



“The danger still hangs over my head” fear of recurrence among Israeli breast cancer survivors

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ABSTRACT

Introduction: Many breast cancer survivors report a fear of recurrence of the disease, which finds expression in anxieties that the original cancer will return or that another form of cancer will begin to develop. The present study evaluated perceptions of and feelings about the fear of recurrence from the point of view of breast cancer survivors, the impact of this fear on their lives, and their means of coping.

Method: Qualitative research was conducted using the phenomenological approach. The sample included 13 breast cancer survivors aged 34-67 who were within 1 year after completion of chemotherapy. Participants included survivors who had been diagnosed with localized breast cancer, Stages I-III, without metastases, and without previous cancer diagnoses. Participants provided their personal details, while details of the disease and treatments were collected from the patients' files.

Results: Two main themes emerged: (1) Along with the desire to gradually return to normal life, the study participants described an ongoing sense of existential threat, a lack of security and a sense of being out of control when any follow-up tests or pain linked to potential cancer caused fear and anxiety and (2) their fears also concerned their family members as they were afraid their loved ones might get sick and go through the suffering they had experienced.

Conclusions: The fear of cancer recurrence is a multidimensional phenomenon. This emotional response can arise as a result of physical symptoms causing suspicions that the disease has returned or as a result of external factors, such as follow-up tests or other people's illnesses.

Key words: Qualitative research; breast cancer; disease recurrence; cancer survivors

INTRODUCTION

Fear of cancer recurrence is defined as fear or concern that the cancer will return or progress in the same or another organ (1). Studies indicate that even after completing their primary treatment and

being declared cancer free, breast cancer survivors continue to live with the cancer experience and harbor anxious and fearful thoughts about disease recurrence (2-7). The incidence of breast cancer recurrence is 10.4% in the first 5 years after chemotherapy (8), but the number of survivors reporting fear of recurrence ranges from 25% to 97% (9-14). Even 8 years after diagnosis, 82% of survivors had a fear of recurrence (15).

High levels of fear of recurrence are characterized by over-testing, over-vigilance, frequent obsessive

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thoughts, poor sleep, and anxiety. These high levels were also found to be related to mental well-being and state of physical health (15-17). Fear of recurrence was also found to be associated with dysfunction, depression and anxiety, stress, and physical symptoms such as pain and exhaustion (5-7,13-15,18-21). In a study of 549 cancer patients 5-10 years after diagnosis, high levels of fear of cancer recurrence were associated with emotional and physiological states (22). Evidence shows that survivors with high levels of fear of recurrence use up more health services (23). They exhibit reluctance to be released from medical follow-ups due to their attempts to find certainty in distinguishing between recurrence and physical changes associated with treatment (24-26) or seek testing for recurrence at a later stage (27-28). A longitudinal study of 161 breast cancer survivors found high levels of fear before mammograms, with a sharp decline in fear immediately after completing the test and receiving the results. Nevertheless, the original levels of fear returned 3 months after mammography (29). Most survivors (62%) expressed interest in talking to the attending physician about their fear of recurrence (30).

Studies point to several variables that predict the fear of cancer recurrence, among them demographic variables, disease variables, and psychological variables. Regarding demographic variables, studies suggest that the fear of recurrence is higher among younger survivors (11,31) than among older survivors and also characterizes the survivors' spouses (32). Survivors who have children, those with low socioeconomic status and those with fewer years of education reported higher levels of the fear of recurrence (15,19,33). Studies on marital status, income level, and ethnicity were inconsistent (13,19). Regarding disease variables, a study of breast cancer survivors suggests that high levels of the fear of recurrence are linked to having undergone chemotherapy, as well as to the presence of muscle pain and fatigue caused by cancer treatment (31,34). Regarding psychological variables, in a longitudinal study of approximately 400 breast cancer survivors higher levels of fear were found among women who also reported high levels of anxiety and difficulties in adjusting to the disease (2,31).

Recurrence in breast cancer survivors has been studied previously. What makes this study unique is that

the sample included only women whose diagnosis was breast cancer. Moreover, all the participants were within 1 year of the end of their chemotherapy treatments and all had been diagnosed with a localized disease. In addition, the study examined the recovery experience from a qualitative perspective to enhance the understanding of the fear of recurrence of cancer.

This study examined breast cancer survivors during the period of their recovery from the effects of the treatments (up to 1 year). All participants had been diagnosed early and are currently without signs of illness. The aim of the study was to understand the fear of disease recurrence as experienced by these survivors and to examine how they deal with this fear after they finish chemotherapy treatments.

METHODS

Study design

This qualitative research study was based on the phenomenological approach, a philosophical approach that focuses on the point of view of the person experiencing the phenomenon (35). The approach seeks to understand how individuals construct the meaning of phenomena. Reality is regarded as multifaceted and subjective and is represented in the perceptions of the observer (36). The starting point is the reciprocal relationship between individuals and their world. Individuals have no existence without their world, and there is no existence or meaning without human beings who experience it. The person and the world are mutually interdependent (35).

Participants and procedure

The current study was approved by the Institutional Review Board (No. 0354-10-RMB).

The physicians in the oncology department recruited women to participate in the study. Before consenting to participate, the women were given both written and oral information about the interview and the study. Those who agreed to participate signed informed consent forms during their meeting with the researcher.

All data from the interviews were stored safely, and only the researcher had access to the data. Interviews

were coded so that the participants' identities remained confidential.

The study included 13 breast cancer survivors, aged 34-67, all living in Israel. Most of them were married, all of them had children, and ten of the participants were employed. The sample was collected using the targeted sampling method (36). The inclusion criteria were as follows: Breast cancer survivors diagnosed at the initial Stages I-III; 1 month-1 year after completing chemotherapy; no previous cancer diagnosis; no diagnosis of dementia or mental illness; and Hebrew speakers. An attempt was made to interview breast cancer survivors who would reflect a diverse and comprehensive picture in terms of their background characteristics. However, the actual sampling took place according to the theoretical saturation method, until the stage in which continuation of the interviews did not reveal any additional themes and meanings. The interviews were conducted in the homes of the participants and took about an hour. All the interviews were recorded, transcribed, and analyzed (Table 1).

Research tools and instruments

The qualitative data in this study were collected through semi-structured interviews. The interviews served as a means of learning about and understanding the experiences of the interviewees and were conducted according to an interview guide that included key areas that were significant but flexible. They were designed to facilitate dialogue between the interviewer and the interviewee and allowed for significant level of personal expression (35).

Personal and medical details

Participants provided their personal details, including age, marital status, number of children, employment status, and income. Details of the disease and treatments, including cancer stage and types of surgery, were collected from the patients' medical files.

Data analysis

Analyzing the data in a qualitative-phenomenological study is based on the assumption that there is a shared essence to all human experiences. This essence contains the main implications of a phenomenon and can be revealed by analyzing the experiences of

different people in the same context. In this study, the interviews were analyzed using content analysis to identify and encode the key themes and patterns. In the first stage, all the interviews were read, the main issues that arose in the interview were identified, and sub-categories were created. The next step was to search for the links between the topics and to group the subcategories into secondary categories. In the last stage, the main themes representing the main points of the study were identified (35).

RESULTS

The content analysis of the findings revealed two main themes:

1. "The danger still hangs over my head": Living in uncertainty. All the women in the study described their fear of recurrence of the disease. They expressed this fear in the form of concerns that their breast cancer might return or that they would develop another type of cancer. All the survivors described concerns they face every day. These concerns were especially strong during follow-up tests, with the main concern being negative results or fears of an incorrect diagnosis. The main feelings the women described included feelings of insecurity regarding the return of the disease, defenselessness, helplessness, and lack of control. Any pain, no matter how mild, was linked by the survivors to potential cancerous disease and caused them anxiety. One of the greatest fears described by women was the fear that the new disease would be much more aggressive than the previous one and that they would not be able to survive it. Nonetheless, the participants also described their desire to gradually return to their normal routine at work and with their family members, as they were before the disease.
2. "No one in my family should have to go through this": Worries about family members. The participants' fear of recurrence extended to include concerns about potential illness of family members or fears of being a burden to their family. The intensity and nature of these fears differed from woman to woman, with some experiencing a continuous sense of existential threat. Some of the survivors indicated

TABLE 1. Background characteristics of the study participants

Pseudonym	Age	Marital status	Number of children	Years of education	Professions	SES	Stage	Type of surgery	Type of chemotherapy	Radiotherapy
Noa	41	Married	3	18	Teacher	Middle	I	Breast-conserving surgery	TC	Yes
Mary	47	Married	4	16	Manager	Low	II	Mastectomy	ACT	Yes
Janet	52	Single	1	8	Caregiver	Low	I	Breast-conserving surgery	TC	Yes
Yael	43	Married	4	10	Nanny	High	II	Mastectomy	TC	Yes
Sarah	37	Married	4	13	Teacher	Low	II	Mastectomy	TC	Yes
Adi	34	Divorced	1	12	Salesperson	Low	I	Breast-conserving surgery	TC	Yes
Tamar	47	Married	3	12	Unemployed	Middle	III	Mastectomy +breast reconstruction surgery	TC	Yes
Leah	65	Married	4	15	Kindergarten teacher	Low	II	Mastectomy +breast reconstruction surgery	ACT	Yes
Katia	62	Married	2	16	Manager	High	II	Breast-conserving surgery	ACT	Yes
Aviva	66	Widowed	2	16	Retired	Middle	II	Breast-conserving surgery	TC	Yes
Naomi	60	Married	4	16	Nurse	High	III	Breast-conserving surgery	ACT	Yes
Julia	60	Married	2	13	Retired	High	I	Breast-conserving surgery	TC	Yes
Shlomit	67	Married	2	14	Salesperson	Low	I	Mastectomy	ACT	No

TC: Taxotere, carboplatin, ACT: Adriamycin, cyclophosphamide, taxol

that they were personally acquainted with former cancer patients in their family whose disease had returned, making the possibility of recurrence more threatening and tangible for them and increasing their fear.

Theme 1: “The danger still hangs over my head:” Living in uncertainty

This theme reflects the fact that the disease had mental as well as physical consequences for the

breast cancer survivors. Participants described a wide range of emotions, among them shock, anger, grief, uncertainty, hope, confusion, pain, fear, guilt, loneliness, relief, and more. The various emotions accompanied the participants from their diagnosis through their efforts to cope with the chemotherapy treatments and throughout the subsequent period. The women indicated that they began experiencing even more anxieties when the treatments ended. All participants, regardless of age, described their desire to gradually return to their normal routine (work

and care for children), but at the same time, they noted that the fear that the disease would return always hovered in the background:

“Let it not come back, let it simply not come back, let me know that it is behind me... and that all I’ve been through, all I went through is in the past tense, and I’m not going to go through any of these things again” (Sarah, 37).

“I really hope we’re done with this thing called cancer... Forgetting it is impossible... The thought is that though I had it, the danger still hangs over my head” (Aviva, 66).

The burning desire to know that this episode of disease was behind them and will never return was evident in the words of the survivors. It was possible to feel their anxiety about another possible outbreak of illness in the future. Some of the participants felt there is no security. Anyone can get cancer, and the disease can return.

“Fear. Yesterday, I sat with someone who said that his sister had it in her uterus... Very simply. She went through everything — chemotherapy, radiation, and this and that... Suddenly, they discovered it, seven centimeters, and she was gone, a 37-year-old woman. Do you understand? So... like, there is always fear. Until I close my eyes, I will be afraid” (Janet, 52).

Janet expresses the sense of lacking any protection that other participants referred to as well – a sense of surprise, helplessness, and lack of control over the situation. They fear that even after experiencing the disease, its pain, and its difficulties, the cancer still can reappear, at any age, and in any form. Some of the participants expressed a sense of temporariness, of life’s fragility, and a feeling of helplessness when it comes to recurrence of the disease. For example, Mary feels she is living on borrowed time and that life is temporary and transient:

“I think about how long I have to live, afraid that it will come back to me again.” (Mary, 47).

Persistent fear has an impact on daily life. Every symptom that the women feel that is somewhat reminiscent of one of the symptoms they experienced before and during the illness causes alarms to go off. Any pain, even mild and common, is linked to potential cancer and the threat is unbearable.

While fear and worry are the daily lots of these women, there are situations in which their fears are

intensified, as, for example, in the case of periodic follow-up tests. The participants expressed great concern and stress over these tests and were especially worried about the test results. Some even raised doubts about the need for follow-up tests and expressed their desire to suppress the information:

“I already think it will be rather difficult to wait for an answer and what-not” (Katya, 62).

“I do not even know if I want these follow-up tests... As soon as, God forbid, there are metastases then... You can’t recover from it, you can only prolong life... So, like, even if I don’t know if I... would want to learn if I had it” (Sarah, 37).

The survivors described the problems involved in carrying out these tests. Follow-up tests bring them back to the oncology department, to its sights and odors, thus increasing their tension and stress regarding the possibility of disease recurrence. Some women even refrain from carrying out follow-up tests because of their problems in coping and their fear of the test results.

For some of the participants, their fear that their disease might return was exacerbated by fears of delays or errors in diagnosis, similar to those they experienced in the past. Adi (34) recounted her frustrating experience of undergoing many tests and receiving various diagnoses other than breast cancer until the disease was finally diagnosed:

“Fear of the disease, fear of life, fear of the fact that you are temporary... fear of how, how can you do tests? They [the doctors] missed it in my case for more than a year. I really fought, so it’s very frustrating, very scary.”

Some participants also described their fear that if the disease returns, it will be more aggressive than previously and they will not be able to cope with it physically or mentally or survive it this time:

“They have already given me really aggressive treatment. So, the next treatment will have to be different, because it must have developed some antibodies... The kind of bomb that I got now, so what [the next one] will be next... I have fears that if it comes back next time, it will come back more... aggressive and less curable.” (Yael, 43)

Yael understands the disease and its significance. Her fear is not amorphous but is based on the familiarity and knowledge she has accumulated during her treatment. In contrast to healthy people who

are afraid of getting cancer, the survivors base their fear of their familiarity with the disease and all its consequences.

Theme 2: “No one in my family should have to go through this:” Worries about family members

The participants also expressed concerns about close family members getting cancer. Their fears are not only about recurrence of their own disease but also about fears that their family members will become ill as well. After experiencing cancer themselves, these women are afraid that their relatives will experience the suffering and pain they experienced. They do not want to be witness to such suffering among their loved ones.

“Let it not happen in my family... no one in my family should ever have to go through this” (Julia, 60).

The fear of cancer recurrence also incorporates concerns about the implications of such a recurrence for family members. Some of the participants stated that they did not want to be a burden to their family members and did not want to cause them pain and sorrow again:

“And not to suffer and not to cause suffering. I am also very attached to my children and grandchildren, and they are also very attached to me and I... really do not want to cause suffering to them and, of course, to myself” (Aviva, 66).

As an older woman and a widow assisted by her children and grandchildren, Aviva describes a unique kind of fear: The fear of becoming a burden, of not being fair to her family members, and of being more dependent and less autonomous.

Janet, a single mother, described how the fear of cancer recurrence affects her ongoing relationship with her family and motivates her actions:

“Always, always... You’re always afraid... Look, I never thought, and I have only one child, and I raised him alone... So now I’m afraid, so I say — I want to make a will... And I’m trying to explain it to my son, like... so that he will know what is happening.”

Janet describes how being a single mother affects how she coped with the disease and how she behaved after the treatment. During the treatments, she tried to protect her son, in his thirties, as much as

possible. To spare him pain, she prevented him from getting all the information about her disease. Now she feels responsible for him and wants to prepare him for the possibility of her future death. During the interview, Janet said:

“Because I’m not finished. With all this... the doctors are telling me that everything is fine... you have gone through everything... I have a feeling... Maybe it will not come now, maybe it will come in a year, in two years. Remember my words.” Janet said that even though she is healthy, she has the nagging feeling that she will get sick again in the near future. Janet described the contrast between her sense that she has no protection from the disease and her feelings of optimism that help her in difficult times: “At the end of the tunnel, there is no... there must be a light” (Janet, 52).

Some of the participants met other cancer patients whose disease has returned. Such encounters make the possibility of recurrence more real and more stressful. Part of the fear stems from knowing relatives or friends who had cancer and their disease recurred. Mary talked about supporting a relative during the course of her cancer, which has returned, and mentioned the closeness between them (Table 2):

“We have someone in the family that her (disease) has returned... It started in her lymph... They treated her... Three years, she was healthy... For three years she had it good... And it came back again... she passed away. She was forty-four... I think about her a lot.” (Mary, 47)

DISCUSSION

The current study documents the fear of cancer recurrence from the point of view of breast cancer survivors. The end of chemotherapy treatments is a psychologically complex stage (5-7,37). It may include feelings of joy and relief that the treatments have ended, optimism, motivation for change, and also sadness about things that were lost, feelings of insecurity and fear of recurrence (14). The participants in this study described that after their chemotherapy treatments they experienced more anxiety than ever before. All the participants, regardless of age, described a desire to return gradually to their routine. At the same time, they noted that the danger that the disease would recur still hovers in the background. Although it

TABLE 2. Summary of the main findings

Theme	Main findings
"The danger still hangs over my head": Living with uncertainty	<p>The feeling that there is no security; everyone can get cancer and the disease can return; feeling defenseless.</p> <p>A sense of helplessness and lack of control over the situation.</p> <p>Any pain, even mild and common, is linked to potential cancer and causes anxiety.</p> <p>The participants expressed concern and great stress regarding follow-up tests and, mainly, their results.</p> <p>Fear that if the disease returns, it will be more aggressive than its predecessor and they will not survive it this time.</p> <p>The participants, regardless of age, described the desire to gradually return to their normal routine.</p> <p>The survivors described concerns regarding delays or errors in diagnosis.</p>
"No one in my family should have to go through this:" Worries about family members	<p>Deep-seated fear of potential illness among their family members (a broad sense of vulnerability).</p> <p>Fear of being a burden to their family members and causing them pain and grief.</p> <p>Familiarity with the treatment of cancer patients who had a recurrence makes the possibility of recurrence more real and stressful.</p>

seems that returning to normal is possible, many survivors must cope with the fear of recurrence for long periods of time, during which every physical symptom causes suspicion and evokes the basic experience of insecurity and uncertainty. Indeed, the clinical and research literature indicates that between a quarter to almost all of the survivors reported the fear of recurrence (10,12,14,20) and that this fear continued for years (13,15,38).

In this study, the participants expressed perceptions of temporariness and fragility of life and feelings of helplessness, defenselessness, and lack of control over disease recurrence. A cancer diagnosis is perceived as the most dangerous threat to life, and this sense of threat persists even after treatment has ended, accompanied by a feeling of lack of control and uncertainty about the future. A cancer diagnosis forces a woman to face her mortality and also her lack of control over her life and her body, accompanied by a loss of independence and a sense of helplessness (39,40). The participants described this anxiety as a daily occurrence. Such anxiety may also arise in response to a follow-up visit to a doctor, various symptoms, and knowledge of someone whose disease has returned exposure to information from the media, and more (41). Patients who fear disease recurrence are affected by their experiences throughout the course of their disease so that their fears of the future are shaped by past experiences (14). Another fear that some participants described is that

if the disease returns, it will be more aggressive than before and they will not be able to cope with it physically or mentally or survive it this time.

One of the main topics that emerged from the analysis of the findings was the extension of personal fears to family members. Breast cancer survivors are aware of the vulnerability and fragility of life. As a result, some participants also expressed concerns regarding possible illness among close family members, thus widening the circle of their fears to include fear for their loved ones as well. The participants indicated that their greatest wish was that their family would never have to deal with cancer and never have to go through everything associated with the disease, as they themselves did. Alongside the significant physical changes and the side effects of treatments, the fear of recurrence always hangs over their heads. In addition to the fear that family members would develop cancer, the survivors described their fear of becoming a burden to family members due to their illness. This is similar to previous studies (42,43), which found that one of the greatest fears of survivors is to become a burden on others. In the present study, one of the most distressing issues for the participants in relation to their family was causing pain and grief to their loved ones. Another experience that survivors perceived as threatening was their acquaintance with family members with cancer whose disease had returned. This made the possibility of disease recurrence more

threatening and tangible and increased their fear.

After cancer, patients complete the intense goal-oriented activity of chemotherapy thoughts, anxieties, and worries often emerge more intensely than ever (13). At this stage, support and psychological treatment also change and diminish. Patients are usually less preoccupied with the disease itself, the treatments, and their immediate implications. They become more preoccupied with the meaning of the disease, existence in general, the uncertainty in the world, and sometimes even with personal growth and development that emerge after a crisis (33). When their treatments ended, the participants faced difficult emotional challenges. One of the most significant losses these women experienced is the loss of the illusion of health. Women who have been forced to cope with a sudden illness that threatened their lives report that they are unable to regain a sense of confidence in their bodies and their health. A heavy shadow accompanies them in the form of the fear of recurrence. In addition, after the end of the treatments, there is a decrease in close monitoring by the medical staff available during the treatments. This monitoring provided a form of protection for the women, who felt confident that their medical condition was being treated and managed. After the treatments ended, the women stated that they were left with fewer active partners concerned about their health. This situation raises a great deal of concern, uncertainty, and confusion.

Studies suggest that health-care providers lack the skills, knowledge, and confidence needed to identify and treat the fear of breast cancer recurrence. Indeed, they do not address this concern even when it is brought to their attention (44). Yet medical staff can play an important role in improving the mental health of survivors (45). By identifying high levels of fear of recurrence, including through the use of proven diagnostic tools (9), health-care providers can help reducing "survivors" fears and improve their mental well-being (28,46). They can do so through direct intervention or through referral to a suitable psychological service. Several studies (47-49) found that intervention by an oncological nurse (47,48) had a positive effect on survivors and reduced their levels of anxiety. Intervention that encourages survivors to participate in meaningful and useful activities (such as contributing to the community) may also be effective in helping survivors cope with the

fear of breast cancer recurrence (11). Cognitive behavioral therapy may also help survivors (50), even in cases of high levels of anxiety (51,52). In addition to the direct benefit to breast cancer survivors, effective treatment to reduce fear levels may save costs for the health system (27,28).

Study limitations

Qualitative phenomenological research facilitates an in-depth examination. This advantage, however, also points to its disadvantage as a method that does not allow the inclusion of large populations. Another limitation is that the study was conducted at a single large oncology institute in Northern Israel. Although this institute serves a diverse population of patients, the research could be extended to other oncology institutes. It is recommended that further studies examine the fear of recurrence in different types of cancer patients at different stages of the disease, as well as among family members or members of the community. In addition, to provide a more in-depth examination of the processes, it is recommended to incorporate diary management in the studies, as well as to use an integrated method of quantitative and qualitative research.

Study implications

The findings have a number of practical implications. One recommendation is that professionals in oncology should be aware of the ongoing fear of recurrence and of the need to examine survivors to gain a better understanding of their personal perceptions. The study recommends identifying those survivors with high levels of fear of recurrence by paying attention to fears of follow-up tests, failure to show up for such tests, or high levels of dependence on health professionals, all of which may indicate the fear of recurrence.

CONCLUSIONS AND RECOMMENDATIONS

This study provides a qualitative overview of the experiences of breast cancer survivors and their fear of cancer recurrence. The study participants described their feelings of uncertainty and defenselessness against cancer recurrence. Their fear increased with the appearance of any symptom, even mild and familiar, that the survivors immediately connected to potential cancer. Survivors also extended their fear

to concerns about family members, both in the form of worrying that family members would become ill themselves and fears of becoming a burden if their disease returns. Fear of cancer recurrence is a multidimensional phenomenon. A woman's emotional response may arise as a result of physical symptoms arousing suspicion that the disease has returned or as a result of external factors such as follow-up tests or other people's illnesses.

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

DECLARATIONS

The Hospital Ethics Committee of Rambam Health Care Campus approved the study, Approval No.0354-10-RMB.

AVAILABILITY OF DATA AND MATERIALS

The research data are available from the authors on request.

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