



The intrapersonal and interpersonal processes of fear of recurrence among cervical cancer survivors: a qualitative study

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Abstract

Objective Cervical cancer’s emotional and mental toll often extends beyond the disease’s duration. Fear of cancer recurrence has been identified as prominent in patients and survivors, yet there is a paucity of studies regarding this population. The present study sought to explore and expand the understanding of the meaning of fear of cancer recurrence among cervical cancer survivors.

Methods In this qualitative study, semi-structured interviews were conducted with 15 cervical cancer survivors. The interviewees’ mean age was 41.33 years (range 34–47 years), and the mean time since diagnosis was 3.1 years (ranged from 0.5 to 7 years).

Results Three central themes emerged that represent intrapersonal and interpersonal processes: The first, “*No longer resilient*” refers to feelings of uncertainty in the face of the illness experienced on the intrapersonal level, where the interviewee mostly engaged with efforts to return to the “normal” state that existed before the cancer diagnosis. The second, “To be afraid in a dyad,” relates to the interpersonal level that included mutual fears shared by the interviewee and her partner. The third “And what if the disease comes back and I die?” represents a combination of intrapersonal and interpersonal processes manifested by the greatest fear — death — expressed by both the interviewee and her partner.

Conclusions The present findings revealed that the fear of cancer recurrence represents intrapersonal and interpersonal processes encompassing three factors — uncertainty, social-cognitive processing, and death anxiety. Accordingly, potential psycho-social treatment options could be tailored to specifically address the prominence of these factors for cervical cancer survivors.

Keywords Cervical cancer · Survivors · Fear of recurrence · Qualitative research

Introduction

Cervical cancer is the fourth most common cancer in women [1]. Surgery, radiation, and chemotherapy represent proven-effective treatments for cervical cancer. However, up to one-third of cervical cancer patients will develop a progressive or recurrent disease [2], which might give rise to a fear of cancer recurrence.

The fear of cancer recurrence (FCR) is defined as: “Fear, worry or concern relating to the possibility that cancer will come back or progress” [3, p.3266]. Although, some degree of FCR may be adaptive in terms of alerting the patient to signs of new or recurring cancer and encouraging positive health behaviors [4], clinical levels of FCR are associated with psychological comorbidity — anxiety and depression [5, 6], reduced quality of life [7], increased healthcare costs due to more frequent emergency room visits [8], and avoidance of tests to identify recurrence in time [2]. Thus, Leeson et al. [9] highlighted the primary importance of addressing FCR among gynecological cancer survivors.

Only one quantitative study has been conducted to date regarding the meaning of FCR among cervical cancer survivors [5], which revealed as the three greatest fears reported by participants: what would happen to their family; pain; and disease progression (items from the Fear of Progression

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Questionnaire [10]). Owing to the paucity of studies regarding the meaning of FCR among cervical cancer survivors, we undertook the invitation [11] to conduct a qualitative study to gain a deeper understanding of FCR among cervical cancer survivors. A better understanding of FCR in cervical cancer survivors can help clinicians manage this problem effectively.

Methods

Research methodology

Qualitative methodology in a phenomenological paradigm was used to facilitate examination of the experiences and voices of participants as they chose to express them, and thus to gain insights that give meaning to the multi-dimensional phenomena of FCR [12].

Participants

Qualitative research is based on small, purposive, non-representative samples [13]. The current study included 15 qualitative interviews with women diagnosed with cervical cancer. The final sample size was determined according to the theoretical saturation principle. Hence, the interviews continued until no new information emerged [13]. Interviewees' mean age was 41.33 years (range 34–47 years); they were 31–46 years old when diagnosed with cervical cancer. Most were married ($n = 13$) and had children

($n = 12$) when they were diagnosed with cervical cancer. Their illness stage was I–II treated with surgery followed by radiation therapy (internal + external) ($n = 1$) or chemoradiation ($n = 14$). Time since diagnosis ranged from 6 months to 7 years (mean — 3.1 years). The variation in demographic variables among participants provided important breadth on the topic of study [14]. Detailed information for participants appears in Table 1.

Instrument

Data were gathered using semi-structured in-depth interviews. This is a flexible framework for examining the meaning of behaviors, feelings, beliefs, and perceptions [12]. An interview guide was constructed using a funnel approach [15] starting from broad questions followed by more detailed ones. The study was based on secondary analysis that aimed to examine a specific aspect of the data [16], based on four FCR-related questions: “Are you busy thinking about the possibility of recurrence of the disease? If so, what is the content of these thoughts?”; “How have these thoughts affected your life?”; “What are the feelings and thoughts when you raise these concerns with your partner?” When needed, clarifying questions were used such as “Can you please elaborate your discussion regarding your fears?” and “Please tell me more about your partner’s FCR.” Finally, selected demographic questions were included to situate the respondents in a sociocultural context.

Table 1 The study participants characteristics

Participant's number	Age when diagnosed	Family status	No. of children	Years since last treatment	Types of treatments
1	38	Married	0	1.5 years	Surgery + chemoradiation
2	37	Married	2	3.5 years	Surgery + chemoradiation
3	38	Married	2	3 years	Surgery + chemoradiation
4	38	Married	0	5 years	Surgery + chemoradiation
5	34	Married	2	3 years	Surgery + chemoradiation
6	40	Married	0	4.5 years	Surgery + chemoradiation
7	42	Married	3	5 years	Surgery + radiation
8	41	Married	3	5 years	Surgery + chemoradiation
9	46	Divorced (now in a committed relationship)			
	2	2.5 years	Surgery + chemoradiation		
10	45	Married	2	7 years	Surgery + chemoradiation
11	47	Married	1	1 year	Surgery + chemoradiation
12	44	Married	2	0.5 year	Surgery + chemoradiation
13	43	Married	2	0.5 year	Surgery + chemoradiation
14	44	Married	2	2.5 years	Surgery + chemoradiation
15	43	Divorce	3	2 years	Surgery + chemoradiation

Data collection and ethical considerations

This is part of a larger qualitative study about women who recovered from cervical cancer. Data were collected between November 2020 and February 2021. The present study and consent procedure were approved by the second author's University's Ethics Committee (approval no. 112003). Participants were recruited through internet forums and websites dealing with cervical cancer, and through social media outlets (Facebook pages focusing on cervical cancer). The inclusion criteria were Hebrew speakers, being above 18 years of age, diagnosis with cervical cancer, and having completed adjuvant therapy (chemotherapy and/or radiation) at least 6 months prior to study initiation. A brief explanation of the general research aims was provided followed by informed consent. Participants were informed of psychological support that would be available to them if they felt emotional distress at any point during the study. None made use of this offer.

Due to lockdown requirements owing to the COVID-19 pandemic, all interviews were conducted by the three authors (separately), using the video-conference platform Zoom. Each participant received a private email invitation.

With participants' verbal permission, all interviews were audio and video recorded to allow access to non-verbal cues such as facial expressions, eye contact, or body motions. The researchers took field notes during the interviews which were later collected; these notes provided a rich source of information as participants describe their experiences during data collection. Confidentiality was assured by numbering each interview and removing identifying information from the transcripts. All audio recordings and transcripts were saved on a password-protected computer with access only for the researchers. The interviews were conducted in Hebrew and lasted 60–80 min; during that time, 20–25 min was spent specifically discussing FCR. We concluded the interview process when we reached content saturation, and

no new data in the form of thematic categories emerged from the interviews.

Data analysis

Each of the three authors utilized content analysis [17]. This consisted of three processes:

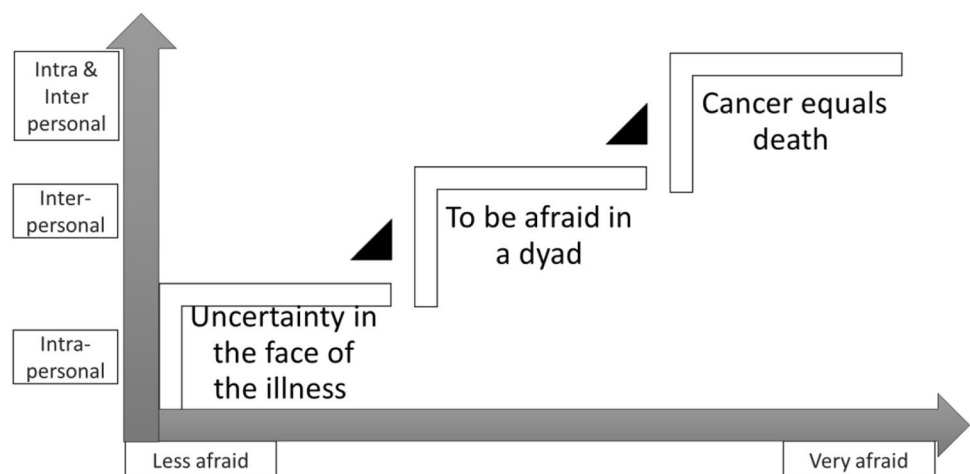
1. Open coding. The researchers independently read each interview transcript line by line, jotting down notes to identify initial units of meaning (categories) emerging from the interviews. Differences between coders were resolved through discussion until a consensus was reached.
2. Axial coding. The researchers gradually detected associations between themes related to context and content. They compared all interviews to consolidate meaning and named the themes. Next, the researchers examined interrelationships among the initial codes and sorted them into higher-order theoretical codes.
3. Integration. The researchers reordered conceptually the core themes that emerged from the data and placed them into context, enabling analysis and integration of large amounts of data and the generation of abstractions and interpretations [12, 18].

Results

Exploring the meaning of FCR among cervical cancer survivors produced three central themes that are illustrated in Fig. 1.

Theme 1 — “No longer resilient” — uncertainty in the face of the illness. Interviewees described how cancer shattered the sense of resilience they had previously felt. However, some interviewees described that FCR and emotional reactions

Fig. 1 Themes of the meaning of fear of recurrence of cervical cancer survivors



somewhat ameliorated over time and that they tried to get back closer to the “normal” state they were in before the cancer diagnosis. Some described more intense fear in the first year.

In the first year I experienced it [FCR] with every breath, today it is much better.... I try to live my life like it was before although it is not easy..something did change ... maybe it is only closer to the “normal.” (Interviewee 2).

I think everyone who is sick [with cancer] always has it that it might come back, it can always come back, it is always possible, but it lessens through the years. Because they [the physicians] gave me such very very aggressive treatment, I tend to trust the doctors who did it so it would not come back (Interviewee 4).

Some interviewees felt that there was no guarantee; anyone could get cancer. Even though time had passed since their initial diagnosis, even mild palpitations were immediately translated into a deadly disease and emphasized the uncertainty of their health. Interviewee 15 described the transition from the feeling of being healthy to a feeling of uncertainty, and as behaving like a hypochondriac who is constantly concerned with her health.

I was an athletic girl and today it’s hard for me. Maybe I’m scared too. I always knew I was a healthy woman, I never thought I would go through something like that. Today I’m scared, even if I catch cold, I’m scared (Interviewee 15).

In addition, interviewees described difficulties in performing follow-up medical tests as it increased the tension and stress regarding the possibility of disease recurrence. Some expressed a desire to be closely monitored in order to know that there is no cancer in their body and thus, to reduce uncertainty.

I have constant fears... I perform a CT scan every three to five months and then suddenly they tell me, “You have something on your ribs.” “Did you break a rib?” “But I did not break, ..., they instilled in me the fear that maybe it came back somewhere else” (Interviewee 5).

... I go with huge fear to follow-up tests. anxieties from here to there... the month that I’m waiting for the PET CT and after that while I am waiting for the results, it takes seven years off of my life... it is very difficult for me to be in a state of uncertainty (Interviewee 6).

The understanding that and ensuing fear that the disease would possibly return was transferred to some of the interviewees non-verbally by the medical staff, which aroused feelings of uncertainty and influenced the confidence of

being healthy. These interviewees described a sense of deception and frustration:

I was sure that when I finished the treatments that that’s it... no more.....After they took out my uterus I said to my doctors: “that’s it”? “I will not have it again, right?” However, then I saw a discomfort in the doctor’s body language, and I realized that it could also be caught on any other tissue (Interviewee 9).

A common means for coping with fear of recurrence was taking antidepressants. Some described dependence on the drug and argued that without it getting back to normal life as it was before the cancer diagnosis was quite hard and that fears of the disease would surely have surfaced.

I just did a CT scan and it’s clean and normal, but there was something in the thyroid that they saw which was abnormal..... if I was without an antidepressant, I would have been more anxious in general and in particular regarding the possibility of reoccurrence [of the disease] (Interviewee 7).

The perpetual fear has an existential effect even on how they viewed and responded to the health of their loved ones. Interviewees described that each symptom and illness of their children caused alarm and aroused doubts. Every pain, even if mild and common, suggested potential cancer, and the threat was unbearable.

I lost my medical confidence. Today I am anxious about everything. If my son has a leg pain, then a I immediately take him to a doctor because God knows what will happen (Interviewee 15).

Theme 2 — “To be afraid in a dyad” — my partner and I in the shadow of fear of recurrence. Coping with the fear of recurrence of the disease was mentioned as a process with interpersonal aspects, in addition to the intrapersonal process that was presented in Theme 1. Some interviewees described FCR as couple coping, in which there was room for dialogue about fears and concerns.

He was really stressed but he was also really supportive, there were also ups and downs, but we talked about everything including fears and concerns.... However, there is no doubt that he is still afraid that there will be a second round of all this (Interviewee 12).

Interviewees described their partner’s resources that enabled them to cope with the fear of recurrence. For example, the spouse’s internal resource of optimism enabled relief from the fear of disease recurrence as described by Interviewee 8.

My husband is very optimistic, he really strengthens me, he constantly conveys that he is not afraid of anything. He keeps telling me that when we are together, nothing can beat us, and it works.

Indeed, another resource in a relationship that can alleviate fear is the feeling of togetherness. The spouse of Interviewee 4 gave her the feeling that she is not alone:

He always says, “We go through this together” ... if there was any small pain, he would say let’s call to check, let’s go to the doctor.

In contrast, some interviewees described how their partners did not allow communication about the disease and fears that accompanied the possibility of disease recurrence. They felt great frustration and loneliness at not being able to talk to them about the fears. Each was closed within his/her own feelings:

There is a fear that the disease will return... I am sure my husband is also afraid. But he does not talk about these feelings and I have a hard time with it. He leaves me alone. He shows no emotion, but he has that fear (Interviewee 11).

The aforementioned examples show a range of ability to share FCR with a spouse suggesting that it is not necessary that both partners share FCR but that each partner’s fear affects the other:

At first if there was any small pain, he would say let’s call to check, let’s go to the doctor. But now, he put the part of the disease behind us and we’re focusing on the future (Interviewee 4).

Theme 3 — cancer equals death — “and what if the disease comes back and I die?”. Some interviewees expressed the perception of the temporality and fragility of life in facing the possibility of recurrence of the disease. They feared and described their existential fear of dying of cancer which demonstrated the intrapersonal aspect in reference to FCR. At the same time, some interviewees argued that although rationally they understood that the probability of dying from their disease was low, the fear remained.

I’m afraid to die if the cancer comes back...as if I have a limited time left to live... unfortunately today I know that you can die...on the other hand, I understand that the probability that I will die from this cancer is relatively low ... rationally, I understand and still when I think about it — I am afraid (Interviewee 1).

Another fear that some interviewees described is that if the disease returns, it will be more violent than before,

and they will not be able to cope with it physically and mentally or survive it the next time.

I’m afraid to cope with the disease,... if the disease comes back again it will be fatal. It scares me (Interviewee 3).

The familiarity of some of the interviewees with recurrent cancer among people in their surroundings makes disease recurrence a real and stressful possibility.

Interviewee 14 said that she is not afraid of harsh and exhausting treatments. The only thing she is afraid of is death.

The fear is not about treatment or further resection. No, no. The fear is of dying because cancer is equal to death ... what if I die of the disease....

The fear of dying was also expressed by close family members, which thus involved the interpersonal aspect of FCR. Fear of dying from cancer if the disease will recur was not only in the interviewee’s mind; it also occupied the minds of their partners and intensified their own fears:

One day he suddenly woke me up at noon. He had tears in his eyes, ‘I love you’, he said. I asked him what happened? He told me that he thought I would die if the disease came back. We cried together (Interviewee 5).

The fear of death following the possibility of recurrence of the disease was described not only as being experienced by the interviewees’ spouses but also by their children. The involvement even of the children with the fears of death established further the interpersonal aspects of FCR, but it was not to remain static either at this level or at this mode of expression. Rather, the interpersonal FCR was followed by its intrapersonal aspect as it caused to the interviewee to feel more fearful of the cancer’s recurrence.

Mom could you die from cancer? My older daughter often asks (age 12). She says to me that it is impossible to live without a mother, children cannot live without a mother. I want to protect her so much... wishing that the cancer will not occur again, and afraid that if it came back she will really live without a mother (Interviewee 6).

One of the children’s ways to cope with fears that their mother’s disease would reoccur was through black humor as described by Interviewee 13.

Don’t ask what nickname one of the girls gave me, she calls me “dying” (laughs). At first I was shocked but then I realized she had to channel her fears that the disease would reoccur (Interviewee 13).

Discussion

The study's findings indicate that the meaning of FCR among cervical cancer survivors is dynamic. Its meaning ranges from the uncertainty that accompanied returning to the "normal" that existed before the cancer diagnosis to the existential fear of dying. It includes processes beginning with intrapersonal experience (a process carried out by the survivor), proceeding to interpersonal experience (a process carried out by the survivor and her partner), and ending with combination of the two processes.

The first theme, "No longer resilient" — uncertainty in the face of the illness, supports quantitative studies which revealed the reporting of FCR in various degrees during survivorship, regardless of the length of the survivorship (e.g., 2, 19). In addition, it seems that external triggers such as follow-up appointments and the illness of a child arouse anxiety and a strong sense of distress. Indeed, Simard et al. [6] identified strong relationships between distress and FCR. Moreover, according to the Uncertainty in Illness Model [20], perception of uncertainty in illness occurs when the meaning of an event cannot be understood because of its complexity, ambiguity, or a mismatch between expectations and the realistic world. In addition, illness uncertainty may also affect stress appraisal, which can in turn affect coping strategies. Thus, it might be that cervical cancer survivors' level of uncertainty affects their stress appraisal, which mostly consists of harm and threat, and consists less of challenges. This is intensified by the body language of some of their healthcare providers that implied that medical treatment does not guarantee full recovery. Thus, it is not surprising that feeling "no longer resilient" emerged as a theme, leading to responses of depression and anxiety which required antidepressant medication.

Regarding the second theme, "To be afraid in a dyad" — my partner and I in the shadow of fear of recurrence, our findings indicate that the presence of a partner during the disease treatments and over the survivorship phase may affect FRC, which in turn might impact the level of distress. In line with this notion, the social-cognitive processing model [21] argues that the social environment can either enhance or inhibit cognitive processing of the cancer experience. Negative social responses to the interviewee's attempts to discuss the cancer experience (i.e., social constraints) may lead to avoidance of thinking or talking about cancer, which, in turn, may inhibit cognitive processing and exacerbate emotional distress [22]. However, positive social responses may allow open discussion which, in turn, may enhance cognitive processing and decrease emotional distress in accordance with the stress-buffering effect of social support [23].

Accordingly, Myers et al. [24] found that among women diagnosed with gynecological cancer, not sharing concerns and negative responses from family and friends were related to increased FCR and, in turn, increased cancer-specific stress. Likewise, Wijayanti et al. [25] found that among gynecological cancer survivors, those with higher social support were more likely to experience lower levels of FCR. Moreover, several quantitative studies noted that spouses of cancer survivors are typically found to have greater levels of FCR than the patients themselves [6], and patient and spouse FCR scores have been found to correlate within-dyad [26, 27]. Given the above, our findings support the importance of dynamic interpersonal contexts of FCR that need to be addressed when considering how to regulate FCR levels.

Finally, the third theme, Cancer equals death — "and what if the disease comes back and I die?" highlights the fear of dying. Indeed, fear of death as a component of FCR was noted in a study conducted among breast cancer patients [28] suggesting that women with all levels of FCR identified fear of death as their worst fear. Similarly, Tang et al. [29] found among cancer patients that their levels of fear of disease relapsed and had detrimental effects on their levels of death anxiety. These two studies support Sharpe et al.'s [30] call to investigate the role that death anxiety has in FCR "because the way in which these fears may best be addressed is likely to differ and hence the actual worst fear should always be assessed if FCR is present" [p. 256]. According to the terror management theory [31], the natural human instinct for self-preservation combined with a self-awareness of mortality creates the potential for debilitating levels of anxiety that need to be managed in order to function. Death awareness produces existential anxiety that is reflected through FCR. Moreover, our findings indicate that death anxiety reflected by FCR is also felt by other members of the cancer survivor's family, which might intensify the survivor's FCR, suggesting the intrapersonal and interpersonal processes involved in FCR.

Several limitations should be noted. First, due to the small number of participants that were interviewed, and the cross-sectional design, findings should be considered as a tentative basis for further investigation. Longitudinal research on FCR is required to gain a better understanding of this concept. In addition, most of the participants in the current study were short-term survivors (mean 3.1 years). Perhaps longer-term cervical cancer survivors might reveal different meanings of FCR. It should be noted that younger survivors and women are more prone to experiencing higher levels of FCR [6]. Thus, future qualitative studies should examine the meaning of FCR with older survivors. Likewise, other family members (spouses, children) and different cultures should be studied, in order to place the knowledge gained in this study in a broader context.

With regard to implications for practice, the present findings suggest that the meaning of FCR encompasses three theories — the uncertainty in illness theory, social-cognitive processing theory, and terror management theory. These theories could help further our understanding of FCR and inform the development of personalized potential treatment options specific to FCR according to the dominance of the content that emerges from the cancer survivor. Similarly, in a systematic review and meta-analysis of efficacy of available psychological interventions for FCR, Tauber et al. [32] suggested tailoring interventions to focus on the individual's FCR symptoms. Specifically, medical personnel and therapists could receive training to address unhelpful cognitive content, including appraisals, cancer beliefs, and concerns that trigger distress and/or maladaptive coping. Accordingly, they could also suggest tools for increasing tolerance for uncertainty, and to facilitate effective communication with significant others and health care providers which might decrease socially constraining responses from others. Also, as death anxiety was found to underlie FCR, cognitive-existential intervention for FCR could be applied [e.g., 33].

Conclusions

The results of this qualitative analysis identified intrapersonal and interpersonal processes that clarify the meaning of FCR in cervical cancer survivors. In addition, FCR found to be a phenomenon encompassing three factors — uncertainty, social-cognitive processing and death anxiety, which are recommended to be addressed in order to promote cervical cancer survivors' wellbeing. Further qualitative studies on FCR are needed as the quantitative measurement of FCR might be insufficient to represent the multidimensional meaning of this phenomenon.

Author contribution YHR, SAS, and IL contributed to the study conception and design and performed the recruitment and the data analysis. The first draft of the manuscript was written by YHR and SAS, and all the authors reviewed and edited the manuscript. All the authors read and approved the final manuscript.

Data availability Not applicable.

Code availability Not applicable.

Declarations

Ethics approval The study was conducted in accordance with the approval of the second author University's Ethics Committee (Approval no. 112003).

Consent to participate All the participants gave their consent to participate in accordance with the ethics approval guidelines of the University's Ethics Committee.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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