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The Lived Experience of Iranian Women Confronting Breast Cancer Diagnosis

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ABSTRACT

Introduction: The populations who survive from breast cancer are growing; nevertheless, they mostly encounter with many cancer related problems in their life, especially after early diagnosis and have to deal with these problems. Except for the disease entity, several socio-cultural factors may affect confronting this challenge among patients and the way they deal with. Present study was carried out to prepare clear understanding of Iranian women's lived experiences confronting breast cancer diagnosis and coping ways they applied to deal with it.

Methods: This study was carried out by using qualitative phenomenological design. Data gathering was done through purposive sampling using semi-structured, in-depth interviews with 18 women who survived from breast cancer. The transcribed interviews were analyzed using Van Manen's thematic analysis approach.

Results: Two main themes were emerged from the interviews including "emotional turbulence" and "threat control". The first, comprised three sub themes including uncertainty, perceived worries, and living with fears. The second included risk control, recurrence control, immediate seeking help, seeking support and resource to spirituality.

Conclusion: Emotional response was the immediate reflection to cancer diagnosis. However, during post-treatment period a variety of emotions were not uncommon findings, patients' perceptions have been changing along the time and problem-focused coping strategies have replaced. Although women may experience a degree of improvement and adjustment with illness, the emotional problems are not necessarily resolved, they may continue and gradually engender positive outcomes.

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Introduction

Breast cancer is the most frequent cancer of women throughout the world and among Iranian women.¹ Unfortunately, Iranian women who experience breast cancer are younger than their counterparts in industrialized countries.² In addition, most of these women survive from breast cancer because of possibility of early detection and effective treatments ways.³⁻⁷ A diagnosis of cancer is a devastating event in women's lives that associated with various psycholo-

gical effects, including feelings of concerns, fears and uncertainty about the future⁸ and patients' response to such a challenge may be affected by several sociocultural factors and vary in the context in which they live.^{4,8-12} In addition, recent research has indicated that fear of cancer recurrence (FCR) is the most common problems among cancer survivors,^{3,8,13-15} and it should be considered that the negative psychological effects of FCR, has confirmed by most of literature, which explored the most common cancer-related concerns.¹³

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Psychological problems, which result from cancer have negative effects on patients quality of life¹⁶ and the coping ways those patients choose to adjust with their situations have profound effect on their quality of life.^{7,10,17}

Women have to deal with enormous psychological problems resulted from breast cancer and they may use different coping strategies to challenge with perceived problems.¹⁸ Coping strategies can influence treatment outcomes and survival rates of women with breast cancer,⁴ and coping is accepted to be one of the core concepts in the context of quality of life.¹⁹ It is found that appropriate interventions enable cancer survivors to apply the suitable coping strategy to manage perceived uncertainty.^{20,21} In addition, the need for improved access to supportive care, which is individually tailored for patients who challenge with cancer related complications, was reported in the literature.²²

There are several research in Iran related to cancer domain, but a few of them have specifically studied patients' experiences and coping strategies of early diagnosis women with breast malignancy. For instance, Joulaee *et al.*, explained that the most important lived experiences of women with this malignancy included affective responses such as weaken their self-confidence, living with fear and alteration of body imagination after mastectomy, those negatively affected their coping behaviors.¹⁰ Taleghani *et al.*, found that the most important factor to accept and cope with the breast cancer after definite diagnosis were strengthen spirituality and positive attitude toward the disease among a group of Iranian women.¹⁷

However, none of studies has clearly defined how women have been aware of their definite disease, how the bad news were given to the patients and their family, what were their first experience facing by the reality, whether they could cope with the diagnosis and what factors were more important to form a better acceptance compared the others. Identifying cancer-related experiences of breast cancer survivors and the coping strategies they use are important in designing

the appropriate interventions for patients to optimize the quality of life in survivors.

Present study was conducted to provide a clear understanding of Iranian women's lived experiences confronting breast cancer diagnosis and coping ways they applied to deal with disease. The ration of the study's design of a qualitative approach was scrutinizing the lived experiences by the patients' narrative and self-expressions and obtain a deep perception in this area those may not be acquired by a quantitative approach.

Materials and methods

A qualitative phenomenology design was used in this study. A phenomenological approach was selected because it defines living experiences, tries to interpret the meaning of phenomena, and enhances our perception of human experiences.²³

Research with a phenomenological approach aims to capture the main concept of a phenomenon and extract a description of the living experience of the phenomenon.²⁴ Using the hermeneutic phenomenological approach in this study enabled us to emphasize women's life experiences through their description of their experiences after facing by absolute diagnosis, changes they confronted and if they cope with the disease. Van Manen proposed six research activities as a methodological structure to guide hermeneutic phenomenology research, and these activities were used in this study. They are: 1) Turning to the nature of the lived experience; 2) Investigating lived experiences; 3) Reflecting on the essential themes; 4) Describing the phenomenon through the art of writing and rewriting. 5) Maintaining a strong and oriented relationship with the phenomenon. 6) Balancing the research context by considering the parts and the whole.

Purposive sampling was conducted among women who met the study's inclusion criteria, i.e., being Iranian woman in any age group with a confirmed

histological diagnosis of primary breast malignant tumor who had completed the adjuvant therapy during 3-6 months prior to the study and who is followed up for disease control by her physicians in the Radiation Oncology Clinic at Shohada-e-Tajrish hospital (governmental center) and a non-governmental hospital for cancer treatment in Tehran, Iran. In addition, to obtain the maximum amount of pertinent information to address the research question, we included the maximum variation of the participants' demographic characteristics.²⁴ The exclusion criteria were as follow: women who were metastatic breast cancer or end stage, and who were mentally ill.

Data gathering and analyses were conducted simultaneously from November 2014 to February 2015. Data were gathered using semi-structured, in-depth interviews with 18 eligible patients by the main researcher (13 women had undergone mastectomy and 5 others lumpectomies).

Every interview took approximately 45-60 minutes. Observational notes including nonverbal activity and main issues of emphasis arising from the interviews were noted by the interviewer. All interviews were transcribed verbatim. Data collection in the qualitative research essentially was based on the ideologies of data saturation, because numbers are not important in ensuring adequate samples since the aim of qualitative sampling is about the depth of the data, not with tentative generalizations.²⁵ The researcher continued to collect data until the analysis no longer indicated anything new or different about the samples. Nevertheless, phenomenology does not look for sameness or repetitive patterns; rather, determines what is singular, and a singular theme or concept may only be seen once in research data.²⁶ In the present study, the researcher attempted to continue the interviews until nothing new was obtained from patient's interviews. At the end of each interview, the researcher

provided a short report (field notes) that indicated important points

As a phenomenological study have a strong central phenomenological question, the research question was formed when researcher was impressed by the challenges and unmet psychological needs that woman encountered. So, it should be determined the main specific question "Please tell me what is the experience of women confronting breast cancer diagnosis?", Then, for enhance more knowledge and elicit accurate information of women's experiences, we used probing, specific and interpreting questions such as, "How did you feel when encountering such a situation for the first time?" "How were you able to cope with the reality?" and "What kinds of things helped you to cope with the disease?" In the second activity, the related literature was studied, and interviews were arranged with Iranian women who had experienced breast cancer diagnosis. In the third activity, we used Van Manen's thematic analysis to recognize the conceptual meaning of the lived experiences of Iranian women with breast cancer-induced complications and their responses that were determined strategies to cope with the disease. In the fourth activity, we provided a comprehensive report of the results of the present study. In the fifth activity, we tried to have continuous reviews of the research question and refrain from relying on abstract theories or classical concepts. In the final activity, we concurrently addressed the whole context based on each component's importance, and we tried to have an inductive-deductive viewpoint and investigate the relationship between meaning units, the main themes, and sub-themes by considering the research question.

Using Van Manen's thematic analysis approach, the major ideas from the narration to create a template for organizing findings and MAXQDA software was used for data management.

For obtaining more rigor and maximum trustworthiness, five criteria that Guba and Lincoln described (credibility, dependability, conformability, and transformability) were used in this study.

To increase the credibility (internal validity) of the attained data, researcher attempted to be deep engaged with the data (interview with negative case analysis, observation, memo writing, and accurate documentation of the stages of the research). Furthermore, the major emerging themes were identified and were rendered to some participants to implement a member check process and for verification and confirmation of the researchers' interpretation of women's experiences.

Dependability (external validity) was done by two peers who were familiar with study design and context of the study setting. In addition, for enhance the reliability, coding and re-coding approach was performed after two weeks of prior coding. To establish the transferability (external validity) we attempted to collect data from one of the main referral cancer treatment centers in Iran, Shohada-e-Tajrish hospital, that patients can be admitted and treated for the cancer from all over Iran at any socio-demographic characteristic and any type of health insurance, and a non-governmental private hospital in Tehran in order to examine probable different responses among Iranian women with breast malignancy. Although, there can be no absolute objectivity in phenomenological studies, researcher should interpret the findings with the least biases and her own perspectives. So, for addressing the issue of conformability external auditory was employed to examine the correspondence between the data and the findings. Two experts in nursing research and reproductive health who were not part of the team were asked to investigate separately the interviews and raw data, as well as the interpretation derived from them.

Following ethical committee approval of Shahid Beheshti University of Medical Sciences, interviews were performed with participants by first researcher.

Written informed consent was obtained from the patients before they entered the study. Participants were informed of the maximum 90-minute time commitment and the audiotaping of the interviews. Except for two interviews (were written word by word on the paper by interviewer), the rest were audiotaped. Each interview opened with an introduction including the aim of the study and asking the research question.

All participants were assured and reminded about confidentiality, and a discussion meant to put them at ease. All interviews were uniquely listened by the first researcher and after transcription, an ID number was given to each of them to ensure confidentiality.

All participants were informed that have right to refuse continuing or to quit at any given time with no consequence. In addition, they were assured to contact researchers if they had any question.

Furthermore, they were allowed to dispense with continuing interview at any time they inclined and this was not affected their routine care.

Results

The number of women who participated the study and were in-depth interviewed were 18 with an age range from 31 to 65 years.

Most of the women were undergone mastectomy surgery and chemo-radiation therapy. The majority of the participants were married (75%) and housewives (55.5%). The demographic and disease characteristics of the participants are presented in Table 1. The following two major themes emerged from the interviews: "emotional turbulence" and "threat control".

The first, comprise three subthemes as, uncertainty, perceived worries, and living with fears. The second include, risk control, recurrence control, immediate seeking help,

seeking support and resource to spirituality. Extracted theme and sub themes are presented in Table 2.

1. Emotional turbulence

The major theme "emotional turbulence" included the entire emotional response of patients confronted cancer diagnosis that in some of them has continued after complement of treatment. Three corresponding subthemes are representations of the narrations shared by the women: uncertainty, fears, and worries.

1.1. Uncertainty

Women experienced a binary response to

the diagnosis of breast cancer that affected their life and involved several types of uncertainties during their illness before and even after the treatment and during the survivorship period.

1.1.1. Uncertainty about the symptoms

Most women in this study were uncertain about their breast cancer symptoms and the severity of their symptoms before the cancer diagnosis because of limited knowledge and information about breast cancer-related changes and symptoms; this led to additional uncertainty, which can contribute to delay in seeking help, which ultimately could affect their survival.

Table 1. Participant’s characteristics

Variable	N (%)
Educational level	
Illiterate	2 (11.1)
Primary	4 (22.2)
Diploma	8 (44.4)
University	4 (22.3)
Job	
Housewife	10 (55.5)
Employee	8 (44.5)
Religious	
Muslim	17 (94.5)
Christian	1 (5.5)
Surgery type	
Mastectomy	13 (72.2)
Lumpectomy	5 (27.8)
Hospital type	
Governmental	12 (66.6)
Private sector	6 (33.4)

Table 2. Themes and subthemes emerged from participants transcriptions

Themes
Emotional turbulence
Uncertainty
Perceived worries
Living with fears
Threat control
Risk control
Recurrence control
Immediate seeking help
Seeking support

Sometimes, they incorrectly assumed that the symptoms they had experienced were related to non-significant disease, such as cysts or milk duct blockages rather than cancer. In addition, as most of malignancy signs had no obviously symptomatic and painful, delaying to seeking help from others or health professionals occurred.

"I first noticed the mass on my left breast. Then, I thought maybe the mass is from the cyst. Because I had the history of cyst in my breast during last year and I ignored the symptom....until now". (P7)

"I noticed a small mass, then, I asked my friend about it. She said it could be swelling from the milk duct as I was just weaning off breast-feeding for my younger daughter. Therefore, I ignored the symptom. I thought I would check again. However, the mass had no pain, so I just ignore it. Then, I didn't know how, suddenly I touched it again and felt it is getting bigger and hard, but it was about one after the first time I felt it". (P18)

1.1.2. Uncertainty about diagnosis

Two patients stated that diagnosis of breast cancer, especially in first stage could be missed, or incorrect and even after visiting by a physician, they were received confusing information that lead to misdiagnosis.

"When I referred to a sonographers for my breast mass, she reassured me that it (the mass) does not seem significantly malignant and probably is a milky inflamed gland". (P21)

1.1.3. Uncertainty about the future

Uncertainty also may have an unfavorable influence on the women's lives and may cause the perception that breast cancer is a fatal illness with no hope for a cure. After breast cancer treatments, almost all of the women were uncertain about their health and future. For example, one of participants stated:

"I don't know how long will I live with this illness? Should I ask the doctor"? (P13)

1.2. Perceived Worries

Living with the worries that women perceived was stated repeatedly by almost all participants affects their lives which cause by several factors such as refractory nature of cancer, unpredictable manner of the disease among different patients, being in a an unfavorable environment in hospital and more importantly, separation from family and children during treatment process among women who were referred by other cities to Tehran.

1.2.1. The transmission of worries

Some women expressed that they didn't tend to transmit their concerns to their families. For example, some participants did not try to disclose their anxiety in front of their family to keep them from problems.

"I didn't tell them (her family) anything about the cancer probability because I didn't want them to be worried". (P9)

1.2.2. Worries about children

Women with very young children expressed great concerns regarding their children, and they worried extensively about the question of who would take care of their children, if they passed away.

"It is the most important concerns that what happen about my children's future, if I die". (P10)

"I have four young sons that have not married yet, and my only wish is to be alive and see their marriage". (P4)

"I hope to be alive to see my daughters growing up. ... All my children are still schooling, they are very young to live without me". (P12)

1.2.3. Worries about the future

Many talked about unknown future. Women who experienced chemotherapy expressed that they worried about the treatment process, especially during chemotherapy, that made them so weak and afflicted and they supposed they could never recover again.

"I felt more pain in my body after chemotherapy, it caused me worry that if the pains and disabilities continue forever". (P10)

1.2.4. Worries of others' pity

Some of participants in the study mentioned that the diagnosis of breast cancer is similar to a stigma for patients; they experienced perceived concerns caused by their perception of the others' different looking and pitiful behaviors. Therefore, they preferred not to disclose their diagnosis to others and kept the news with themselves.

"I dislike pity. I didn't disclose my disease to my colleagues because I was afraid of their pitiful behaviors". (P16)

1.2.5. Worries of spouse's acceptance

Young participants shared that they were worried about their spouses' reaction after diagnosis and if they accepted them by their new condition. They believed breasts are a sexual part of a woman's body and they worried about losing their breasts and then loss of attractiveness and beauty.

"I didn't know how I could tell my husband until I underwent mastectomy. I worried about my husband's sensation of my appearance after surgery". (P5)

1.3. Living with fears

A most common finding among participants was fear that was described in several aspects.

1.3.1. Fear of death

Although, in the initiation of the interviews a few participants feigned calmness and carelessness to their situation, as interviews went on degrees of fear and dread could be elicited through their expressions.

"Thinking about death comes to my mind every night, however, I am not afraid of death, but since I was aware of my cancer, I think about it". (P10)

"Whenever I hear the word "cancer," the "death" occurs to my mind and I'm afraid of dying during treatment process. I don't know how long I am able to live with cancer". (P14)

1.3.2. Fear of cancer recurrence

It was the greatest fear that the women frequently stated in this study. Many

patients also were scared of recurrence of the cancer and treatment once more.

"Now my greatest fear is returning the cancer and progress to the other sites of my body". (P4)

1.3.3. Fear of aggravation of disease

The participants who had undergone lumpectomy, were frightened more than counterparts with mastectomy, because they thought the source of cancer had not been completely eradicated and their condition may be endanger by everything else. Also, women who experienced more illness during chemotherapy, shared similar experience and were frightened by aggravation of their disease.

"I have not had sexual intercourse with my husband since I got cancer. My treatment finished but I have fear of getting sick if I have sex". (P7)

2. Threat control

Participants identified multiple strategies to alleviate their emotional distress resulted from receiving shocking news and coping with the related problems.

2.1. Risk control

The cancer diagnosis induced some positive changes in some of the patients' lifestyle, such as dietary modifications and physical activity. Dietary change was part of their new behaviors for controlling the risk of the recurrence of breast cancer. Some patients said that they did not have regular exercises before cancer diagnosis, while after treatment was completed, they mostly turned to the regular exercises and more physical activity.

"Now I consume safe food always. I try to eat fish and vegetables more than before. I rarely eat red meat, fast foods or industrial fruit juices, instead, I drink milk more than before" (P 11).

"I did not use to do regular exercises before my cancer diagnosis, but now I participate in yoga classes every day, try to exercise as much as possible. It makes me relaxed and I hope that it helps me to prevent the cancer recurrence". (P7)

2.2. Recurrence control

Patients tried to control the probability of cancer recurrence and its risks by programming a regular follow-up and necessary examinations.

"I have planned every six-month routine visits my physician to control and detect probable recurrence". (P9)

2.3. Immediate seeking help

Asking immediate support and medical help armed women with necessary information and interventions by physicians and oncology staffs. Patients described their seeking help by visiting a physician as soon as possible in case of warning or suspicious symptoms.

"Now I have information about the expected symptoms of breast cancer and contact my doctor immediately when I feel any symptom". (P17)

2.4. Seeking support

2.4.1. Caregivers support

Patients' family (including spouse, mother, sister, brother and children) and in a few cases, a close friend, formed the main caregiver of the participants. Their support included as financial support, tangible assistance (attendance at or transportation to the hospital or physician's office, helping in house chores...) and emotional support (empathy, assurance). The patients in the study reported that the emotional support of their family members enabled them to stand disturbance of losing hair following chemotherapy

"After third session of chemotherapy I lost my hair, I never forget what my brothers did; all of them scarify their hair and do this until the end of my chemotherapy treatment. They surprised me and that was a great emotional impact. I realized that I was not alone even though my husband didn't support me during this terrible period". (P8)

2.4.2. Health care providers supports

Some participants experienced that the information supports by health care providers and interaction with nurses and physicians had a positive impact on their lives that helped them to cope with the disease.

"My doctor is a nice and pious man... a great person. He always encourages me, listen to my

complaints and let me to open out my heart and explain about my treatment process. As he's a doctor his advices have positive impact on my husband". (P 24)

2.5. Resource to spirituality

A sense of calmness, providing hope and giving meaning to the life were common terms that participants of study had reached them by resorting to the religious affairs and strengthen spirituality. All participants with different attitudes believed that religiosity served as a source of power and comfort that helped them to cope with their situation.

2.5.1. Spiritual attitude

Patients believed that their disease is a kind of God will; God had selected them for a great test, only the Lord is able to definitely cure them; so all of them tried to trust God and lean on him.

"I am not worry about anything, because I believe that life is as a great exam and the signs of this exam may vary in people's lives such as this (breast cancer). This makes me to be hopeful every time". (P9)

2.5.2. Seeking spiritual help

Most of the patients emphasized the positive role of spirituality and religious rules or ceremonies on their recovery. They remarked that praying helped them to cope with problems, standing the crisis that resulted from cancer diagnosis.

"When I heard I got cancer, I asked our sanctities to help me. I called on a priest before going for mastectomy, and asked him to pray for me, then I felt comfort". (P7)

"I pray every time and just I want from the Lord to protect me against the cancer recurrence and this is the only way I feel calmness and I always pray to God and want him to help me through this life strain. I 'm sure that He really hear my voice". (P13)

Discussion

Based on our knowledge, few studies have concentrated on the lived experiences of Iranian women with breast cancer after

confronting diagnosis and coping ways they applied.^{4,10,17} Emotional response was the immediate reflection to cancer diagnosis. Uncertainty of diagnosis, being worry about the future and fear of death were the most common immediate experiences, whereas, problem solving responses, mainly cancer threat control, appeared subsequently. However, during post-treatment period a variety of sensations and emotions such as uncertainty about the future, fear of cancer recurrence and intrusive thoughts and worries about children were not uncommon findings, patients' perceptions have been changing gradually and problem-focused coping strategies have replaced.

For younger women, this illness has psychological negative effect and convey a great distress, whereas for older ones, engenders a positive change in their perspectives. In comparison with older women, breast cancer diagnosis in the younger ones induced more burden of worries and fear, especially fear of recurrence. The majority of studies manifested that uncertainty about the future and fear of recurrence were the greatest concerns of these patients,^{17,25-27} even though cancer survivors face uncertainties about the future. This finding is in agreement with previous studies that confirmed that uncertainty about the future was a major concern among the survivors of breast cancer.²⁸⁻³⁰

Consistent with some prior research³¹⁻³³ our participants' expressions of positive emotions such as resource to spirituality, confirmed that religiousness and spirituality can help patients to cope with chronic diseases such as cancer. Spirituality and religiosity are well known as factors that positively impact patients' quality of life and satisfaction and support for patients' spiritual needs is associated with better health care and less aggressive care at the end of life.³² These finding assert that participation in religious services are associated with reduced sense of hopelessness, fear, anxiety and allowing patients to adjust to their situation.

However, Thuné-Boyle et al., found that perceived spiritual support did not serve as predicting factor adjustment every time. For example, sometimes patients who rely on religion believe that disease is just the God will and they accept events that they perceive to be outside of their control. For this reason, such patients may not make any attempt to cope with the problems associated with the diagnosis and treatment of illness.³⁴ Nonetheless, in Islamic instructions, there are a great difference between fatalism and leaning to the Lord.

Fatalism individuals believe in lack of internal control over external events in their life and perception of fate, chance and destiny and feelings of powerlessness and convey pessimism rather hope, in contrast, Islamic rules prohibit hopelessness and encourage humankind to attempt for life improvement, therefore, religious beliefs do not take a way people's responsibilities to their health behaviors. This study recommends that interventional programs would be implemented in routine psychosocial support care and services.

The present study's results showed that there were positive alterations in women's lifestyles, including changes of dietary habits and physical activity after breast cancer treatment. They coped with the fear of cancer recurrence through safe lifestyles, and, in fact, it helped them to have a better feeling that are able to control over the probability of the breast cancer recurrence. Lifestyle changes are mental strategies that the women used to enhance their abilities to recover from the disease more quickly.

Trying to have positive changes in one's lifestyle is one of the common coping strategies that can result in a successful adjustment. This is observed mostly among patients who believe they can control the cancer recurrence through changes in their lifestyles.^{28,29,35}

Our findings indicated that seeking help and support, especially from family, friends, and healthcare professionals, helped women to better cope with the illness after diagnosis. The

role of caregiving in cancer is well recognized that can be effective to improve the patients' quality of life and is in line with the literature.³⁴⁻³⁶ Although women did not differentiate clearly effects of emotional support, tangible assistance, financial and information supports, having an understanding of these patients' needs and challenges by health healthcare professionals can provide sensitive support for women during a critical period of their life. It was remarkable that some patients in our study preferred to be isolated from others because of their personal perceived worries. Generally, most of the women wanted to be treated as usual and avoid any behaviors induced by the stigma of cancer.

They believed that others' pity and compassion might cause negative emotional effects. Drageset *et al.*, and Jassim and Whitford also found the same tendency for cancer patients to isolate themselves from others.^{12, 36}

Conclusion

Finally, although women may experience a degree of physical improvement and psychological progression and adjustment with illness along the time, this does not mean emotional problems are necessarily resolved, they may last and gradually engender positive outcomes. This understanding is important to the development of oncologic care programs.

Notable strengths of this study include diversity in socioeconomic status and open-ended research questions in eliciting the deep layers of patients' statements and allowed patients to express their experiences openly, but like ever qualitative study suffered from some limitations.

Firstly, lack of a longitudinal perspective on women' progress did not allow us to scrutinize the exact experiences of patients in transition of diagnosis to post -treatment period. Secondly, the small size of the study sample, like most of qualitative studies, our findings are not generalizable to the broader population of Iranian female patients with breast cancer.

Thirdly, as the interviews were dominantly performed in a setting of oncology clinic, some patients were in hurry to visit their own physicians; or sometimes because a few patients' psychological distress and excitement (chucking with tears, crying ...), some of interviews have to be interrupted of necessity and postponed that would affect the data, however, the broad nature of the interview questions reduced this possibility.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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