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Threat to survival, the main concern of breast cancer survivors: A qualitative content analysis

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Abstract--Background: Breast cancer is the most commonly diagnosed cancer in the world. The evaluation of breast cancer patient's experiences, allows the identification of those areas of care that require to be improved. The present study aimed to explain breast cancer survivors' experiences. Methods: This qualitative study was conducted using semi-structured interviews with 21 breast cancer patients who were in various stages (surgery, chemotherapy, radiotherapy, immunotherapy, and post-treatment period), seven family members of the patient, five nurses, and four specialists. Sampling was performed by the purposive method. Data were analyzed using the conventional content analysis method. The interviews were first recorded and transcribed, and then the data were analyzed using the Granheim and Lundman's method. Data management was done with MAXQDA software version 10. To achieve trustworthiness, the criteria presented by Lincoln and Guba were used. Results: Four categories were emerged as a result of the data analysis process. the category "mental distress" comprised the emotional strain and negative consequences of treatment, the category of "perceived concerns" consist of financial concerns and disturbances

in emotional life. The category of "confusion in care" consist of inadequate knowledge about the disease, symptom management and lack of supportive care center. The last category "threatening of progressive disease" comprised fear of recurrence and living with uncertainly. Conclusions: Breast cancer survivors live with multidimensional problems. Establish centers for supporting and educating of patients and their families, enhancement of public knowledge about breast cancer along with allocating more budgets to take care of these patients can help patients for passing from concerns and enhancing their QOL.

Keywords---*Breast Neoplasms; Cancer Survivorship; women; Qualitative Research.*

Introduction

Each year, the number of persons diagnosed with cancer over their lifetimes rises(1). According The GLOBOCAN 2020 estimates of female breast cancer as the most commonly diagnosed cancer with 2.3 million new cases (11.7%) and (6.9%) fatalities. Death rates for female breast were noticeably higher in transitioning The annual incidence (2).versus transitioned countries (15.0 vs 12.8 per 100,000) rate of breast cancer in Iran is 1.28 per 100,000 individuals(3).Significant improvement has been achieved in cancer survival by focusing on early cancer detection and effective therapies(4). Survival from cancer is a dynamic process that encompasses a broad spectrum of diagnosis, treatment, recovery, and palliative care(5), happens in similar or different ways across survivors and is connected with life-altering experiences(6). Since the American Institute of Medicine report, the definition of cancer survivors has expanded to include the individual from the time of cancer diagnosis and throughout his life, as well as their family members who provide care(6, 7). "Cancer Survivors" are individuals with unique experiences with a cancer diagnosis, treatment, and life after cancer therapies(8).In the studies Rosenberg(9) and Suwankhong(10) the survivors of breast cancer had endured diverse physical and psychological experiences throughout the disease and treatment period that led to stress and emotional load in them. The majority of breast cancer patients in Iran consult their oncologists. The evidence demonstrates that in oncologist-centered visit, the primary focus is on physical problems, and there is little opportunity for patients to express their emotional concerns, resulting in patients with multiple physical and psychosocial problems resulting from cancer and its treatments(11,12). Due to cultural and religious sensitivities, as well as a reluctance to disclose sensitive health concerns such as sexual function difficulties, reproductive challenges, and mental problems, breast cancer survivors confront more complex issues(13).Using patients' personal experiences is a new approach for enhancing care. Comprehensive information is supplied to connect patients to specialist services and help cancer survivors throughout their lives by understanding the impact of cancer and its treatment on the daily lives (14-16).Also, helping patients to make critical decisions about their lives and their health means helping them to be aware of the impact that different treatments may have upon their ability to look The knowledge collected from the .after their own families or continue to work(17)

individualized experiences of patients also facilitates patient-centered care and encourages health care workers to relate patients' issues to their own(18,19). Nurses are known as key professionals in empowering patients, families, and communities to obtain the best achievable level of health(20-22).The effort of this professional group for complete awareness of the real problems and challenges of patients appears essential. Considering the significant increase of breast cancer survivors in Iran, identifying the specific concerns of these patients can provide health providers with valuable information to formulate care plans. This design of in-depth studies, which include an analysis of the patients' experiences, provide a better understanding the patients' conditions, and may act as a guide for all those who administer care(23). Therefore, the present study was conducted with aim of investigating the experiences of breast cancer survivors

Materials and Methods

Study Design

In 2021 and 2022, this qualitative study was conducted utilizing the conventional content analysis method. The content analysis aims to organize and extract meaning from the compiled data and to show significant conclusions from it. The use of qualitative methods provides the possibility of discovering confidential information that can only be revealed through this way(23). Identifying the problems of breast cancer survivors prepares them for the process they have to face and for the consequences of medical treatments, and helps to reduce their worries and improve their quality of life. The study report presented using the consolidated criteria for qualitative reporting research (COREQ) (24)(Supplementary File 1).

Study Environment and Participants

The present study was conducted at Razi Hospital, a leading cancer referral hospital and specialized and sub-specialist clinic of Besat in the Iranian province of Guilan. Participants included women with breast cancer undergoing active surgical treatment, chemotherapy and radiation, and immunotherapy, as well as patients who have finished treatment, their families, nurses, and specialists. A total of 37 participants were selected in the study using purposive sampling with maximum variation (Table 1&2).

The inclusion criteria were willingness to participate, verbal communication skills, an established diagnosis. The subjects gave their informed consent to participate in the research. Participants were permitted to withdraw from the research at any time. The exclusion criterion was an unwillingness to continue participating in the study. No participants refused to participate or withdrew after giving their consent. The first participant was a 35-year-old female who had experience post-treatment period. The first interview was transcribed by the NM and listened to several times by the research team. The interview was critiqued. Interviews were conducted by appointment at a convenient place.

Interviews were conducted by N.M, Ph.D. student of nursing with 10 years of nursing experience. she had participated in a qualitative study course and had

received training in the qualitative study, interviewing, coding, and reporting The FA and RT and FJ have enough experience in performing and writing qualitative studies. The interviews were recorded with an mp4 recorder.

Table 1: Demographic characteristics of the Breast Cancer Survivors

Participant	Age (year)	Stage of the disease	Marital Status	Education Level	Employment Status	Residence
1	41	Surgery	married	diploma	Housewife	Urban
2	40	Chemotherapy	married	Bachelor's degree	Employed	Urban
3	31	Chemotherapy	married	Post-diploma	Housewife	village
4	36	Chemotherapy	married	Master's degree	Teacher	village
5	59	Chemotherapy	married	elementary	Housewife	village
6	65	Chemotherapy	married	illiterate	Housewife	village
7	49	Chemotherapy	married	illiterate	Farmer	village
8	39	Radiotherapy	married	high school	Housewife	Urban
9	40	Radiotherapy	Single	diploma	self-employed	Urban
10	46	Radiotherapy	married	high school	self-employed	Urban
11	38	Radiotherapy	married	diploma	Housewife	Urban
12	46	Immunotherapy	Divorced	diploma	self-employed	Urban
13	58	8 years after treatment	married	Master's degree	Retired	Urban
14	52	6 years after treatment	married	Master's degree	Faculty member	Urban
15	43	3 years after treatment	married	Bachelor's degree	nurse	Urban
16	44	2 years after treatment	Single	Master's degree	Government employee	Urban
17	42	1 years after treatment	married	Bachelor's degree	nurse	Urban
18	57	10 month after treatment	married	Bachelor's degree	Retired	Urban
19	63	15 years after treatment	married	Master's degree	Retired	Urban
20	69	11 month after treatment	married	high school	Housewife	Village
21	37	1 years after treatment	married	high school	Housewife	Urban

Table 2: Demographic characteristics of Family member and Providers

Participant Family	Age(Year)	Relative To The Patient	Employment Status	Education Level
22	52	Spouse	self-employed outside the home	diploma
23	44	Spouse	self-employed outside the home	diploma
24	30	daughter	housewife	Bachelor's degree
25	34	daughter	housewife	Bachelor's degree
26	42	Sister	housewife	high school
27	46	Spouse	self-employed outside the home	Post-diploma
28	37	Spouse	self-employed outside the home	diploma
Expert	Age(year)	Gender	Education	Work experience in cancer care
29	28	female	bachelor of Nursing	3
30	31	female	bachelor of Nursing	5
31	30	female	bachelor of Nursing	5
32	42	female	bachelor of Nursing	15
33	54	female	bachelor of Nursing	22
34	41	female	Radiation Therapist	7
35	44	male	General surgeon specialist	6
36	54	male	oncologist	14
37	42	female	oncologist	10

Data Collection

From September 2020 through November 2021, data were collected through individual, face-to-face, in-depth semi-structured interviews by the first researcher. Interviews were conducted in a quiet place preferred by the interviewees. The researcher introduced himself and the objectives of the research obtained permission to record conversations and the possibility of referral to validate the data and then asked the participants to describe their experiences. Each interview lasted between 30 and 61 minutes on average.

The main research question of patients was "What problems did you face?" Describe some examples of your experiences regarding problems?" Also, exploratory questions based on participants' experiences were asked to obtain more detail about the causes of concerns. In addition, the researchers recorded interactions, communication, ambient conditions, and nonverbal signals. The interviews continued until no further new data was obtained. Data collection and analysis were performed concurrently. The researcher captured all audio files in the right location and translated them. The portions of the interview transcripts that could have revealed the patient's or doctor's identity were eliminated. Data saturation occurs when there is enough information to repeat the study, when the

ability to obtain additional new information is obtained, and when most coding is no longer possible(25).

Data Analysis

Data were analyzed in MAXQDA software ver.10 using the method proposed by Graneheim and Lundman (23). Following Graneheim & Lundman's approach, after several listening times, the contents of all interviews were transcribed verbatim into Microsoft Word files. Afterward, the transcripts were compared to the audio data to ensure accuracy. To immerse themselves in the data, one of the researchers precisely reviewed the text of each interview several times. Subsequently, content analysis was started to serve as the background for extracting codes. At first, meaning units were identified; then, meaning units were summarized and designated with appropriate codes. Following that, similar primary codes were condensed and merged into subcategories, and the main categories were extracted.

Rigor

The credibility, dependability, conformability, and transferability criteria proposed by Lincoln and Guba(26) were used for ensuring trustworthiness. Credibility was ensured through diversity of experiences resulted from age, disease phase, marital status, occupation, and education level, member checking, peer checking, and prolonged engagement with the data. For peer checking, the first author performed data collection and analysis and the co-authors controlled and approved these steps. selection of the most appropriate method of data collection and results of content analysis are particularly linked to credibility, the coauthors confirmed the best data collection method was chosen to answer the research questions of interest. In addition, the co-authors confirmed the credibility of the analysis checking for the representativeness of the data as a whole. Dependability was ensured through member checking. Transferability was also ensured through providing clear descriptions of the study setting, participants, and data collection and analysis.

Ethical considerations

Ethics approval and consent to participate Code of ethics (IR.GUMS.REC.296) was obtained from Guilan University of Medical Sciences, and the research environment license was received. The importance, purpose, and method of research were explained. The interviews were recorded. Participants' informed consent obtained was written. Confidentiality and anonymity at all stages were met and the time and place of interviews were mutually decided. The participants were free to participate in or to withdraw from attendance. The researcher's characteristics and the way of access to results were explained to the participants.

Results

Data analysis resulted in the development of 10 subcategories in 4 main categories, namely Mental distress, perceived concerns, confusion in care and

threatening of progressive disease. These four categories recognized the common theme of these categories as the major concern of the patients, titled **threat to survival**, (Table 3). As one of the patients noted during treatment, Patient said:

"We are like a person who has a pistol behind their head, which may be fired at any time; a cancer patient is in a similar scenario; there is always a threat following you; it never leaves your mind."P21

Table 3: The Theme, Main categories and Subcategories

Theme	Main category	Subcategory
Threat to Survival	Mental distress	Emotional Strain
		Negative consequences of treatment
	Perceived concerns	Financial concerns
		Disturbances in emotional life
	Confusion in care	Inadequate knowledge about the disease
		Symptom management
		Lack of supportive care center
	Threatening of progressive disease	Fear of recurrence
		Living with uncertainty

Mental distress

When confronted with the diagnosis and the earliest phases of therapy, patients believe that this condition is unique and as a result experience emotional discomfort. In breast cancer survivors, mental anguish was associated to emotional pressure and unfavorable treatment outcomes.

Emotional strain

Survivors of breast cancer develop many emotional responses when confronted with unknown settings, including dread of death, anxiety, and sadness. compared the experience of chemotherapy to the sensation of death. Patient said:

"Chemotherapy was a disaster. I occasionally peered out the window to see if an angel had arrived since I feared I was dying but didn't realize it. The agony was so excruciating; It did not respond at all to painkillers."P17

The oncologist's comments corroborate the patients' apprehension:

"The very name of cancer is horrible; for you may have several diseases which are less likely to results in death at the end, but the concept that everyone who has cancer will die produces double concern."P36

Some women had severe levels of anxiety and sadness for months or years following their diagnosis due to their prolonged fight with the illness and its treatment. who had passed eight years since her therapy mentioned: ***"I was***

unable to comprehend why this happened to me; I tell myself that this was not my right and that this should not have occurred... I did not want the remainder of my life to be dominated by an illness." P13

Negative consequences of treatment

This subcategory is subdivided into two primary subcategories, encompassing physical issues and bothersome mental issues resulting from long-term disease and therapy. Due to the unique characteristics of the illness and the side effects of chemotherapy and radiation, breast cancer survivors have a variety of physical issues. In this context, patient said:

"Today is my third chemotherapy treatment. When I returned home following the prior session, I felt queasy, my hands and feet were freezing...I had a fever and chills, and I got so sick I believed I was going to die."P5

In relation to mental issues caused by treatment side effects, one of the chemotherapy nurses states the following on:

"Hair has a one hundred percent impact on women's appearance. They believe it makes them unattractive. Not having hair bothers them so much. I believe this is more painful than chemotherapy."P31

Financial concerns

Financial challenges are one of cancer sufferers' most pressing concerns. who had passed a year from therapy, stated:

"Continuation of therapy is also quite costly. Even with insurance, medications, hormones, bone-building ampoules, vitamin and mammography... The situation is really tough." P21

Disturbance in emotional life

Breast cancer patients experience a sudden change in their lives. When the mother of the family is affected by cancer, it puts a lot of pressure on the patient's family, which sometimes leads to problems. Patient stated in this regard:

"When I was undergoing chemotherapy, my daughter beat my sister-in-law's child twice. Even the second time, she hit the child very badly. I was so bad, I was unable to manage this matter, I was in a bad state. I told her father He talked to her, my daughter said that I was very upset that my aunt dyed her hair, but my mother has no hair." P16

As a result of chemotherapy, surgery, and endocrine therapies, women with breast cancer are susceptible to a variety of sexual abnormalities, which poses a barrier to their mental wellbeing. a 36-year-old lady said:

"The adverse effects of the medications were too numerous, I had too many issues, I lacked information, I did not know my age, my husband was young, and I feared he would leave me."P4

Chemotherapy nurse of stated, ***"The lady claims that her husband and she have not had an intercourse for the last five months, which is distressing for the patient since they cannot be with their spouses."***P30

Confusion in care

Inadequate information of the disease, inadequate symptom management, and the absence of a supportive care center caused breast cancer survivors to experience confusion in their care.

Inadequate knowledge about the disease

One of the patients' issues was a lack of treatment and care-related knowledge. described his postoperative experience as follows:

"After the surgery, one seems to be in a new universe; much like the movie character who is dead and doesn't know what to do, I had no idea what to do. He wants someone to take his hand, assist him, and let him know that he is now on this route and that he must continue along it; the old paths are no longer available and have ended. There is now a new path. However, they did not tell me these there."P1

Symptom management

One of the issues that patients experienced during this procedure was a lack of knowledge on how to manage chemotherapy-related adverse effects. Who was on his third chemotherapy treatment, stated:

"The first session caused me to have terrible nausea, but I was unsure of what medication to take. In my next appointment, I asked the doctor to "please explain exactly what medication I should take for nausea and headache."P4

In the phase following the completion of therapy, participants suffered side effects such as tiredness, joint discomfort, and muscular cramping. The participant who was three years after her treatments stated:

"There are countless negative effects of chemotherapy. Since several months, my foot muscles have been quite uncomfortable. I have no idea what to do."P15

Lack of supportive care center

The lack of a care center to refer participants in receiving care for treatment-related side effects, how to utilize medications, dietary adjustments, etc..., exacerbated breast cancer survivors' perplexity. According to Oncologist, the lack

of a particular care facility for cancer patients was the cause of inadequate patient treatment: ***"I write the required things, but the cancer patient should go to the support center and tell them, 'You feeling nausea; if these drugs don't work, then take this medication and...'"*** P37

Threatening of progressive disease

The protracted illness and treatment process places patients at risk for disease progression. This category included two subcategories: fear of recurrence and living with uncertainty.

Fear of recurrence

Fear of disease recurrence induced insecurity and pain in the vast majority of patients. Fear of cancer recurrence silently ruled their life. Participant stated, ***"This sickness is always on my mind, it never leaves my mind; when I observe the little change in my body, I think, this should not happen again..."*** P13

Living with uncertainty

Cancer is a chronic and life-threatening disease that causes a great deal of anxiety among breast cancer survivors due to the disease's lengthy progression and unclear prognosis. ***"Sometimes I tell myself that it's over, and then I wonder whether it's truly finished. Does this imply that I should view myself as a chronic individual? Or not? Do I consider myself a healthy individual?"***P17

Discussion

The purpose of this study was to explaining the experiences of breast cancer survivors of problems throughout treatment and recovery. The data revealed that the four main categories of issues reported by breast cancer survivors include mental distress, perceived concern, confusion in care, and the threatening of progressive disease.

Mental distress was one of the main problems of breast cancer survivors in the present study.as one of the subcategories of mental distress, emotional strain resulted from the participants' fear of death, anxiety, and sadness. Consistent with the findings of this study, several studies on the early treatment experiences of cancer patients showed the occurrence of negative emotions, anxiety, and depression as prevalent psychological issues(27-29). It appears that the emotional strain experienced by patients stems from their comprehension of the disease's nature. After receiving a cancer diagnosis, the majority of patients experience the strain of confronting their own demise and the misery of living the remainder of their life as cancer patients. Therefore, effective therapy of anxiety and depression symptoms is a top priority in cancer patient care.

The second subcategory of mental distress was negative consequences of treatment. In our study, breast cancer survivors experienced physical issues such

as acute pain, nausea and vomiting, tiredness and disturbed sleep, as well as unsettling mental consequences such as hair loss and skin burns, which hindered their capacity to care for themselves. This conclusion was also documented in prior research(30,31).It can be said that physical problems and other unavoidable mental discomforts during the treatment process hinder patients' ability to perform normal life activities, increase their dependence on others to perform daily tasks, and cause them to experience anxiety and depression from a psychological standpoint. In such a circumstance, nurses may play a significant role in enhancing patient care outcomes by administering the proper therapies and providing comprehensive care.

The third subcategory of perceived concerns was financial concern. Cancer patients have financial concerns owing to the chronic nature of the disease and the financial burden of therapy, according to prior research(32,33). Survivors of breast cancer frequently have financial difficulties due to their treatment. economic burden persists for years after a diagnosis is made. Cost increases in cancer care frequently have a direct impact on patients and their families, delaying treatment and follow-up and endangering patients' physical health. Paying attention to the financial concerns of cancer patients on an individual and systemic level should be an important part of a comprehensive approach to cancer treatment.

The fourth subcategory of perceived concerns was disturbance in emotional life. The 2021 study by Hosseini et al(13) revealed that breast cancer patients face several sexual issues following therapy. This means that due to the taboo nature of sexual issues, particularly for women in Iran, who are sometimes too ashamed to ask medical professionals their queries, leaving their concerns unresolved.

Confusion in care was the second category of breast cancer survivors' issues. Inadequate knowledge about the disease was one of the subcategory of this category. In keeping with this conclusion, earlier research has demonstrated that the majority of cancer patients require more information regarding the disease and its treatment(34, 35). In order to make informed decisions about self-care, cancer patients must comprehend complex information about their diagnosis and management, as well as learn health terms. However, they are under a great deal of stress due to their cancer diagnosis and treatments, so they have more trouble comprehending and recalling the information and demonstrate less knowledge.

Symptom management was the second subcategory of confusion in care. In the current study, breast cancer survivors expressed confusion over the management and control of treatment-related side effects. This result was also observed in further research. According to Suwankhong et al (10) women receiving chemotherapy receive relatively little professional help on chemotherapy-related side effects. In 2019, Lovelace et al (36)examined the difficulties breast cancer patients encounter with relation to long-term treatment effects. Using patients' experiences as much as possible to assist patients in managing treatment-related unpleasant effects.

A Lack of supportive care center was one of the factors that contributed to breast cancer survivors' perplexity. Walsh and colleagues found that a failure in the

transition between primary and secondary care prevented cancer patients from obtaining sufficient treatment(37). Despite increased focus to palliative care in Iran, a 2022 study by Rassouli et al(22) revealed that palliative care is a novel method that is fragmented and available at a few centers. In support of this conclusion, it can be stated that patients have traditionally received care only by meeting with oncologists in oncology clinics in government centers or private offices, whereas breast cancer survivors face numerous obstacles during treatment and the transition to the recovery period that must be overcome. There are centers where patients and their families may go on an ongoing basis to obtain physical and mental-psychological care, to control the bothersome side effects of therapy, to receive counseling.

Threatening of progressive disease represented the third category of perceived concerns. Fear of recurrence was the first subcategory of the threatening of progressive disease and the most significant psychological stress factor among breast cancer survivors. Fear of recurrence of the disease was the primary concern of breast cancer survivors in the majority of studies(38, 39). Despite advances in therapy and longer patient survival, breast cancer survivors and their family worry a recurrence of the illness, and this fear can cause suffering for years after discharge. Therefore, it is necessary to design care programs for breast cancer survivors that address their concern of illness recurrence.

Living with uncertainty was the second subcategory under the category of threatening of progressive disease. In keeping with this conclusion, a number of prior research have revealed that uncertainty impacts a variety of topics, including future planning, financial concerns, health, and patient relationships(40-43). Uncertainty is a recurrent concern for cancer survivors and their families, and as a psychological stressor, it can have far-reaching effects on their quality of life. During clinic visits, health care providers might give a chance to discuss this topic.

In conclusion, breast cancer survivors encountered multifaceted, diversified, and widespread issues in the areas of mental distress, confusion in care, and threatening of progressive disease. Therefore, policymakers and health care providers can by addressing the issues of breast cancer survivors in personal and treatment programs and by establishing supportive clinics to provide education, emotional support of breast cancer patients and their families. Future research can leverage the present study's findings to design plans to improve quality of life of breast cancer survivors along the cancer continuum, from the treatment phase through the post-treatment period.

Although we tried to increase the transferability of the results by sampling with maximum diversity, this research has some shortcomings. Firstly, our participants come from only one oncology specialty hospital, so multi center studies are required in the future. Secondly, due to the prevalence of COVID-19, some participants were reluctant to be interviewed in person. The researcher unriddle their concerns by Compliance with health issues and using a mask, and in two cases, she used phone interviews.

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Authors' Contribution Statement

All of the authors initially developed the concepts with contributions. Mirfarhadi interacted with the participants, performed interviews, carried out transcriptions, and the initial analysis. Tabari-Khomeiran & Ahmadi and Jafaraghaee assisted in the reviewing of the coding scheme. Mirfarhadi wrote the initial draft with contributions from all authors during the editing procedure. All authors provided comments and approved the final version.

Conflict of Interests: There is no conflict of interest.

Ethical Approval: Research involving human participants have been performed following the declaration of Helsinki and code of ethic from the Institutional review board approval was obtained from the Ethics Committee of the Guilan University of Medical Sciences, Rasht. (IR.GUMS.REC.296).

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Informed Consent: Before study enrollment, informed written consent was obtained for all study participants.

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