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“A kaleidoscope of relationships” — cervical cancer survivors’ perspectives on their intimate relationships: A qualitative study

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Abstract

Objective. Cervical cancer is known to affect survivors’ intimate relationships, as well as their communication and coping. Yet little is known about the perspectives of these survivors on their intimate relationships in the context of their needs during and after medical treatment. Additionally, only a few studies have focused on survivors’ perceived needs or on existing psychosexual support. Understanding these perceptions can help provide a tailored response and improve dyadic interventions. The aim of this study was to examine cervical cancer survivors’ perspectives on their intimate relationships during and after their treatment.

Method. The present study adopted a qualitative-phenomenological approach. In-depth, semi-structured interviews were conducted with 15 survivors of cervical cancer between the ages of 38 and 44 who were diagnosed at stages I–II and were treated with radiotherapy or chemo-radiotherapy and surgery. Data collection continued until saturation of concepts was reached. The results underwent thematic analysis.

Results. Analysis of the findings revealed two key themes: (1) Together and apart in the shadow of cervical cancer. This theme focuses on the recovery period as a potential opportunity for changing and improving the couple relationship, such that men no longer withdraw but rather provide their partners with needed support and encouragement. (2) Changes in sexual life and couple intimacy. This theme focuses on changes in sexual relations, which have become a burden, painful, and something to avoid.

Significance of results. The study provides a comprehensive picture of intimate relationships during and after cervical cancer treatment and highlights the women’s needs and desires for support from their intimate partners. The discussion notes that oncology providers can better facilitate supportiveness on the part of cervical cancer partners by offering better couple-oriented education and interventions to promote couple communication.

Introduction

Cervical cancer is the fourth most common cancer among women. In 2018, an estimated 570,000 women were diagnosed with cervical cancer worldwide and about 311,000 women died from the disease (World Health Organization, WHO, n.d.). Today’s improved screening and diagnostic methods facilitate the diagnosis of nearly half of all cervical cancer cases at stage I, and more than three-fourths of cases are diagnosed at stage II (Iyer et al., 2016). As such, the overall 5-year survival rate for stage I disease is 91%, and 68% of all cases are expected to survive 5 years (Jemal et al., 2017).

Nevertheless, the quality of life of cervical cancer patients is lower than among the survivors of other gynecological cancers and worse than that of the general population (Ferrandina et al., 2012). This difference may be explained by treatment-related effects, such as urinary, gastrointestinal, and neurological side effects found to disrupt the long-term quality of life (Pfaendler et al., 2015). Moreover, because cervical cancer survivors tend to be relatively young — the average age at diagnosis is 49 (Center for Disease Control and Prevention, 2020) — their intimate relationships are liable to be affected as well.

Sexual distress, defined as sexual discomfort or dysfunction leading to stress and anxiety, includes dyspareunia, vaginismus, vaginal dryness, decreased libido, and difficulty achieving orgasm (Soleimani et al., 2018). Indeed, a qualitative study conducted among cervical cancer survivors and their partners revealed that about half of the women and their partners reported feelings of sexual distress such as guilt, grief, or loneliness in their sexual relationship (Vermeer et al., 2016). Most studies showed that around one-third of cervical cancer survivors experienced distress and sexual dissatisfaction due to vaginal sexual symptoms, particularly dyspareunia (Aerts et al., 2014; Bradford et al., 2015). These studies suggest that these symptoms have

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an impact that goes beyond physical sexual dysfunction (Vermeer et al., 2015). In addition, both women and their partners experienced communication difficulties. Some reported that their partners avoided sexual contact and/or seemed to have lost interest in sex. Others, in contrast, felt their partners were pressuring them to be sexually active or were aware that their partners had difficulties accepting their sexual limitations (Vermeer et al., 2016). Likewise, Abbott-Anderson et al. (2020) used conventional descriptive content analysis to show that survivors of gynecological cancers (including cervical cancer) felt that their cancer treatment had a negative impact on their sexual activity and functioning as well as on their sex lives and relationships. Most participants in this study reported changes in sexual activity after their cancer diagnosis but no improvement. Nevertheless, little is known about aspects other than the psycho-sexual aspect affecting the experiences of cervical cancer survivors with their partners in the period after their treatment. Specifically, regardless of the cancer site, after treatment couples need to negotiate their transition to “normal” life, as each partner may desire to return to a different “pace” (Silver, 2004).

Sexuality and intimacy difficulties are often reported in other cancer types due to post-treatment symptoms (e.g., fatigue, pain, anxiety, and depression) (Carter et al., 2013; Dorros et al., 2017). Treatment for cervical cancer frequently results in changes in vaginal anatomy and function, and consequently in changes in sexual functioning (Vermeer et al., 2016). The long-term consequences of radiotherapy include shortening or narrowing the vagina and reduced lubrication (Abbott-Anderson and Kwekkeboom, 2012). A systematic review showed that the prevalence of female sexual dysfunction was above 60% regardless of the cancer site, with the highest figure for gynecological cancers (Maiorino et al., 2016). According to Manne and Badr (2008), the main tasks for couples after treatment entail making changes and adjustments in life plans and health behaviors and dealing with the impact on patient functioning. In line with this notion, an in-depth qualitative analysis among dyads of breast and prostate cancer survivors found that the survivors’ main concerns focused on issues related to the cancer and to treatment, whereas their partners’ concerns centered on the well-being of their spouse/partner who had cancer and what they could do to help their loved one cope (Dorros et al., 2017). Indeed, Syse and Lyngstad (2017) noted that spouses provide resources that help the family continue to function that go beyond those provided by the cancer patient, and these resources may help shape survival prospects after diagnosis. Similarly, Manne et al. (2004a) found that survivors whose partners also revealed personal feelings and cancer-related concerns were less distressed than survivors whose partners showed fewer concerns. In addition, in couples in which the partner exhibited such concerns while accepting, understanding, and caring for the patient, intimacy was also greater (Manne et al., 2004b). Moreover, a recent longitudinal study conducted among breast cancer survivors found that those with greater relationship satisfaction from their married/domestic partners exhibited lower perceived stress from visit to visit in the follow-up and throughout the study. This lower degree of stress was linked to lower levels of inflammation 6 and 18 months after treatment (Shrout et al., 2020).

As indicated above, the literature highlights that providing support is important for interpersonal coping (Bodenman, 2005; Bodenmann et al., 2011). In the case of chronic illnesses such as cancer, one or both partners in an intimate relationship are liable to experience stress. Couples can engage in dyadic

management of this stress by working together as a unit (Bodenman, 2005). Yet only a few studies have focused on the experience of sexual intimacy among survivors of gynecological cancers (Vermeer et al., 2016; Abbott-Anderson et al., 2020). In this study, we also focus on the general quality of the relationship, including emotional intimacy. A deeper understanding of marital relations after treatment will enable healthcare providers to tailor effective psycho-social interventions and promote advanced care planning for cervical cancer survivors.

Methods

The study adopted a qualitative-phenomenological approach (Patton, 2002). This approach attempts to obtain an in-depth understanding of the studied phenomenon by penetrating the world and experiences of the participants. Such a paradigm enables researchers to examine the voices and experiences of informants as they choose to express themselves, thus providing a deeper understanding of the interviewees and arriving at insights that give meaning to multidimensional phenomena (Creswell and Poth, 2018).

Sample

The research population included 15 survivors of cervical cancer between the ages of 38 and 47. For the study, we sought participants who best represented the post-treatment female cervical cancer population in terms of age, education, and familial and socioeconomic status. Such a heterogeneous research population should shed the most light on the studied phenomenon. Participants were recruited by convenience sampling, such that all participants who met the inclusion criteria were asked to participate. The inclusion criteria were as follows: diagnosis of cervical cancer stages I and II; currently free of disease and without any previous cancer diagnosis; over the age of 18; Hebrew speaker; and currently undergoing follow-up at a major oncology unit in Israel.

The participants’ average age was 41.33 (38–47), and their average level of education was 17.13 (12–37) years. Most of the respondents were married ($n = 12$, 80%), two were divorced, and one was single; twelve were mothers. The unmarried women reported being in a couple relationship during their treatment and recovery. Some described conflicts in their pre-cancer relationship which they believe may have accelerated their separation, while others described new conflicts that arose as a result of dealing with their cancer. The time elapsed since their cancer diagnosis ranged from 6 months to 7 years. Most of the women had undergone chemotherapy treatment (93.33%), and all of them had radiotherapy or chemo-radiotherapy and surgery (Table 1).

Procedure

Prior to commencing the study, the researchers obtained authorization from the Ethics Committee xxx (Authorization No. 112003). Participants were recruited between January and February 2021 from the only Israeli Facebook support group for cervical cancer survivors. Of the 21 women who responded to our ad, six did not fit the inclusion criteria, such that 15 were selected to participate in the study. Because the data were collected via social networks, we cannot assess the rate of response.

After receiving a comprehensive explanation about the general research aims, interviewees signed an informed consent form. The interviews were conducted either in the interviewees’ homes or via the Zoom platform to minimize personal contact during the COVID-19 outbreak. The interviewers promised to maintain

Table 1. Demographic and medical characteristics of participants ($n = 15$)

Characteristic	<i>n</i>	%
Age (range, mean, and standard deviation; years)	38–47, Mean = 41.33, SD = 3.73	
Years of education (range, mean, and standard deviation; years)	12–37, Mean = 17.13, SD = 6.31	
Number of children (range, mean, and standard deviation; years)	0–3, Mean = 1.73, SD = 1.03	
Family status		
Single	1	6.66
Married	12	80
Divorced	2	13.33
Country of origin		
Israel	12	80
Other (USA, Africa, and Europe)	3	20
Income ^a		
Low	1	6.66
Moderate	9	60
High	5	33.33
Time since diagnosis ^b (range, mean, and standard deviation; years)	0.5–7, Mean = 3.10, SD = 1.90	
Chemotherapy		
Yes	14	93.33
No	1	6.66
Radiotherapy		
Yes	15	100
No	0	0
Brachytherapy		
Yes	12	80
No	3	20
Chronic diseases		
Yes	6	40
No	9	60

SD, standard deviation.

^aAverage income per household, as published by the Israel Central Bureau of Statistics.

^bTime in years.

interviewee anonymity and confidentiality and participation was voluntary. Participants were informed they could withdraw from the study at any time and could refuse to answer any question. None of the participants dropped out. No incentives were offered. Each interview lasted 60–90 min. The interviewers (I.L., Y.H.-R., and S.S.-A.) were female. Two of them are social workers (PhD) and the other is a psychotherapist (PhD). All are experienced in conducting qualitative research.

The interviews were conducted in Hebrew, recorded, and then translated into English. Each translation was verified by two native speakers, one of whom is a professional translator. Data collection proceeded until theoretical saturation was reached (i.e., additional interviews yielded no new material for analysis) (Creswell and Poth, 2018).

Research tools and instruments

The qualitative data for this study were gathered by means of in-depth semi-structured interviews (Brinkman and Kvale, 2015). We chose interviews as the research instrument to help us learn about and examine the participants' experiences (Appendix 1). The interviews were conducted based on an interview guide that included significant key areas but were flexible enough to allow a dialogue to develop between the interviewer and the interviewee and to facilitate meaningful self-expression (Creswell and Poth, 2018).

Data analysis

The data collected in the interviews were analyzed thematically (Brinkman and Kvale, 2015). Prior to conducting the interviews, the interviewers underwent a process (Finlay and Gough, 2008) that included reflecting on the identities, social locations, assumptions, and life experiences they brought to the research endeavor, along with thinking about their interactions with the interviewees. In the first stage, the researchers read all the interviews and analyzed them line by line. Next, comparisons and contrasts were made to identify themes that were repeated across interviews. At this point, sub-categories of meaning were collapsed to represent a conceptually meaningful summary of the findings. Then, the main themes of the interviews were identified, along with sub-categories. In the next stage, the researchers looked for related themes and grouped the sub-categories into secondary categories. In the last stage, the researchers identified the study's central themes. The core themes or main categories emerging from the data were reordered conceptually and placed back into context, enabling the researchers to analyze and integrate large amounts of data and to generate abstractions and interpretations (Brinkman and Kvale, 2015).

Trustworthiness

Trustworthiness was achieved in several ways. The interview material was transcribed verbatim so that the researchers were able to consult the original narrations. The depth and breadth of the interviews enabled the researchers to claim they had obtained a comprehensive and authentic understanding of the experiences and meanings of the respondents. The researchers used credibility criteria that can be met if the data are presented in terms of a dense and detailed description of multiple, contextually based realities (Anney, 2014).

Results

The qualitative analysis of the interviews yielded two main themes.

Theme 1: Together and apart in the shadow of cervical cancer

Exposure and sharing versus distance and closure

Cervical cancer survivors described various patterns of communication with their intimate partners during their treatment and recovery. Thirteen women noted a significant discrepancy between themselves and their partners in how they coped with the cancer. The women mentioned their desire for support, help, compassion, and concern, while their partners tended to balk and withdraw from them. Eleven women described partners

who were there and yet not there. While the partner would accompany them to treatments and doctor appointments, he would have difficulty providing help, particularly in the form of emotional support. One of the women described her husband's fear of knowing about her cancer and his desire to distance himself from it, as opposed to her desire to delve more deeply into it. In addition, she stated that only today, as a survivor, she understands that she was unable to be there for him. According to her, neither of them could meet the different needs of the other.

We were very different. I always asked for information and clarifications, while my husband comes from a place where if you ask for clarifications you will discover things you don't want to know. He was not a partner to the treatment process. That is, he came with me, he was always with me. I know that the process was very hard for him because knowing did not help him, made him uncomfortable and led him to develop posttraumatic symptoms (married, 37).

The women's descriptions emphasized the discrepancy between their needs, which were primarily emotional, and the response they received from their partners. This discrepancy caused ongoing frustration, a sense of having lost the relationship they had prior to their cancer, and an unclear picture of what the future would bring. One of the women stated that although her husband provided instrumental help at home with the shopping, the cleaning, and the children, they no longer have any emotional ties. She laments the loss of their intimate relationship and describes their current relationship in terms of being roommates, without any intimacy:

My husband will do everything that is necessary. He'll clean up if I vomit, prepare food, drive the children places. But that's it. When it comes to technical matters he functions, but for anything related to emotions, to closeness, he's simply not there. I already feel awful with the stoma and everything that's going on in terms of my physical functioning, and he's simply not there for me. In this sense I am always alone. But what can I do? Divorce him? If I do that, I won't even have the help he gives me now. And what about the children? And what about me? So we are together, but not really ... (married, 45).

Four of the women stated that during their treatments they witnessed their partners exhibiting emotions they were not accustomed to seeing. These women described resilient men with a tough exterior who do not often engage in emotional discourse or show emotions. Yet the sight of their partners in a weakened situation and in emotional and physical distress aroused sides of these men that the women had never seen. They were surprised and very moved to see this and felt this brought them together as a couple.

There were a few days when I felt extremely bad physically. It was upsetting and stressful. There was one night when he put me on his shoulders and took me to the ER. ... When I began feeling better, he started to cry and said, "Listen, you really scared me. I was so worried and I'm happy you feel better now" (married, 38).

Shared or separate decision-making

Twelve of the participants described how they made complex decisions on their own, even though both partners were influenced by the consequences of these decisions. They indicated that making these decisions aroused past conflicts between the two or created new ones. They felt their relationship lacked equality. One of the participants used an apt image to describe this:

"It's like a pregnancy. We say *we* are pregnant and it's *our* pregnancy, but actually only the woman carries the fetus and goes through the labor of giving birth." The women experienced a sense of frustration when their fantasy of being one united front was shattered by reality. The use of an image from the world of pregnancy and birth is not coincidental, for the main decision mentioned in the interviews was the decision to have a hysterectomy. Some of the women described this decision as traumatic for themselves and for their relationship. This fateful decision left them feeling alone and isolated.

This was one of the most difficult decisions we made together as a couple, but ultimately, I was the one who decided on my own to have the hysterectomy without retrieving more eggs, a decision that was very difficult for my husband. He was afraid, and rightly so, that we would be left with no eggs. He could not imagine a situation in which we would not have children or that he would not have my biological children. This is a major trauma for a couple (married, 38).

Moreover, some of the women reported making joint decisions regarding treatment type, returning to work after the treatments, and the children's education during this period. One interviewee stated:

When it came to the children, we were in complete agreement and everything was easy... when and what to tell them, who would take care of them when I was feeling weak. When I decided to go back to work on a part-time basis only, we discussed this together and considered what it would mean to us financially (married, 39).

Growth versus regression in a relationship during the recovery period

Cervical cancer survivors described their recovery period as a potential opportunity for change and progress in their relationships. Some reported inner reflection that had an impact on their relationship, while others described developments in the relationship. Eight participants stated that as they recovered, a relationship in which the woman was ill and in need of support turned into a close relationship, not one between patient and caregiver but rather one that is close, empathetic, and more intimate:

It began out of need but turned into something we simply do. At first he would not let me take a shower alone because at one point I was very weak and sometimes the steam in the shower made me feel bad. So I started using a chair in the shower, and until now we take showers together. The coronavirus crisis started toward the end of my treatments, giving us lots of time together (married, 38).

Twelve women stated that before their diagnosis they were caught up in the rat race of life: work, children, and money. In this race for survival, they paid no attention to the little things of value in their relationship. One woman described problems in her relationship prior to her diagnosis, but after coping with cancer things turned around and the relationship improved. The cancer brought the couple together emotionally and diminished the level of conflict, which was replaced by a sense of control over the relationship, leading to a major improvement. A sense of well-being emerged from the chaos and pain of the illness.

As a couple, we were busy merely surviving. Today we are no longer one against the other. We are together with a common goal. To see my husband cry a bit was good for me. It's sad to say but it made me feel better. His difficulty brought us together emotionally ... so the cancer was good

for our relationship. I always say that cancer is the best couple therapist we ever had (married, 42).

The cancer led some of the women to think about their role in the relationship and about their life priorities and made them demand things they had not demanded previously. One woman stated: "I need to be heard. I want to leave a mark on the world." For these women, the fragility of being ill and their sense of no longer being immune to sickness and death may have served as a catalyst for reexamining their relationship with their partner.

I think that because he is so dominant and I am less so, after my cancer I decided to begin demanding things of myself, to believe in myself and to stop being transparent ... In our relationship I think that things have only recently begun improving. I now see more things, I want him to do things around the house. Why do we always talk only about him? Why don't we talk about me? Why am I never asked? Why is what I think not of interest? I actually began demanding to be heard. Once I had no opinion. Now I speak out. I am no longer transparent. I am here (married, 38).

Eleven women indicated that in the past they had placed the other family members at the head of their priorities and suppressed themselves and their own needs. Their frustration and sense of having missed out over the years erupted during the period of their recovery. Even events that once seemed essential took on different proportions during their recovery, and some of the women learned to value small things in the family circle. The women indicated that now, more than ever, they know how to rely on others and to talk about their emotions in dealing with their difficulties without seeing this as a weakness.

Today I am more self-aware. I say what I feel. I once would say, okay, it's fine. Today I know how to say that something hurts me. I know how to say that something does not suit me. I do only what's good for me. I know how to ask for help (married, 44).

This has brought us much closer. At least for me, this has strengthened our relationship and has made us much much closer. Even after my recovery, every Tuesday we have a date at the beach for a stroll along the seashore. We never did that before. It's as if we feel a need to take advantage of every moment. We've learned to value every day that we wake up together. In short, it has brought us together (married, 41).

Several women reported that contrary to their sense of growth during the recovery period, they experienced a regression in their contacts with the social environment and their spouse. They noted that they began receiving significantly less help from the family and that their husbands expected that their intimate relations would return to what they had been before the illness. They were overwhelmed with loneliness and frustration:

When I was sick I felt I was held within a large embrace, totally enveloped. All of a sudden I feel that everyone has abandoned me and I've been left alone. Everyone around me simply said, even without words, that now you need to manage. Go back to work, cook, clean, be a wife. I was capable of none of those things (married, 41).

Theme 2: Changes in sexual life and couple intimacy

Problems in sexual intimacy

Fourteen of the participants stated that their sexual relations had changed immeasurably and had become a necessary burden. Sexual intercourse entailed a great deal of pain and suffering, such that they avoided or postponed sexual relations.

Nonetheless, they understood that sexuality is part of couple relationships. Hence, they stated that they made an effort to engage in sexual intercourse to satisfy their partners. The women described a decline in their libido and in their femininity. Indeed, the treatments and surgical procedures dealt a serious blow to their femininity as well as to their sense of self-worth.

You need to fight for your sexuality, you need to work on it, you must. It's not as if you suddenly feel like having sex and you can do whatever you want. You don't feel like it, it hurts, it does not bring you pleasure, all of your sexuality is gone ... you know you are broken, you are damaged goods (divorced, 46).

The way I look at it, I just want to be left alone, who wants this now? But my partner, he's the type that demands it ... even if I don't really enjoy it, but in this case I can say that I rise to the occasion ... and I do it when he initiates it (married, 47).

Cervical cancer survivors stated that their cancer exerted a major influence on their intimate relations with their partners. All the women recalled themselves as being lively and passionate from the time they were young. Cervical cancer and the treatments they underwent destroyed their pleasure in engaging in sexual intercourse. Nine women stated that they no longer recognize themselves and need anti-depressants to cope with this painful loss:

I have no desire for it. The possibility of penetration was taken from me, I can't touch myself there, it's unpleasant and uncomfortable, my skin there is tender and very sensitive. Just live with it. I'm still young ... do you know how many times I cried because I felt my life was over, there's nothing left to live for. They took away my joy in life, it's gone. I no longer recognize my body. You have no idea what a bitter disappointment this is, to the point that I had to start taking a psychiatric medication (married, 41).

Overcoming challenges in intimacy versus feeling helplessness

Thirteen women indicated that their intimate relations had changed, yet it was still important for them to make a joint effort with their partner to restore their relations. These women stated that while their relations would never return to what they had been, together with their partners they needed to learn what was possible and how to derive mutual pleasure so as not to relinquish this aspect of their relationship. They made an effort to use a vaginal dilator to prevent the vagina from closing and saw this as an intimate activity that drew them together:

From the outset it was very important that he be with me when I used the vaginal dilator. Even now when I use the vaginal dilator, I tell him and if he wants to he joins me. Sex between us is different, it does not entail penetration ... the cancer has undoubtedly reduced some of the sense of urgency in sex. But in our case, our intimacy has increased tremendously (married, 38).

These women stated that it took a long time until they were able to have intercourse with their partners. They asked their partners to demonstrate sensitivity, flexibility, and understanding to enable them to proceed, step by step, to the level of sexual intimacy of which they were capable. Some said their partners had difficulty providing them this space and took their refusal as a personal insult.

He was not willing to understand that I have no desire to do anything ... He refused to accept this and would eventually say that it's not that you have no desire, but rather that you just don't want me ... That harmed our relationship quite a bit, to the point that I began to withdraw. He didn't understand and he refused to be supportive (married, 38).

Table 2. Classification of main categories and subcategories

Theme	Subthemes	Subcategories
<i>Theme 1: Together and apart in the shadow of cervical cancer</i>	<ul style="list-style-type: none"> • Exposure and sharing versus distance and closure • Shared or separate decision-making • Growth versus regression in relationship during the recovery period 	<ul style="list-style-type: none"> • Significant discrepancy in coping between survivors and their partners • Desire to delve more deeply into the cancer and need for emotional support, while partners tend to balk and withdraw • Frustration and loss of intimate relationship; some described renewed closeness and partner demonstrating emotions, concern, and compassion • Making complex decisions on their own, though both partners were influenced by the consequences • Closeness and decline in conflicts during the recovery period • Changed priorities and desire to assert themselves in their couple relationship as well • After the illness, they know how to rely on others and talk about their emotions in dealing with their difficulties without seeing this as a weakness
<i>Theme 2: Changes in sexual life and couple intimacy</i>	<ul style="list-style-type: none"> • Problems in sexual intimacy • Overcoming challenges in intimate versus feeling helpless 	<ul style="list-style-type: none"> • Cancer exerted a major influence on intimate relations with partners • For most, sexual relations changed immeasurably and became a necessary burden • Sexual intercourse entailed a great deal of pain and suffering, so they tried to avoid it • Some made an effort to engage in sexual intercourse to satisfy their partners • Decline in libido; loss of femininity and sense of self-worth • Some asked partners to show sensitivity, flexibility, and understanding to achieve sexual intimacy but did not always receive this

In contrast to these women, two other women reported totally refraining from sexual intercourse due to severe vaginal pain. They described their sense of isolation, helplessness, and sadness. One of them said: "I feel defective." She felt she had nothing to give a partner during sexual relations and sees no hope for the foreseeable future. One of these women is single and was concerned about her inability to have an intimate relationship in the future, while the other did not have a supportive husband. They described their external bleeding as an internal emotional scar and a deep sense of sorrow they must bear (Table 2):

Even today I am not capable of engaging in sexual intercourse, I don't want to, no, no. I was with one man and I did not stop bleeding ... as soon as you lose your ovaries, your sexual desire also declines. I have no desire for a man to touch me. I'm telling you, I once was an extremely passionate woman. Do you understand, today I no longer have the life I once had. I'm living the life of a 70-year-old woman, not a woman who is 40 ... I am emotionally shattered (single, 40).

I don't relate to myself as a woman. I am not a woman. The internal radiation treatments caused vaginal adhesions. Intercourse is not an option, certainly not with the stoma. At one point I tried special physiotherapy that entailed vaginal massages. I used plastic and tubes, and all that is quite unpleasant after all the incisions, scars, fecal pouch. But the hardest thing is that my husband wasn't there to support me. I did everything alone (married, 45).

Discussion

This study sought to examine cervical cancer survivors' perspectives on their intimate relationships during their medical treatment period and afterward. The findings show that the participants wanted and needed their partners to provide support, help, compassion, and concern during their cancer treatment and recovery, while they perceived that most of their partners tended to balk at showing support and withdrew from them. This study adds to the literature on relationship quality, including emotional

intimacy as well as to the few studies that examined sexual intimacy among gynecological cancer survivors (Abbott-Anderson and Kwekkeboom, 2012; Vermeer et al., 2016). Partner support is an important element in the recovery stage. Indeed, research shows that identifying and addressing supportive emotional needs can prevent patient distress and poor quality of life (Maguire et al., 2015; Vermeer et al., 2016). Studies have reported a wide range of emotions and needs among cervical cancer survivors, including feelings of depression, a need to cope with loss of self-esteem, concerns about emotional well-being, uncertainty, self-blame, and feelings of being old or empty (Ashing-Giwa et al., 2004; Tangjitgamol et al., 2007; Bilodeau and Bouchard, 2011; Afyanti and Milanti, 2013). Our findings suggest that alterations in bodily functions are just one dimension of the multifaceted needs of cervical cancer survivors.

The findings of the current study reinforce the above finding but also place emphasis on the additional dimension of the impact upon the women's psychological and social well-being. The study also reveals a discrepancy between these women's need for emotional support and the instrumental support offered by their partners. This discrepancy generated frustration and loneliness among the women (Tangjitgamol et al., 2007; Bilodeau and Bouchard, 2011; Afyanti and Milanti, 2013). Indeed, emotional support from partners was much more valuable than instrumental or practical support as it made the women feel cared for and loved (Pfaendler et al., 2015). Emotional support motivated cervical cancer survivors to survive despite their suffering (Zuardin et al., 2019). A study among breast cancer survivors post-chemotherapy reveals a similar discrepancy between their need for emotional support and their difficulty in allowing themselves to be helped, particularly when the support was not given or was inappropriate to their needs (Levkovich et al., 2019).

Cancer survivors and their partners experience levels of psychosocial distress that are higher than among the general population (Traa et al., 2015). Stress in couple relationships was no

longer conceptualized as an individual phenomenon but rather as a *dyadic stressor* (Bodenman, 2005; Bodenmann et al., 2011). Dyadic coping entails mutual involvement of both partners in coping with the stress: providing and receiving support from each other and engaging in joint problem-solving activities and shared emotion regulation (Revenson and DeLongis, 2010). Therefore, in facing cancer these couples may react as a unit rather than as individuals.

In the current study, the women described a variety of independent coping and decision-making strategies. These findings are reinforced by a study that examined cervical cancer survivors using focus group interviews (Gilbert et al., 2009). The women described a lack of support from their partners and indicated feeling burdened by the way their partners coped with their cancer diagnoses. Concurrently, survivors' partners may also experience negative emotions as a result of changes in their sexual life (Vermeer et al., 2015). A cross-sectional survey that assessed 26 couples up to 2 years post-treatment found that both members of the couple experienced disruptions in relationships, intimacy, and instrumental life domains. Facing cancer as a 'we-disease' may help strengthen the relationship between partners (de Groot et al., 2005).

A qualitative study conducted among cervical cancer survivors in South Africa found that some women had the full support of their partners, others received limited support, and some were even abandoned. Indeed, the issue of giving and receiving support was challenging for the women and for their life partners as well (Maree et al., 2013). In a qualitative study of 20 women, all indicated they needed moral support more than anything else, experienced their cervical cancer in solitude, and seldom shared their experiences with their partners (Pelcastre-Villafuerte et al., 2007). According to Koffman et al. (2012), patients living with advanced cancer associate the support they receive from their life partners with the way they cared for them in their relationship. This type of support, reinforced by love, reciprocity, and marital obligation, is built over time and is a natural part of a relationship of love and affection. In line with this notion, Badr et al. (2008) found that couples who reported engaging in more frequent discussions about their relationship within 1 month of the beginning of lung cancer treatment experienced greater marital adjustment and less psychological distress up to 6 months later.

In the current study, participants indicated that they often made complex decisions on their own, even though the consequences of these decisions influenced both partners. Women perceived living with cervical cancer as highly stressful, regardless of their background or the time elapsed since their diagnosis. Often the women had to deal with feelings of isolation, shame, or embarrassment, and they even felt lonely within the marital relationship (de Groot et al., 2007). Moreover, the self-esteem of cervical cancer survivors tends to be lowered due to their disrupted femininity and difficulties in fulfilling their sexual role (Laranjeira et al., 2013; Afyanti et al., 2020). Women who underwent radiation therapy, and especially those treated with combined treatments (i.e., surgery plus external beam radiation plus brachytherapy), reported the highest levels of sexual dysfunction (Lloyd et al., 2014; Mirabeau-Beale and Viswanathan, 2014; Pfaendler et al., 2015). The most pronounced physical changes among women treated by radiation included decreased lubrication, loss of sensation, reduced libido, and shortened vagina (Lloyd et al., 2014).

In the present study, participants reported that their cancer treatment had a negative impact on their sexual activity and

functioning. Sexual intercourse entailed a great deal of pain and suffering for them, leading them to avoid or postpone sexual relations. These findings are supported by studies, showing that sexual dysfunction is a major side effect of treatment, with 23–70% of cervical cancer survivors reporting problems with their sexual functioning (Gilbert et al., 2011; Abbott-Anderson et al., 2012; Lammerink et al., 2012). Emotional distress involving guilt, embarrassment, or sadness is a common consequence of sexual dysfunction (Park et al., 2007; Vermeer et al., 2016). A longitudinal study during the 12-month posttreatment period showed that early-stage cervical cancer patients tended to exhibit persistent sexual dysfunction, female sexual distress, sexual worry, and lack of sexual desire (Froeding et al., 2014). In a cross-sectional study, survivors reported three times more sexual distress, poorer body image, lower sexual and/or vaginal functioning, and more sexual worry than controls (Vermeer et al., 2015; Bakker et al., 2017). In a qualitative study among 13 cervical cancer survivors, all participants reported on pain during sexual intercourse and/or a dry and shortened vagina (Afyanti and Milanti, 2013). Some even reported bleeding after sexual intercourse following the cancer treatment (Afyanti and Milanti, 2013). Studies have shown that sexual distress was related not only to physical problems (e.g., vaginal symptoms) but also to psychological issues (e.g., anxiety or depression), in line with the biopsychosocial perspective that female sexuality is multidimensional (Bakker et al., 2017).

The women in the current study stated that they made an effort to engage in sexual intercourse to satisfy their partners. The women described a decline in libido and a sense of diminished femininity. All the women in our study underwent surgery and radiation or chemo-radiation therapy. Surgery can alter sexual organs, surgery and chemotherapy can induce premature menopause, and radiotherapy can damage the vaginal mucosa, often resulting in stenosis and fibrosis (Carter et al., 2013). Hence, these findings of decline in libido and diminished femininity may be explained by Schain's (1986) model of socio-sexual development, according to which the main sexual concerns of adults (20–45 years old) are sexual adequacy, performance, and fertility. Studies have found that women often deny their own needs in order to satisfy the perceived needs of their partners (Juraskova et al., 2003; Ye et al., 2018).

In the current study, cervical cancer survivors described their recovery period as a potential opportunity for change and progress in their relationships. The cancer caused some of the women to think about their role in the relationship and about their life priorities, leading them to demand things they had not demanded previously. As women approached the end of their treatment, their concerns about their relationships with their partners seemed to increase significantly (de Groot et al., 2007). These findings may possibly be explained by the notion of posttraumatic growth (PTG), which refers to positive psychological changes and growth beyond previous levels of functioning, thus implying both an outcome and a process (struggle after a traumatic event) (Tedeschi and Calhoun, 1995).

According to Tedeschi and Calhoun (1995, 2004), growth is essentially an internal change that leads to expanding individuals' cognitive-emotional ability to understand themselves and the world around them. The authors stress the notion of rumination, which is at the core of growth. In the current study as well, rumination appears to have helped the survivors reevaluate their cancer, cope with it, and instill it with new meaning. This new meaning can ultimately lead to a sense of growth. The most

prominent dimension in the current study is the recognition of new possibilities and the change in priorities. The findings show that cancer is not just an individual disease, since it also involves the patient's partner. Indeed, aspects of growth and positive changes have been observed in partners (Manne and Badr, 2008; Cormio et al., 2014). A study using a sample of 224 patient/partner dyads showed very similar levels of PTG in patients and partners (Zwahlen et al., 2010). A study examining patients with various types of cancers and their partners found higher levels of PTG in the partners (Cormio et al., 2014). Other studies confirm that cancer may produce deep changes not only in the individual, but also in his/her caregiver, who may experience growth after the cancer experience (Kim et al., 2007).

In our study, some of the participants indicated that prior to their diagnosis they focused primarily on the needs of their family, sometimes to the point of relinquishing their own needs. Their cancer changed their perceptions and their priorities, causing them to acknowledge their own needs and recognize their importance. Tedeschi and Calhoun (2004) found that following a traumatic incident, people begin to understand that they are capable of living better lives, discover new opportunities they had not seen previously, and are prepared to make the changes in their lives necessary to take advantage of these opportunities. In the current study as well, many of the participants described how this crisis became integrated into the flow of their lives. They noted changes in their self-perception, stressing their vulnerability after their cancer but also their newly discovered inner strengths.

Study limitations

This study employed the phenomenological qualitative method, which provides an in-depth understanding of interviewees' experiences. Nevertheless, the qualitative research used only a small sample of participants from Israel, and hence its results cannot be generalized to broader population groups. Moreover, time elapsed since diagnosis was not one of the inclusion criteria, which only required that participants be currently free of disease and undergoing follow-up at an oncology unit in Israel. We recommend that time elapsed since diagnosis be limited in future research. In addition, due to COVID-19, the interviews were conducted via a virtual platform. This online design biased the sample toward population groups that are digitally literate or have access to digital resources and toward those who may be more socially connected, at least virtually. Furthermore, the recruitment method via a Facebook support group may not fully represent all cervical cancer survivors, such that the recruitment method also constitutes a limitation. The experiences of cervical cancer survivors over the long term and their perspectives on their intimate relationships require further observation and assessment in future studies.

Study implications

Healthcare professionals must be made aware of the important role of the cancer trajectory among cervical cancer survivors to enable them to obtain psychosexual support by taking into account aspects such as sexual distress and relationship satisfaction. Additionally, both cervical cancer survivors and their partners should be offered more practical and reassuring information about communication and relationship consequences during and after cervical cancer. The findings of the current study

highlight the importance of presurgical information and counseling both for the patient and for her partner, especially about persistent vaginal changes that may affect sexual functioning. Interventions focused on promoting couple communication can be effective in improving intimacy, and couple-oriented education may help improve psychosexual well-being, fertility, and communication.

Oncology healthcare providers should take the initiative in providing psychosexual care for women diagnosed with cervical cancer by assessing their concerns and needs. Patients tend not to raise sexual issues unless specifically asked. Communication on topics related to sexuality requires being sensitive to patients' cultural and religious backgrounds as well as establishing rapport. Intervention should be tailored to the needs of the survivors and their partners.

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Appendix 1. Interview questions posed to cervical cancer survivors

- Please go back to the time when your cancer was discovered. Tell me how it was discovered.
- How were you informed that you have cancer? Who was with you when you found out?
- Tell me about your partner's reactions to the specific type of cancer you have. How did you feel about his reactions?
- How did people close to you react to you during the period of your treatments?
- How did you feel about the changes in your body and your daily routine?
- If you were asked to describe your life before and after the discovery and treatment of your cancer, what has changed? What has remained the same?
- What have you discovered about yourself and your partner as a result of your cancer diagnosis?
- If you were to divide the way you coped with your cancer from the beginning until now into sections, how would you divide it? What name would you give to each section?
- How has your cancer affected your relationship with your partner compared to the way it was before your diagnosis?
- In your opinion, how have your treatment and recovery influenced the intimate relations between you and your partner?
- What helped you cope? How did you feel about this help?
- Tell me about your communication with your partner as you coped with your cancer.
- When you bring up your fears and difficulties about your cancer in discussions with your partner, what are your thoughts and feelings?
- What advice would you give to other women diagnosed with cervical cancer?
- What advice would you give to the partners of women diagnosed with cervical cancer?