient communication	Patient's obstacles
	Provider's obstacles

**[Table/Fig-3]:** Classification of categories and subcategories regarding Barriers to communicate about sexuality with partner and provider.

**E12 a reproductive health specialist said:** "There is not much discourse between couples. Husbands seldom tell their wives (verbally or non-verbally) that they do not care about not having a breast."

**P13:** "I really liked if there were somewhere, or even someone I could talk to. At that time I was young and I was embarrassed to talk about sexual issues, but when I became older, I accepted presence of this instinct.

In the field of sexuality, the intrapsychic experience of women with breast cancer includes lack of physical attractiveness, lack of sexual attraction, loss of femininity, and loss of sexual desire towards themselves.

**P6:** "Because of shock and discomfort resulting from this disease, emotional relationships break-up."

**P3:** "I wanted my husband to embrace me. He treated me as if I felt I got Hansen's disease. He would not come close to me" Specialists

also agree with this statement.

**E8:** "In fact, when they got the disease, their husbands behaved so inappropriately that they did not like to keep their relationship with their husbands anymore"

It seems that, quality of relationship after cancer is a stronger predictor of sexual satisfaction in comparison to physical or medical injuries to the body.

**P12:** "Intimate relationship is even most effective for patient recovery, so people must change their minds and know that even if there is no ability to have sexual intercourse, building intimacy can have positive effect on patient's spirit"

Majority of participants mentioned that they had lower sexual desire in comparison to their partners. Communication factors, stress, and medical reasons may cause this difference.

**P8:** "My husband is not a man who wants sex once a week. He needs twice or three times a week. So, I was under pressure.

**P7:** "I myself tend to have sex once every two weeks, but my husband wants twice a week"

Husband's reaction is considered as an important factor for patient adaptation to the disease.

**P4:** "Husbands should change this mindset that their wives can no longer have sex due to their disease"

**P6:** "He thought cancer was a contagious disease and it may be transmitted through intercourse."

Sexual dysfunction may happen simultaneously in both partners. Both disease and drug consumption were effective for sexual dysfunction.

**P6:** "My husband had prostate problem. I was worried if his disease could affect my health. No one could guide me."

In one case, although there was no medical restriction, fear of exacerbation of the background disease was the cause of sexual dysfunction in partner.

**P3:** "We had little sex. My husband had heart surgery 8-9 years ago".

### Provider-Patient Communication

Patients believe that the most significant factors that prevent them from communicating with treatment team are disease-centeredness of providers, ignoring patients' problems, cultural taboos, and also lacking emotional connection between patient and treatment team.

**P9:** "I had a question and wanted to call my doctor, but I did not want to disturb him constantly.

**P7:** "Doctor ... is always bad-tempered and strict. Patient often doesn't dare to ask questions about their concerns."

**E10 a radiation oncologist:** "Although I am their physician and in our culture doctors are trustworthy, most of my patients get embarrassed talking about sexual problems"

**P5:** "I thought if I tell to doctor, she says: "She does not think about her disease. She just thinks about sexuality. Especially because my doctors were men, I always thought that they would think of me as a woman of a different style."

Lack of time, concentration on main disease and considering sexual issues as taboo were some of providers' reasons not to enter into patients' sexual issues. These cases include both patient and specialists' viewpoints.

**E4:** "Sometimes they do not believe that this is so significant" (E4)

**E3:** "Sexual issues? We did not think of it at all" (E3)

**P7:** "I think they believe it does not necessitate as the doctor... himself talks about other issues, not sexual dysfunction"

**P6:** "he was working with his computer and reading jokes while he was asking me, "What is wrong with you?"

**P7:** "Doctor ... is always so busy, that could not spend time with patients and talk about these issues" (P7)

**E10:** "It is better than the list of specialities such as psychiatrist, psychologist, and sexologist, to be framed in teamwork, so we should not be scattered"

**P4:** "Doctors focus on disease control. He cannot address all marginal issues in a short time".

### DISCUSSION

The aim of the current study was to illustrate unmet communication needs of cancer patients in terms of sexual issues. Analysis of participants' interview emphasized that relationship between couples have significant effect on patient's recovery process. This was aligned with other studies, so women's health and well-being were significantly affected by their husbands' reaction. During the recovery period, couples are likely prone to break-up and relationship problems and intimacy concerns exists [12-17]. Participants mentioned multiple barriers including marital conflicts, weakness of the sexual discourse, reflection of disease in relationship, lack of intimacy, and partners' viewpoint to the disease, partner's physical and sexual problems. Due to cultural characteristics and lack of sex education, couples have less sex talk. Both survivors and key persons agree with this. In a study conducted by Hawkins Y et al., only 19% of women and 14% of men talked about sexual relationship after cancer [18]. In our study, sexual discourse weakness can be attributed to this view that talking about sexual issues is considered to be a taboo in Iranian culture. In this study, more than 85% of survivors believed that after cancer diagnosis and treatment, they had more intimacy and relationship with their husbands. This finding has also been reported in other studies [19-24]. In a study conducted by Laitala VS et al., irrespective of treatment, no increase in the separation rate was observed in early stages of breast cancer. However, attitude towards breast cancer and marital stability depends on time period and community [25]. Even in study of Ussher JM et al., relationship with partner increased in a small proportion of participants [26].

Most participants believed that just intercourse can be considered as sexual relationship. Key informants altogether believed that lack of knowledge about sex in most Iranian couple's leads to this misunderstanding. In subclasses "partner's viewpoint to the disease" and "reflection of disease in relationship" few patients were sad due to their partners' reaction to their disease. At the same time, most patients mentioned their husbands as the most valuable sources of support. Some studies showed different results [27-29]. Partner's reaction results from patient's anxiety, depression, and physical appearance [30]. On the other hand, in this study, there was an incompatibility in couple's sex drive. Also, Mark KP et al., noted that mismatched sex drive is one of the most significant predictors of sexual relationship quality [31]. Evidence suggests that compared to women, men show more sexual desire [32]. The present participants acknowledged that this incompatibility in sex desire had already existed and has increased due to sexual dysfunction following breast cancer diagnosis and treatment.

The other category obtained from data analysis was patient-provider communication barrier. About 92% of patients reported that treatment team did not talk about possible sexual problems. Patients believed that treatment team concentration on main disease as well as ignoring patients' sexual concerns up to 54%, were the most important barriers that prevented treatment team from paying attention to patients' sexual problem. The amount that treatment team talked about patients' sexual concerns is even less than other studies. Although in those studies, talking about patients' sexual problems and concerns was generally very low and was limited to treatment side effects, in these cases, they often waited for the patient to start talking about sex [2,32,33]. In most other studies, like our study, patients expected the treatment team to be conversation starter and ask them about their sexual issues [33-35]. Considering sex as taboos seem to be a powerful reason for talking less about sexuality compared with other studies. According to Hughes MK et al.,

patients don't start talking about sexual issues, so the treatment team is responsible to start talking to break silence [34]. In present study, most of key persons referred to lack of team-treatment approach and concentration merely on main disease as the most significant barriers to communicate with patient about sexual issues. The results of the study are in line with other qualitative and quantitative studies and most of these cases were noted by health care providers [2,6,36,37]. Just there were differences in the priorities. Difference in hierarchy can be attributed to differences in demographic characteristics of participants in the study design (qualitative or quantitative) and also difference in societies in which the study is conducted.

## LIMITATION

In this study, patients' husbands were not interviewed while almost all patients mentioned their husbands as the most valuable sources of support and that was our study limitation. So, identifying husbands' communication needs are suggested for future studies.

## CONCLUSION

After diagnosis and treatment of cancer, patients exposed to multiple sexual problems. Most patients expect that cancer treatment as well as, their concerns and sexual problems to be focused. So, it is recommended that treatment team to start conversation about this topic.

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