

Ovarian Cancer Survivors: Qualitative Analysis of the Symptom of Sexuality

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Ovarian cancer is the fifth-leading cause of death in women and, according to the American Cancer Society (2011), one of the most difficult to treat, diagnose, and manage. A myriad of symptoms and side effects are caused by treatment; however, sexuality is one of the most prevalent and under-addressed factors with enduring effects on quality of life (Bodurka & Sun, 2006). Despite the pervasive impact of ovarian cancer treatment on sexuality, beginning with the surgical removal of the uterus and ovaries and followed by chemotherapy, this treatment-induced side effect is rarely addressed by healthcare providers. Providers admit that their own lack of knowledge creates a barrier to helping women manage issues with sexuality (Stead, Brown, Fallowfield, & Selby, 2003). The purpose of this study was to add to the body of knowledge about ovarian cancer treatment-induced changes in women's sexuality from the patient perspective, to learn how women manage these changes in sexuality, and to identify what information they want from nurses about this symptom.

The American Cancer Society (2011) estimated that 21,990 women in the United States were diagnosed with ovarian cancer in 2011 and about 15,460 died from this disease, with the majority of these women being older than age 60 at the time of diagnosis. Ovarian cancer, if detected early when the disease is still localized, has a 94% survival rate at five years. However, only about 15% of cases are detected that early. Detection at later stages has a lower survival rate; those with regional metastases have a five-year survival rate of 73%, whereas patients with distant disease only have a 28% survival rate at five years (American Cancer Society, 2011). The literature indicates that, no matter at what age a cancer diagnosis is experienced, an estimated 25%–80% of women experience alterations in sexual behavior as a result of cancer or cancer treatments (Bruner & Boyd,

Purpose/Objectives: To better understand treatment-induced changes in sexuality from the patient perspective, to learn how women manage these changes in sexuality, and to identify what information they want from nurses about this symptom.

Research Approach: Qualitative descriptive methods.

Setting: An outpatient gynecologic clinic in an urban area in the southeastern United States served as the recruitment site for patients.

Participants: Eight women, ages 33–69, receiving first-line treatment for ovarian cancer participated in individual interviews. Five women, ages 40–75, participated in a focus group and their status ranged from newly diagnosed to terminally ill from ovarian cancer.

Methodologic Approach: Both individual interviews and a focus group were conducted. Content analysis was used to identify themes that described the experience of women as they became aware of changes in their sexuality. Triangulation of approach, the researchers, and theory allowed for a rich description of the symptom experience.

Findings: Regardless of age, women reported that ovarian cancer treatment had a detrimental impact on their sexuality and that the changes made them feel “no longer whole.” Mechanical changes caused by surgery coupled with hormonal changes added to the intensity and dimension of the symptom experience. Physiologic, psychological, and social factors also impacted how this symptom was experienced.

Conclusions: Regardless of age or relationship status, sexuality is altered by the diagnosis and treatment of ovarian cancer.

Interpretation: Nurses have an obligation to educate women with ovarian cancer about anticipated changes in their sexuality that may come from treatment.

1999). Treatment for a gynecologic cancer, in general, creates sexual problems that can range from loss of desire, decreased ability to reach orgasm, and dyspareunia caused by a shortened vagina (Wilmoth & Spinelli, 2000). However, little is known about specific problems

of sexuality and sexual function that result from ovarian cancer treatments (Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004).

Literature Review

A literature search using the term *ovarian cancer and sexuality* identified 49 articles published since 2001. Only nine of these articles specifically focused on ovarian cancer treatment-induced effects on sexuality; four of the articles were data-based reports on sexuality, whereas the other five were literature reviews. This suggests that the prevalence of sexual concerns in ovarian cancer survivors is either underreported or understudied. This paucity of data prevents nurses and other healthcare providers from providing evidence-based anticipatory guidance to women living with ovarian cancer.

The few published studies that have examined treatment-induced sexuality issues in women with ovarian cancer underscore the critical need to further explore the unique needs of these women. Stewart, Wong, Duff, Melancon, and Cheung (2001) surveyed 200 ovarian cancer survivors with a mean age of 55 years at two years post-treatment. Fifty-seven percent of the women reported that their sex lives had been adversely affected by cancer, and 75% labeled their sex life as adequate or poor. Younger women were more likely to report a negative impact on their sexuality following diagnosis. In all, 45% of respondents said they had a moderate to great sense of loss about their sexuality following treatment for ovarian cancer. Although validating that ovarian survivors *have* sexual difficulties, this study did not examine in detail the range of the sexual difficulties experienced or how they were managed.

In a second study, Carmack Taylor et al. (2004) assessed sexual physical factors predictive of sexual satisfaction and dissatisfaction, sexual discomfort, and sexual habits. Of the 232 married women with advanced ovarian cancer, 47% reported little to no sexual desire postdiagnosis and 80% experienced vaginal dryness. Eleven percent of the participants reported that fatigue interfered with their sex lives. Predictive of greater levels of sexual activity were satisfaction with the appearance of one's body, being younger than age 56, not in active treatment, and being married.

In addition, ovarian cancer survivors (N = 70) being treated with second- and third-line chemotherapy were asked by Sun et al. (2005) to rank order 27 common health states that resulted from treatment. Sexual dysfunction was reported as a common complaint and was of greater concern in women receiving second- and third-line chemotherapy than in women receiving first-line. However, the sample included women receiving treatment for newly diagnosed ovarian cancer as well as those who were being treated for a recurrence of the

disease, and the term *sexual dysfunction* was not defined, leaving the meaning open to individual interpretation.

The sexual symptoms caused by ovarian cancer treatment are as important to understand as are the other symptoms common to cancer survivors, such as fatigue. Knowledge about sexual symptoms also is critical to understanding their impact on quality of life. Sexuality is a highly personal construct with meanings derived from culture, religion, ethnicity, and life experiences. Historically, the most common framework used in sexuality research has been limited to function and satisfaction (Masters & Johnson, 1966). However, as a multidimensional concept, sexuality must be operationalized as such and include communication with intimate partners, relationship quality, perception of one's own femininity, as well as the more traditional technical and functioning aspects (Wilmoth & Tingle, 2001). Each of these dimensions may be adversely affected by ovarian cancer surgery as well as by the types of chemotherapy used in treatment. The ability to understand women's sexuality concerns and how they manage them during their initial treatment for ovarian cancer offers the best opportunity to mitigate adverse long-term sexual consequences.

Surgical treatment involves a total abdominal hysterectomy (removal of ovaries and uterus) that causes surgical menopause in menstruating women or removes the source of circulating hormones produced by ovaries in postmenopausal women. Removal of a woman's reproductive organs also has emotional and psychological meanings to many women, regardless of menstruating status (Andersen, Woods, & Copeland, 1997). First-line therapies initially are used in treating the cancer, whereas second- and third-line therapies are attempted when prior therapies failed to cure or control the disease or stopped working effectively (National Cancer Institute, n.d.). In the treatment of ovarian cancer, first-line chemotherapy consists of platinum and taxane compounds.

Hughes (2009) provided a detailed account of cancer treatment and its sexuality-associated side effects from a nursing perspective. Although Hughes (2009) covered sexuality side effects from all types of cancer, certain problems are central and cross-cutting regardless of specific diagnosis. Chemotherapy is associated with short- and long-term side effects. Fatigue, nausea and vomiting, weight change, loss of libido, and loss of hair often are seen in patients treated with chemotherapy. Although temporary, the combined physical effects often affect body image. As a result, poor body image affects sexuality (Hughes, 2009). In addition, preexisting sexually transmitted diseases often flare as a result of chemotherapy-induced immune suppression. Although these more commonly known short-term sexuality effects subside after treatment stops, other less known and longer-lasting (even permanent) chemotherapy effects can influence sexuality in a profound but often pernicious

way. For example, neuropathies often are associated with platinum and taxane therapies. Neuropathies present in many forms and manifest in multiple organ systems (i.e., clitoris, glans of the penis, and hands) affecting sensation and pain tolerance, symptoms not readily attributable to chemotherapy.

In summary, little is known about how women with ovarian cancer experience changes in their sexuality caused by treatment, what the range of sexual issues are that they experience, how distressing they are, or how women manage these sexual problems. In addition, literature that documents the types of support or information women believe would be helpful as they deal with changes to their sexuality is limited. This study examined the sexual experiences of newly diagnosed patients with ovarian cancer to better understand the effect of this disease on sexuality.

Methods

This was a descriptive, qualitative study designed to describe the impact that ovarian cancer has on sexuality in women who were receiving first-line treatment for this disease. The study was designed to use content analytic techniques with focus group methodology (Krueger & Casey, 2000; Neuendorf, 2002) to answer the following questions.

- How do patients with ovarian cancer describe the changes in their sexuality that they have experienced since their diagnosis? How do they manage these changes?
- What information and education do patients with ovarian cancer feel they need about this symptom of treatment?

Participants

Eighteen women gave the clinic staff permission to provide their name and phone number to the principal investigator (PI) for additional explanation of the study. Of these 18 women, 13 agreed to participate in the study; 8 participated in one-on-one interviews with the PI and 5 participated in a focus group. Those who chose not to participate indicated they were not interested, were too busy, or did not return the PI's voice message. The final sample for this qualitative study consisted of 13 women with a mean age of 56 years, with three of the women younger than age 40 at the time of the interview (range = 33–75) (see Table 1).

Time since diagnosis ranged from 6–24 months for women who had one-on-one interviews and from 6 months to 8 years in women who took part in the focus group. All of the women who participated in the one-on-one interviews were either receiving first-line chemotherapy or had completed treatment within six months of their interview. Chemotherapy agents ad-

Table 1. Sample Characteristics

Characteristic	Individual Interviews (N = 8)		Focus Group (N = 5)	
	\bar{X}	Range	\bar{X}	Range
Age (years)	52.75	33–69	62.2	40–75
Characteristic	n		n	
Race				
Caucasian	7		5	
Asian American	1		–	
Marital status				
Married	4		5	
Divorced	3		–	
Single, no partner	1		–	
Education level				
College graduate	6		2	
Post-graduate	2		–	
High school graduate	–		2	
Technical school	–		1	
Stage at diagnosis				
1	2		1	
2	2		1	
3	3		2	
4	1		1	
Type of surgery				
TAH	2		2	
TAH with BSO	3		1	
Oophorectomy	3		–	
Do not know	–		1	
Missing data	–		1	

BSO—bilateral salpingo-oophorectomy; TAH—total abdominal hysterectomy

ministered to the participants included carboplatinum (n = 6), paclitaxel (n = 9), paclitaxel protein bound (n = 1), cisplatin (n = 5), topotecan (n = 2), etoposide phosphate (n = 1), and liposomal doxorubicin (n = 1).¹ All participants engaged in some form of regular exercise, both before diagnosis as well as during chemotherapy. Women engaged in a range of types of exercise, such as walking, yoga, gardening, and aerobics as well as a range in intensity of exercise. The majority of women (n = 8) had gained weight since being diagnosed with ovarian cancer, with weight gain ranging from 4.5–17 lbs; however, one woman had not gained or lost any weight and four lost weight (range = 2–23 lbs).

The five women in the focus group differed from the rest of the sample only in that the time since diagnosis had a wider range—spanning six months to eight years from the date of diagnosis. One of the participants was terminal, one was newly diagnosed with ovarian cancer and just beginning chemotherapy, and three had not experienced any recurrences of their cancer since completing their initial treatment at the time the focus group was held.

¹ The participants may have received multiple drugs as part of their chemotherapy treatment.

Procedures

After receiving institutional review board approval from the Carolinas Medical Center and the University of North Carolina–Charlotte for the study, flyers were posted in a variety of places within the gynecologic cancer clinic at the designated urban-based outpatient cancer treatment center in the southeastern United States. Staff nurses working in the clinic were briefed on the study and a graduate student was available via e-mail to answer any questions that the staff may have had. One staff nurse, who had worked on a previous project with the PI, was the primary contact person between the researcher, staff, and patients. She informed all potential participants about the study and asked whether they would like to be contacted about participating. If they were interested, the PI was provided with the individual's name and contact information. The PI then contacted each individual and provided a full explanation of the study. If an individual agreed to participate, a time and place for the interview was determined. When the participant arrived for the interview, the PI reviewed the informed consent letter with the participant and had her sign it. Participants then completed a demographic data form prior to proceeding with the interview and were given a gift card to thank them for their time when the interview was complete.

Design

The study design had originally called for sole use of focus group methodology for data collection (Kruegar & Casey, 2000); however, the realities of scheduling group meetings around clinic operations prevented this from materializing. In addition, potential participants typically planned their clinical appointments around their work schedules. Therefore, the majority of interviews were done on a one-on-one basis. The focus group was held after all interviews were completed and served as a member check of findings during the final analytic phase of the project (Neuendorf, 2002).

The interview with each participant began after the consent form and demographic data forms were completed. Participants were first asked to describe what the term *sexuality* meant to them and that meaning was then used as a frame of reference when asking about other aspects of cancer and their sexuality (see Figure 1). Questions were then sequenced to ask about factors in participants' lives which may have influenced their sexuality immediately prior to diagnosis and in the months following diagnosis. The interview then proceeded to questions designed to further refine the symptom, such as when changes in sexuality were first noted, how severe were these changes, how distressing were these changes, and what effect might they have had on intimate relationships. Sequencing of questions also followed published guidelines related

- Describe your definition of sexuality.
- What physical problems or other illnesses have you had that may have had an impact on your sexuality before being told you had ovarian cancer?
- What was your relationship like with your partner before your diagnosis? What other events were going on in your life that may have affected your intimate relationship?
- Please describe how your sexuality has been affected by your cancer diagnosis.
- What has been the most troubling change in your sexuality:
 - Interest?
 - Arousal?
 - Ability to have an orgasm?
- Have you experienced pain during intercourse?
- When did you notice these changes? How severe have they been?
- How has your partner reacted to these changes? Have you discussed your concerns about your sexuality with your partner?
- What have your doctors and nurses shared with you about cancer and sexuality? What would you have liked to have been told? When, during treatment, is the best time for sexuality discussions to occur?

Figure 1. Sample Interview Questions

to conducting sexual interviews, starting with the least sensitive items first and progressing to more sensitive and intrusive questions (Wilmoth, 2006a). After several interviews had been conducted and an initial analysis of the data performed, the questions were modified to more directly ask participants about their experience with each aspect of the symptom. Specifically, one key question that was added asked participants to identify, on a scale of 1–10, the intensity of the changes they had experienced in their sexuality since the ovarian cancer diagnosis.

Focus group questions mirrored the basic structure of those asked in the individual interviews. That is, the discussion moved from less intrusive to more sensitive questions, asking the group to first describe what sexuality meant to them. The interviewer then asked participants to respond to themes identified in the individual interviews (e.g., timing of the occurrence in altered sexuality, describing the changes and how they were managed). How the group participants felt about these changes and how the changes had affected them and their intimate relationships were addressed. Finally, participants discussed what they had been told by their healthcare team as opposed to what they would have liked to have been told.

Interviews and the focus group discussions all were recorded and then transcribed for analysis. The research assistants (RAs) listened to each audiotape and read the transcription to ensure accuracy, making corrections when necessary. Once accurate transcriptions were ensured, analysis began by using descriptive content analytic techniques with words and phrases as the unit of analysis (Neuendorf, 2002). The PI and RAs analyzed

each transcribed interview individually and then met to discuss themes that were identified. Coding was done at the level of units of words and a code book was developed to ensure consistency for all analysts using human coding rather than a software program (Neuendorf, 2002). This made for more fruitful analytic discussion sessions across the authors. The Theory of Unpleasant Symptoms (Lenz, Pugh, Milligan, Gift, & Suppe, 1997) was used as a framework to guide questions asked about the data during the analytic process. This ensured that both the meaning of the experience of altered sexuality in these women's lives was examined as well as the underlying range of the symptom experienced by participants.

Results

Sixty-two percent of the women interviewed ($n = 8$) indicated that the diagnosis of cancer had a detrimental impact on their sexuality, using wording such as "no longer whole" to describe its impact. The intensity of this symptom experience varied across the group, with 4 of the 13 participants indicating a low level (range = 1–3 on a 1–10 scale) of intensity of change to their sexuality by the disease, with another clustering ($n = 4$) reporting intensity at the higher range (7–10). Both older and younger (younger than age 60) women, premenopausal and postmenopausal at the time of diagnosis, indicated that cancer had a detrimental impact on their sexuality. Women at the lower levels of intensity indicated either that only a minimal impact on their sexuality occurred or that they had only experienced a slight decrease in sexual desire as a result of their diagnosis. None of the participants reported a moderate change (range = 4–6), and those who had experienced a high degree of intensity of altered sexuality described the changes with strong wording. For example: "No one wants to touch you," "I felt as though part of my life was gone," "You lose your hair, you put on 20 some pounds, and you don't feel very sexual; so it has been greatly affected." It may be possible that women reporting a low degree of effect on sexuality may actually have experienced greater degrees of insult on their sexuality than reported since, as one woman stated, "It [sexual change] is sub rosa until someone asks about it."

Women defined sexuality in broad terms as the way they felt about themselves as a woman and included their figure, clothing, and how they presented themselves to others. They also made a distinction between this more global aspect of sexuality and their intimate sexual lives. Global sexuality was defined by one woman as "feeling good about yourself, feeling attractive," whereas a more personal view of sexuality was described as "how I relate to my husband and all the things that go along with lovemaking."

Factors Influencing Sexuality

To provide context for responses, each interview was analyzed for the physiologic, psychological, and situational factors that may have influenced the participants' experience with this symptom (Lenz et al., 1997). Physiologic influencing factors included hormonal alterations resulting from the surgical removal of ovaries as well as loss of the uterus and resultant scarring. Physiologic side effects reported from chemotherapy included changes in cognition, peripheral neuropathy, weight changes, and symptoms of menopause (e.g., hot flashes). The ability to be fertile post-treatment (both surgery and chemotherapy) was a key physiologic issue for one participant who placed a strong psychological influence on her sexuality. The changes in weight that accompanied treatment were identified by 12 of 13 participants as both a physiologic and psychological factor that negatively affected their sexuality.

Psychological influencing factors reported by participants included perception of the effect of the surgical scar ($n = 5$) and presence of the implanted port ($n = 3$) for chemotherapy administration on body image as well as perception of alopecia ($n = 8$). One woman of child-bearing age just needed to know that she would be able to have more children and flatly rejected the notion that she had cancer. The ability to engage in a satisfying form of exercise had a positive impact on the participants and led to a positive sense of self. For example, one woman said, "I have a walking partner; we walk three mornings a week. My energy level is a lot higher." Another said, "I started exercising again and it was like I was reborn."

Situational influencing factors revolved around participants having or wanting a significant other in their lives. One 75-year-old focus group participant missed having an active sex life with her spouse, who had dementia. One woman's comment validated the importance of the significant other in adjusting to changes in her sexuality.

Our relationship has gotten better. He still showed sexual interest even though I was sick and had lost all my hair.

Another felt validated both emotionally and sexually by her husband's frequent comments about how beautiful she was and how much he loved her.

Dimensions of the Changes in Sexuality

Describing the complex changes in sexuality caused by ovarian cancer treatment was more difficult. Although the majority of participants had indicated the diagnosis had affected their sexuality across a range of intensity, when they first noticed these changes and how long they lasted were unclear. Two participants indicated that they had not really thought about sexuality until the interview, whereas others indicated that

changes in sexuality had been apparent immediately after surgery. For example,

The first time we had sex [after surgery], I was in tears because I thought this is how it will be now . . . this is the way it is going to be.

Those who noted immediate changes to their sexuality were more likely to define sexuality as a global and pervasive aspect of their life (e.g., "Sexuality is how you think of yourself as a female, a sexual being, and within yourself.") rather than being identified by having a specific body part (e.g., presence of a uterus). Others noted changes to their sexuality once they had been given permission by the surgeon to resume sexual activity, generally six weeks postsurgery. For example, "Once I physically recovered, everything pretty much returned to normal." One woman stated, "I wasn't sexually active during the chemo[therapy]," indicating a cessation of sexual activity during this portion of treatment. Although difficult to ascertain from one interview, comments implied a process was involved in adjusting to changes in sexuality, just as it was a process involved in adjusting to living with cancer: "I think it takes longer, and I do have issues with dryness." Six of the eight women in the individual interviews said they were bothered by vaginal dryness that hindered their sexual activity; four of these same women said that intercourse was very painful following surgery. Their vaginas had been shortened from the surgical procedure and only one had been told to "take more control during sex and to avoid the missionary position."

A question asked of the data was, "How distressing were the changes in sexuality caused by these participants and how do they manage these changes?" One individual said, "It hasn't had a horrendous effect and it's been manageable," whereas another participant indicated that, although her sexual interest had decreased, she felt "that was just part of it . . . and it's not that important." Five of the eight women reported that these changes were very distressing; the other three indicated that the sexual changes had caused a low level of distress. For example, one woman indicated she had experienced a great deal of distress over sexual changes when she stated, "Painful intercourse caused a distance between us." Another indicated a high level of distress when she said, "It was never addressed [by the surgeon or nurses], so I thought that was the end of my sexuality . . . no more physical contact, but you don't feel complete."

None of the women who identified vaginal dryness as a problem reported having had any over-the-counter vaginal lubricants recommended to them by their healthcare team. One of the younger women said, "We were trying to have a baby and that was taken away immediately." And another said, "My intimate life is null and void."

Women may have indicated that changes in their sexuality were manageable; however, few were able to

describe how they did, in fact, manage the more intimate changes in their sexual lives. Hints were provided by stories of taking control of side effects more visibly managed, such as one woman who had her school-aged daughter play with her hair once it began to fall out.

"I'm your Barbie doll, go to town and do what you want with it." She had a blast making all sort of hairdos. We were all laughing and thought it was funny . . . we took something bad and made it good . . . I hoped it helped them.

Painful intercourse was mentioned by four women, but they did not discuss how they managed this aspect of the symptom.

In attempting to gauge the meaning of these changes to their sexuality, the data were examined for descriptions of the symptom by women. Eight women described the quality of their sexuality since diagnosis as "asexual" or "no longer whole." Their comments ranged from "I don't feel very sexual/haven't felt very sexual since surgery" and "I feel like I am dissected" to "I felt kind of hollow inside for a short time but I don't think it changed my sex life much."

Role of the Nurse in Discussing Sexuality

Participants were unanimous in that they felt that the healthcare provider should initiate discussions of sexuality. One participant stated, "I wish the initiation [to discuss sexuality] would come from them [doctor or RN]; it's hard for me to get the courage to bring up the topic." What women really wanted to know, in addition to whether or not having sex was permissible, was whether they needed to consider or be concerned about anything in particular. That information was never provided. None of the participants reported receiving any information regarding changes in their sexuality that they should expect or might experience prior to surgery or prior to beginning chemotherapy from their surgeon or oncologist. One woman reported that her gynecologist had indicated she might experience a renewal of hot flashes following surgery, but no explanation was given as to why this should be expected or how they might be managed.

Participants provided a range of answers as to when they felt nurses and physicians should provide information about the sexual effects of ovarian cancer and its treatment. Their responses ranged from prior to surgery to the latter half of the chemotherapy regimen. One woman suggested, "Maybe they should talk about it [sexuality] every time and then, when patients are ready to hear it, they will hear it." None of the participants recalled receiving a copy of the American Cancer Society's (2008) booklet *Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner*. One participant suggested that the notebook the clinic provides to each patient with descriptions of each symptom with suggestions

on how to manage them should be expanded to include sexual symptoms following surgery and chemotherapy.

Focus Group Session

The focus group discussion, consisting of five women whose length of survival spanned the entire diagnosis-terminal spectrum, served as a check of the findings from the one-on-one interviews. As a group, the women determined that sexuality was how one was defined as a woman, to include touching, talking, and the ability to fulfill the woman's traditional responsibilities in the household. The spouse or significant other was identified in having a critical role in influencing how the woman had experienced changes in her sexuality, followed by communication and a sense of acceptance. As one woman said, "My husband has continued to tell me he loves me and how beautiful I am and he has continued to tell me without hesitation and, believe me, I watched for that hesitation." Physiologic influencing factors experienced by this group echoed what women in the individual interviews had indicated (e.g., alopecia, scar from the surgical incision, symptoms of menopause). Psychological influencing factors for these survivors were grounded in the emotions surrounding fears of recurrence, resumption of chemotherapy because of recurrence, and, for one woman, coping with a terminal status. One participant said, "Acceptance. That's what we want and what we need."

The intensity of the changes in sexuality experienced by members of the focus group also appeared to have a range, with one woman at the lower end of intensity saying,

I had a hysterectomy at age 34 . . . so just to have ovaries removed . . . I didn't feel anything, you know, as far as losing my sexuality or anything from having that done.

Another participant, age 40, indicated a highly intense change in sexuality. "I was like hot flash city, and my husband and [since diagnosis] my intimate life has been null and void." Women in this group were all in long-term marriages and indicated that the quality of their sexuality had modulated over the course of the marriage and again since diagnosis.

I think one of the things for me, my husband is older than I am, so probably the sexual intercourse doesn't happen a lot, but I can live with that. I can go and curl up with him and we can visit. To me, that's a more intimate act to me now than probably what I had.

However, at the age of 75, she also indicated that she would "love some intimacy" (e.g., more physical touching). Distress over changes in sexuality was expressed more in relation to the daily experiencing of physiologic

influencing factors, particularly alopecia and fatigue. One woman summarized her distress by providing several examples of how her life had changed using the terms, "I was . . . and am now. . . ." Timing of altered sexuality began for most following surgery and also was related to physiologic issues such as poor wound healing. Exemplar statements include, "you have this hole in your side that has to be dressed," "scars are like an embroidered pattern," and being told by the surgeon that "your bikini days are over." Each of these women described exercise, whether it be walking, yoga, or gardening, as the way to cope with "changes in your self" caused by cancer. Additional corroborating data from the individual interviews about the lack of information related to sexuality provided by healthcare providers is reflected in a statement made by one woman.

My husband had told me he was going to ask the nurse when we could have sex. So I said, "I'll leave that up to you." So when she was doing [removing] the stitches and he went ahead . . . he was very careful how he asked and the nurse turned around and looked at him and said, "Well, she's not ready yet." I think that kind of stunned him and she never really did say [why].

At a later visit, they revisited that question with the physician who said, "Sex is great . . . it's great for everything, your mental. . . . Yes, anytime." Again, none of these women had their healthcare provider initiate the discussion of when intercourse could be resumed or of the treatment effects on sexuality.

Discussion

The purposes of this study were to learn how women with ovarian cancer described the changes in their sexuality from treatment, to hear how they managed these changes, and to identify what information they wanted from their nurses and physicians about this common side effect of treatment. The majority of women who participated in this study indicated that sexuality was or had been an important aspect of their lives, regardless of their age or menopausal status at the time of diagnosis. Eight of the 13 participants (62%) indicated that their sexuality had been negatively affected by this diagnosis and subsequent treatment. This is within the range of alterations in sexuality caused from cancer treatment reported by Bruner and Boyd (1999) and in patients with ovarian cancer by Stewart et al. (2001). The feelings that surrounded the assault of ovarian cancer on these women's lives mirror the findings of Ferrell, Smith, Juarez, and Melancon (2003), who examined meanings of illness in ovarian cancer survivors. The majority also indicated that their healthcare team had not discussed the possibility of changes in their sexuality prior to surgery, nor were they provided with guidance

on how to manage common side effects following loss of ovaries, uterus, and cervix coupled with chemotherapy. This lack of professional guidance on what to expect in relation to sexuality is a longstanding issue and common complaint in many different cancer populations (Stead, Fallowfield, Selby, & Brown, 2006; Waterhouse & Metcalfe, 1986).

Although there did not appear to be a specific point in time following diagnosis and treatment when these participants began to experience symptoms related to their sexuality, consistency was noted in their descriptions of the quality of their sexuality following diagnosis. Eight of the 13 women in the study made comments such as "asexual" or "no longer whole." The negative impact of gynecologic cancers on sexuality to the point of ending sexual activity or leading to a sexual dysfunction has been reported by others (Bodurka & Sun, 2006; Sun et al., 2005). Stead et al. (2006) reported similar findings in their qualitative study of 15 ovarian cancer survivors. Women in that sample questioned their sexual desirability following hair loss and reported a lack of sexual desire, vaginal dryness, and painful intercourse.

The range of intensity and degree of distress caused by changes in sexuality varied across a continuum, which may not be unusual given the age range, time since diagnosis, varying marital and relationship status, and varying prediagnosis menopausal status of the women who participated. Other researchers have noted a varying degree of effect of ovarian cancer on sexuality, with one study finding 75% of participants reporting a diminished sex life (Stewart et al., 2001). Analysis of the current study's interviews suggests that the presence of a significant other and the quality of that relationship along with previous sexual concerns has an influence on the degree of distress caused by this symptom. The literature (Carmack Taylor et al., 2004; Stewart et al., 2001) supports this and may provide direction for the development of interventions aimed to modulate sexual side effects.

Participants mentioned other common symptoms caused by cancer treatment that influenced their experience of the symptom of sexuality. These symptoms were fatigue, changes in weight, emotional status, and, to a lesser extent, fatigue. These symptoms have previously been proposed as a clustering of symptoms common in women with cancer (Wilmoth, Coleman, Wahab, & Kneisl, 2009; Wilmoth, Hester, & Laboy, 2007). Comments from two of the women in this sample link two or three of these symptoms, "Very tired; no interest in sexuality," and "You lose your hair, put on 20 pounds and you don't feel very sexual . . . and I'm tired a lot." Exploring the potential for a cluster of symptoms that may be amenable to a similar intervention is a topic for future consideration.

That these survivors had received little to no information about the possible effects of surgery and

chemotherapy on sexuality and sexual functioning was not unusual and is reinforced by the literature (Southard & Keller, 2009; Stead et al., 2006). The survivors who participated in this study reported that sexuality had not been discussed in any of the monthly gynecologic cancer support group meetings. Unfortunately, this also is not unusual and has been reported in a variety of other reports on sexuality (Penson et al., 2000; Stead, Fallowfield, Brown, & Selby, 2001). No clear indication from these women pinpointed when sexuality became a concern or when information on sexuality was most needed. One woman suggested talking about it often, at every visit, and "then, when patients are ready to hear it, they will hear it."

Limitations

A key limitation of the study revolved around the difficulty in obtaining participants for the project. The lead researcher had a preestablished relationship with the clinic staff and physicians, who assured her that it would not be difficult to obtain an adequate number of participants for the project. Feasibility of the use of focus groups also was validated with clinic staff prior to initiating the study. However, subject accrual did prove to be difficult. Offers to brief clinic nursing staff on the study so that they would be supportive and refer potential participants to the research team were not responded to by nursing leadership. An unexpected barrier was difficulty gaining access to potential participants through the gynecologic oncology support group. This was resolved by having a support group staff member attend the focus group session, which may have hindered some aspects of the focus group conversation.

Combining focus group methodology with individual interviews and descriptive content analytic methodology was not the original plan for this project. However circumstances beyond the researchers' control drove this unexpected triangulation of data sources, which has resulted in a rich analysis. The ability to present thematic findings following analysis of individual interviews to a focus group with a broad range of experience of living with ovarian cancer allowed for refining of the themes and to add new richness to their description. The three analysts also provided a unique triangulation; one was an experienced researcher and oncology nurse and two had no previous experience working with patients with cancer. They asked questions from the perspective of a novice to both the data and the method, which allowed for analyst triangulation. Finally, use of the Theory of Unpleasant Symptoms (Lenz et al., 1997) to further refine the symptom allowed for some theoretical triangulation (Patton, 1999).

Strengths of the project included the wide age range of the participants, validating the fact that sexuality remains a part of a woman's life regardless of age.

Another was the permission this study gave to these women to voice concerns about their sexuality relative to the diagnosis, often for the first time. It allowed women to give voice to some of their concerns and to learn that they were not alone with these concerns. Several women suggested that little is known about ovarian cancer, particularly compared to breast cancer, and that they were glad to learn that ovarian cancer was important to researchers.

Implications for Nursing Practice

This study documents the clear need for nurses to educate all women with ovarian cancer about the expected effects of surgery and chemotherapy on their sexuality (Wilmoth, 2006a). Discussion of the impact of a disease and its treatment on sexuality is within the accepted scope of practice for all nurses and, in oncology nursing, discussing sexuality with the patient and partner is standard of practice (Nishimoto & Mark, 2010). A few awkward moments may occur at first, but most women will be appreciative when a nurse shows that level of care and concern. Simply acknowledging that this is an expected side effect of treatment can be reassuring for many (Southard & Keller, 2009). Nurses should provide anticipatory guidance for women about sexual symptoms that come from treatment. For example, a standardized preoperative education protocol should inform women about the possibility of a shortened vagina and what sexual positions may be helpful in reducing painful intercourse (Wilmoth, 2006b). As one of the participants in this study indicated, the sexual side effects of treatment should be routinely assessed at every gynecologic oncology clinic visit with nursing and medical staff.

More research is clearly needed on the full impact of ovarian cancer on sexuality as well as interventions devised to reduce the severity of this symptom. The Theory of Unpleasant Symptoms, which hypothesizes that multiple symptoms can be experienced simultaneously with a synergistic effect on performance (Lenz et al., 1997), may provide a useful framework for future

research. The theory suggests that symptoms may be influenced by physiologic, psychological, and situational factors. This theory postulates that four dimensions exist for each symptom: intensity, timing, level of distress, and quality. Intensity refers to strength or severity of the symptom reported by a patient, timing of a symptom includes its duration and frequency of occurrence over time, and level of distress is the perception of degree of discomfort. Quality of the symptom experience is a descriptive labeling of the symptom (Lenz et al., 1997). Pilot work suggests that the Theory of Unpleasant Symptoms may be useful in describing the clustering of symptoms that result from cancer treatment (Wilmoth et al., 2007, 2009).

Conclusion

The diagnosis and treatment for ovarian cancer have a negative effect on sexuality in women no matter what their age or relationship status. The intensity and level of distress of this symptom may vary from woman to woman and in each woman across the treatment trajectory. Additional research should be conducted to better understand this symptom in ovarian cancer survivors as well as in developing evidence-based interventions to reduce or control the symptom. The Theory of Unpleasant Symptoms (Lenz et al., 1997) may prove to be a useful framework for better understanding the dimensions of this cancer treatment symptom.

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References

- American Cancer Society. (2008). *Sexuality and cancer: For the woman who has cancer and her partner*. Atlanta, GA: Author.
- American Cancer Society. (2011). *Cancer facts and figures 2011*. Atlanta, GA: Author.
- Andersen, B.L., Woods, X.A., & Copeland, L.J. (1997). Sexual self-schema and sexual morbidity among gynecologic cancer survivors. *Journal of Consulting and Clinical Psychology, 65*, 221–229.
- Bodurka, D.C., & Sun, C.C. (2006). Sexual function after gynecologic cancer. *Obstetrics and Gynecology Clinics of North America, 33*, 621–630.
- Bruner, D.W., & Boyd, C.P. (1999). Assessing women's sexuality after cancer therapy: Checking assumptions with the focus group technique. *Cancer Nursing, 22*, 438–447.
- Carmack Taylor, C.L., Basen-Engquist, K., Shinn, E.H., & Bodurka, D.C. (2004). Predictors of sexual functioning in ovarian cancer patients. *Journal of Clinical Oncology, 22*, 881–889.
- Ferrell, B.R., Smith, S.L., Juarez, G., & Melancon, C. (2003). Meaning of illness and spirituality in ovarian cancer survivors. *Oncology Nursing Forum, 30*, 249–257. doi:10.1188/03.ONF.249-257
- Hughes, M.K. (2009). Sexuality and cancer: The final frontier for nurses [Online exclusive]. *Oncology Nursing Forum, 36*, E241–E246. doi:10.1188/09.ONF.E241-E246
- Krueger, R.A., & Casey, M.A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.
- Lenz, E.R., Pugh, L.C., Milligan, R.A., Gift, A., & Suppe, F. (1997). The middle-range Theory of Unpleasant Symptoms: An update. *Advances in Nursing Science, 19*(3), 14–27.
- Masters, W.H., & Johnson, V. (1966). *The human sexual response*. Boston, MA: Little Brown and Company.
- National Cancer Institute. (n.d.). Dictionary of cancer terms. Retrieved from <http://www.cancer.gov/dictionary?Cdrid=346494>

- Neuendorf, K.A. (2002). *The content analysis guidebook*. Thousand Oaks, CA: Sage.
- Nishimoto, P.W., & Mark, D.D. (2010). Altered sexuality patterns. In C.G. Brown (Ed.), *A guide to oncology symptom management* (pp. 423–455). Pittsburgh, PA: Oncology Nursing Society.
- Patton, M.Q. (1999). *Qualitative evaluation and research methods* (2nd ed.). Thousand Oaks, CA: Sage.
- Penson, R.T., Gallagher, J., Gioiella, M.E., Wallace, M., Borden, K., Duska, L.A., . . . Lynch, T.J. (2000). Sexuality and cancer: Conversation comfort zone. *Oncologist*, 5, 336–344. doi:10.1634/theoncologist.5-4-336.
- Southard, N.Z., & Keller, J. (2009). The importance of assessing sexuality: A patient perspective. *Clinical Journal of Oncology Nursing*, 13, 213–217. doi:10.1188/09.CJON.213-217
- Stead, M.L., Brown, J.M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*, 88, 666–671.
- Stead, M.L., Fallowfield, L., Brown, J.M., & Selby, P. (2001). Communication about sexual problems and sexual concerns in ovarian cancer: Qualitative study. *BMJ*, 323, 836–837. doi:10.1136/bmj.323.7317.836
- Stead, M.L., Fallowfield, L., Selby, P., & Brown, J.M. (2006). Psychosexual function and impact of gynaecological cancer. *Best Practice and Research. Clinical Obstetrics and Gynaecology*, 21, 309–320.
- Stewart, D.E., Wong, F., Duff, S., Melancon, C.H., & Cheung, A.M. (2001). "What doesn't kill you makes you stronger." An ovarian cancer survivor survey. *Gynecologic Oncology*, 83, 537–542. doi:10.1006/gyno.2001.6437
- Sun, C.C., Bodurka, D.C., Weaver, C.B., Rasu, R., Wolf, J.K., Bevers, M.W., . . . Rubenstein, E.B. (2005). Rankings and symptom assessments of side effects from chemotherapy: Insights from experienced patients with ovarian cancer. *Supportive Care in Cancer*, 13, 219–227.
- Waterhouse, J.M., & Metcalfe, M.C. (1986). Development of the sexual adjustment questionnaire. *Oncology Nursing Forum*, 13, 53–59.
- Wilmoth, M.C. (2006a). Life after cancer: What does sexuality have to do with it? *Oncology Nursing Forum*, 33, 905–910. doi: 10.1188/06.ONF.905-910
- Wilmoth, M.C. (2006b). Sexuality. In M.L. Lubkin (Ed.), *Chronic illness: Impact and interventions* (pp. 285–304). Sudbury, MA: Jones and Bartlett.
- Wilmoth, M.C., Coleman, E.A., Wahab, H.T., & Kneisl, J. (2009). Preliminary work in validating the symptom cluster of fatigue, weight gain, psychologic distress and altered sexuality. Retrieved from http://snrs.org/publications/SOJNR_articles2/Vol09Num03Art13.html
- Wilmoth, M.C., Hester, C., & Laboy, S. (2007). Symptom cluster identification in ovarian cancer patients: A pilot study [Abstract S69]. *Psycho-Oncology*, 16(Suppl. 1), S69.
- Wilmoth, M.C., & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 29, 413–421.
- Wilmoth, M.C., & Tingle, L.R. (2001). Development of psychometric testing of the sexual behaviors questionnaire. *Canadian Journal of Nursing Research*, 32, 135–151.

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1. Women who have been diagnosed with ovarian cancer may not ask about sexual side effects of surgery or treatment at the time of diagnosis. Why do you think women and their partners do not ask those questions early in the diagnostic process?
2. What issues have the participants in this study identified as concerns?
3. What resources are available in our institution to help patients with ovarian cancer address sexuality issues?
4. What is the purpose of this qualitative study? What are the contributions of qualitative studies in general?
5. How can nurses help cancer survivors adapt to changes in sexuality?

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