

■ Article

Development of a Patient Education Resource for Women With Gynecologic Cancers: Cancer Treatment and Sexual Health

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The diagnosis of gynecologic cancer has a dramatic impact on the emotional, social, and sexual domains of a woman's life. The complexities of human sexuality are broad, particularly for people coping with life-threatening illness. Healthy sexual expression can affirm love, relieve stress and anxiety, foster hope, accentuate spirituality, and distract one from the emotional and physical sequelae of chronic illness. This article reports on the development of a sexual health education guide for women diagnosed with ovarian cancer who experienced a recurrence and were undergoing treatment. Extensive literature and the findings of this study document that patients often feel that sexuality has been ignored in their cancer care. This article provides examples of the responses from study participants and the resulting integration of those responses into the guide.

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The complexities of human sexuality are broad, particularly for people coping with life-threatening illnesses (Matzo, 2010b). Healthy sexual expression can affirm love, relieve stress and anxiety, foster hope, accentuate spirituality, and distract one from the emotional and physical sequelae of chronic illness (Matzo, 2010a; 2010b). However, maintaining sexual health along the trajectory of cancer treatment can be difficult because of the communication complexities surrounding this topic.

This article reports on the development of a sexual health educational guide for women diagnosed with ovarian cancer (OVCA). This pilot, community-based, participatory research study of women with recurrent OVCA used individual and focus group interviews to help increase understanding regarding sexual health needs and the effect of OVCA treatment on intimate relationships. Community-based participatory research is a collaborative research methodology that involves all partners in the research process and recognizes the unique strengths that each brings (Wallerstein & Duran, 2006). This methodology allowed

for the combination of knowledge and action, with the goal of achieving social change to improve health outcomes.

Background

OVCA is the most common cause of cancer death from gynecologic tumors in the United States with a lifetime risk of 1 in 70 for a woman developing epithelial OVCA (American Cancer Society, 2014). Early disease causes minimal, nonspecific, or no symptoms; therefore, most cases are diagnosed in the advanced stage (Woodward et al., 2007). Because prognosis of OVCA is closely related to its stage at diagnosis, overall survival for patients remains poor, with a five-year survival rate of less than 30% and an overall survival rate of 15%–30%; in addition, about 70% of OVCA will recur at some point (American Cancer Society, 2014). Patients may suffer from progressive disease, leading to bowel obstructions, pain, cachexia, malignant ascites, and poor overall quality of life (QOL) (Herzog & Pothuri, 2006). Many investigators have evaluated sexuality concerns in relation to QOL (Matzo, Ehiemua

TABLE 1. Sample Characteristics (N = 16)

Characteristic	\bar{X}	Range
Age	56	34–70
Age at diagnosis	49	31–68
Characteristic	n	
Race		
Caucasian	11	
Hispanic or Latino	5	
Highest degree		
High school	7	
Graduate or professional school	9	
Marital status		
Married	9	
Single	5	
Widowed	2	
Religion		
Protestant	7	
Catholic	5	
Other	4	

Pope, & Whalen, 2013; Robinson & Molzahn, 2007; Rummans et al., 2006), recognizing that many treatments for serious illness have a potential negative effect on sexual health (e.g., pain, fatigue, loss of interest, changes in body image) (Cort, Monroe, & Oliviere, 2004). Sexual dysfunction for cancer survivors may result from various cancer treatments, such as surgery, radiation therapy, chemotherapy, hormonal manipulation, and cytostatic medication (Cort et al., 2004). In addition, psychological distress experienced by the patient or her partner during diagnosis and treatment can impair a healthy female sexual response cycle (Krychman, Pereira, Carter, & Amsterdam, 2006).

Communication

Many studies regarding sexual health document seemingly universal themes related to communication about sexuality and intimacy between patients and their healthcare practitioners (HCPs). These tend to fall into two categories: need and interaction.

Patients

Patients have questions and concerns about their sexual health that they would like to talk about with their HCPs (Matzo & Hijjazi, 2009). However, with regard to communication, patients indicate that they do not initiate these conversations because (a) they think HCPs are too busy; (b) they don't want to bother the HCPs; (c) they think that they should just be "grateful to be alive"; (d) they think that sexual health is a private matter (Kralik, Koch, & Telford, 2001); or (e) they think that if something could be done about the situation, the HCPs would raise the issue (Matzo & Hijjazi, 2009).

Healthcare Practitioners

Of equal interest is the interaction between the HCPs and the patient. HCPs have indicated that the reason sexual health

is not routinely assessed is because (a) they believe the patient will bring it up if it is a concern; (b) the perception that people are "too sick" to be sexual (Caruso-Herman, 1989); (c) lack of their own comfort with the topic (Caruso-Herman, 1989; Dunn, 2004; Epstein & Street, 2007; Grigg, 2002; Wilmoth, 2006); (d) preconceived ideas, attitudes, and values regarding sexuality (Grigg, 2002; Wilmoth, 2006); (e) perceived lack of time for this conversation (Dunn, 2004); and (f) the feeling that "more important" issues need to be addressed (Ananth, Jones, King, & Tookman, 2003; Smith, 1989). In addition, sexual health is not emphasized in HCPs' professional education (Caruso-Herman, 1989; Dunn, 2004; Grigg, 2002; Institute of Medicine, 2007; Penson et al., 2000). The outcome, in relation to sexual health, can be a lack of communication, resulting in a conspiracy of silence and a dominant communication pattern of evasiveness (Grigg, 2002).

Findings from research studies regarding survivorship indicate that compromised sexuality and intimacy, common in cancer care, can lead to diminished QOL. In 2009, 1.2 million people were newly diagnosed with cancer, with breast and prostate cancers most prevalent, and about half of the women who had long-term treatment for breast and reproductive organ cancers reported long-term sexual problems (Howlader, Noone, & Krapcho, 2011). Insufficient data exist regarding what information patients want from their HCPs regarding sexual health, when they want help, its degree of value to them, and how they would find this help to be of most use. To date, little empirical data inform HCPs of this information, how to assess for it, and how to care for people with cancer regarding sexual health (Matzo et al., 2013). The findings from the current study begin to address a gap in the literature, and the *A-Z Guide* offers women an empirically based education resource.

Methods

This study focused on women diagnosed with OVCA who experienced a recurrence and were undergoing treatment. The researchers received institutional review board approval, and eight women were interviewed regarding their sexual health concerns. The interviews were recorded, transcribed, and analyzed using qualitative content analysis methodology (Elo & Kyngäs, 2008; Neergaard, Olesen, Andersen, & Sondergaard, 2009), which involved a dynamic analysis of verbal data directed toward summarizing its informational content. The investigator and the research team reviewed the transcripts and identified key themes throughout the participant interviews. The qualitative data then were used to formulate the focus group questions.

An additional eight women took part in a focus group, which also was recorded, transcribed, and analyzed using the same methodology as the individual interviews. The women were asked to discuss what information they received regarding sexual health, identify if there were gaps in the information, and explain what they perceived to be the ideal timing for receiving the information. The transcripts documented participants' concerns and experiences since diagnosis regarding their sexual health. Qualitative analyses, including participants checking the findings to determine if the identified themes were an accurate representation of

TABLE 2. The A–Z Guide: Addressing Sexual Health During Cancer Treatment

Title	Interview Quote	Content Quote
A afraid to ask about sex	What do I do with this? And this? And this? . . . I would have been able to plan and think about, and just kind of know what the likely impact of this would be on our sex life.	This booklet is an attempt to answer some of the questions you may have, and to anticipate some you may not have yet thought of. Feel free to blush or giggle in the naughty parts.
B oth of you	I would like him to come and talk more than anything. I think just a really open conversation.	Your partner may be afraid of adding to your burden by discussing fears with you, and you may not wish to burden him/her with your sadness or uncertainty.
C ancer treatments	But, you know, you have to work at it.	Be willing to accept a new normal and be patient with yourself as you work toward your sexual goals.
D ilators and devices	It's not as much fun.	So, don't be intimidated and just lube up and get started!
E xhaustion and exercise	The safest and most secure place of all was laying my head on my husband's chest and just wrapping myself, kind of in a ball or something, and just lying in there.	You may not have the kind of energy you are used to during your treatments, but that doesn't mean that your relationship should be put on hold.
F ear factor	They're scared that they're gonna hurt you. So, I think the intimacy is gone when you are going through treatment. But then afterwards, you know, . . . kind of finding your way back to it is kind of hard.	Your partner may fear hurting you.
G oing "downtown"	I enjoy giving my husband pleasure.	Don't be afraid to explore.
H ot flashes	I woke up going through the change immediately.	They can be particularly severe in women who have sudden menopause because of their cancer treatment.
I ntercourse	It was more painful, and we had to really work at it. And my husband, at first, did not really understand it.	A lot of the anxiety associated with getting back to love making can come from fear of disappointing your partner if you get started and aren't able to continue.
J oin a support group	I think it would be helpful to have like a class or a support group or something where you could go as a couple, and talk about it.	. . . most women find very good practical help from other women who are facing, or have faced, these exact issues before. So, find a support group, join it, and share openly.
K egel exercises	Well, I miss feeling like it used to feel.	There is a lovely side benefit to doing Kegels. They may actually increase your sexual pleasure (whoo-hoo!).
L aughter	I would much prefer to read a book because that's down time and calm instead of trying to feel really fired up and ready to go. So, and I will say to him, "You know, this is only for you this time . . . it'll be my turn one of these days," and he says, "I'm waiting." So, we do laugh a lot about where we are in our life.	Why not take the attitude that if you can laugh at yourself, you will at least go through all this with a smile on your face? Sexuality is serious business, but it doesn't have to be somber business. Why not let it be monkey business?
M oisture	I know with me and my husband we're having to, you know, to use KY and stuff like that to, you know, make it so it doesn't hurt me.	The important thing to remember is that your discomfort will be greatly reduced with plenty of lubricant. Remember, without it you lubri-can't, but with it, you lubri-can!
N ight time is the right time?	I'm tired most of the time. And that, of course, has a big impact on sexuality. . . . A lot of nights I lay down, and we just curl up together and go to sleep, and that's just it.	There is nothing that says you can only make love after dark. That's why they make curtains!
O pen communication	My husband's idea of intimacy is having sex. He does not initiate affection—he initiates sex.	You are going to have to tell your partner what you are ready for and when. Don't expect them to guess; spell it out.
P atience	I think to give yourself a break, both mentally and physically.	You aren't going to get better all in one day.

(Continued on the next page)

TABLE 2. The A–Z Guide: Addressing Sexual Health During Cancer Treatment (Continued)

Title	Interview Quote	Content Quote
Q uickies	I think it might have to do with your own attitude about it too.	Don't underestimate the intimacy you can share in a shorter period of time.
R eaching orgasm!	Orgasms are not nearly as strong as they used to be, and it's a lot harder for me to reach orgasm than it used to be.	Your intensity of orgasm may change, particularly if you have experienced vibration of the uterus with your past orgasms. Because your uterus may no longer be there, that component of your orgasm will obviously change.
S olo satisfaction	Based on opening up and letting myself into a new relationship and you know, not knowing where my health is going . . . getting involved with somebody that I may not be able to have a long-term relationship with, if I'm not able to treat this, you know?	Some partners may reject you because of your cancer and surgery, but there are partners who will reject you for much less, so try to be brave, honest, and open. If they can't deal with someone who has health problems, they wouldn't be a good partner in the long run anyway. Nobody's continued health is guaranteed.
T ouching	I've chosen relationships with men and women, of mostly my married friends. They still provide me that comfort and support; it's just not in a sexual relationship.	If you aren't in a relationship, hug people.
U se it or lose it!	It's more mature, and we discuss the past as a child would discuss their childhood. Remember how we behaved when . . . why don't we do that now?	Whatever age you are, ask yourself if you are ready to give up being a sexual person for the rest of your life.
V ibrators and sex toys	It's not necessarily just the act of pleasure, as much as it was.	You need to floss to keep your mouth healthy—you need to work at recovering your sexual health just as religiously.
W igs, wigs, wigs!	I had worn a blond wig. I'm brunette with gray, normally	Thanks to wigs, you can offer your partner lots of different people without ever straying!
X plore New Options	He's been really supportive, okay. So . . . and that's what makes me feel even worse because . . . he's always liked having sex. It's been almost two years.	Play footsie during breakfast. Slip a sexy note into the sports section before your partner leaves for work, so that it will fall out over coffee at his or her desk. Take new opportunities to express your love and foster intimacy to replace old intimacies during this time. The options for this are limited only by your imagination and creativity.
Y ou are more than just a patient with cancer!	We didn't want cancer to define us as a couple, how we played or worked or worshiped, or whatever; although, it did.	We all have lots of hats, and this should not define who you are. It is just something you are going through, like a tax audit, only slightly less fun.
Z a-za-za-zoom!!	Because I remember, gosh, I think it was maybe a day or two after my surgery, and I still had a tube drains hooked up and all that stuff, and I was like, this is how I'm going to make my statement to my husband, that I'm not going to let cancer take us over. I actually made the moves on him. And he was totally shocked . . . and I'll tell you, from my experience that empowered me so much. It's kind of like, ha, cancer, you're not taking this. And so, in a way, you know, I have to say I wasn't really exactly wanting it, you know, I wasn't in the mood or anything. But this was more of a conscious decision that I was looking cancer in the eye and saying, "You're not doing this."	You get to say what your future sexual health will be. Cancer can take a lot of things from you, but good sexual health doesn't have to be one of them. Now go out, and make the rest of your life exciting and sexy!

their experiences, identified two primary areas of concern regarding changes in sexual health, lack of education and communication regarding what could be expected following their cancer treatments, and what to do to manage symptoms. In response to the participants' identified need for information, the authors of the current article used the women's responses from the individual and focus group interviews to

develop the sexual health education booklet, *Everything Nobody Tells You About Cancer Treatment and Your Sex Life: Your A-Z Guide* (<http://kanwa.org/sexual-health/a-z-guide>), using systematic conceptualization, construction, and evaluation. Participants were given the guide and asked to edit and evaluate it regarding the content that they identified as being important for other women to know. They also were asked to

evaluate the tone and relatability of the guide, and the guide was edited accordingly.

Findings

The participants were primarily Caucasian, aged 56 years, and married (see Table 1). They were, on average, aged 49 years at the time of their OVCA diagnoses.

Education

The women reported that they wished they had been better informed about what to expect regarding possible sexual health alterations, so that they could be more proactive in sexual health maintenance following their cancer treatments.

I prefer that, at least, I have information, so the more information I have, the more I'll be [informed], if it's online, or if it's a speaker, or whatever. . . . I just remember getting all the information I could; however, information about intimacy was very limited out there. You know, could you have sex, could you not? What was viable [and] what wasn't after surgery? Frankly, no one ever talked to me about that, if you want to know the truth. Anything that I did find, I pursued it and looked for it, but it was a bullet point, or two or three in a brochure that was given to me by a nurse or a doctor or whoever. That's all I got . . . a couple of bullet points, and that's really not enough.

The women explained that the literature available to them in their oncologists' offices did not meet their education needs and, in addition, it was given to them too late after their diagnosis.

The participants were asked in the pilot study what they thought would have been helpful for sexual health as they navigated their cancer therapy. The women verbalized a need for a less academic sexual health cancer guide.

Well, why couldn't you put [out] a pamphlet? . . . Something that you could feel comfortable talking to someone [about] (Woman 1). Yes! (General enthusiastic agreement).

Gotta read something while you're [in treatment]. [The pamphlets] should be everywhere!

What about the husbands or boyfriends who don't really know too much, and the wife [won't] discuss it with them? . . . They're going to want to pick [a pamphlet] up.

A primary barrier regarding written information about the effects of cancer and its treatment is that the person for whom it was intended often cannot understand it (Burhansstipanov & Olsen, 2004). Typically, educational materials are written at a grade 12–14 reading level, whereas the general population reads at a grade 5–7 level (Bardarudeen & Sabharwal, 2010). In addition, the wording and sentence structure may not be culturally sensitive or easy to understand (Burhansstipanov & Olsen, 2004). The *A-Z Guide* has a Flesch Reading Ease, a formula to assess the difficulty of a reading passage, score of 68.3 (range = 0–100; 90–100 equates to reading level at age 11 years) and a Flesch-Kincaid Grade Level of 7.6, which provides a standardized way to judge the readability level of a document

Implications for Practice

- ▶ Use the *A-Z Guide* in patient sexual health education and support.
- ▶ Treat patient concerns regarding sexual health in the same manner as any other symptom.
- ▶ Empower women to maintain their sexual health by using the *A-Z Guide* to normalize concerns and answer questions.

(Flesch, 1948). Together, those scores indicate that a seventh grader would be able to read the document.

The guide was designed to address an unmet need regarding the availability of a short, comprehensive, and user-friendly guide that offered women specific information regarding maintaining sexual health after their cancer diagnosis. This article documents examples of the responses from the study participants and the resulting integration of those responses into the *A-Z Guide* (see Table 2).

Communication

Many cancer survivors say they were not prepared for the changes in their sex lives. Cancer and its treatment can lead to sexual and reproductive dysfunction, loss of self-esteem, depression, and the disruption of supportive and crucial relationships. Anticipation and validation of patient concern also can alleviate emotional suffering (Matzo et al., 2013; Robinson & Molzahn, 2007). The *A-Z Guide* was written as a resource for women to help them anticipate the sexual health changes their bodies may experience throughout cancer treatment and validate their experiences throughout survivorship.

Implications for Nursing Practice

The most effective communication addresses different types of unmet patient needs at each stage of illness. Communicating with patients with cancer is a dichotomous situation in that the disease is life-threatening, while, at the same time, potentially treatable or curable (Epstein & Street, 2007), causing uncertainty and stress for the patient. Because patients expect to participate in their health care and take responsibility for their health (Waddell & Davidson, 2000), the traditional paternalistic, authoritarian model of communication is becoming less efficacious. Two factors influencing healthcare consumers are the mass media and the Internet. This patient-driven approach challenges traditional communication models, and nurses should be prepared to offer education resources to patients on topics that are important to them. Nurses should assess and manage sexual health concerns in the same manner in which they address pain, fatigue, or any other symptom. Normalizing concerns and answering questions, along with using the *A-Z Guide* as an educational resource, helps empower women to maintain their sexual health.

Oncology nurses have been at the forefront of advocacy for attention to sexuality and overall QOL concerns. Continued pursuit of this topic will be a valuable contribution to patients

and their partners. Sexual health, including expressions of love and closeness, is a human need throughout the trajectory of illness.

Conclusion

Sexuality remains a key aspect of QOL. Extensive literature and the findings of this study document that patients often feel that sexuality concerns have been ignored in their cancer care. The *A-Z Guide* is a resource that can be used in patient education and support. Future research is needed to test new educational approaches by adapting and using resources such as the *A-Z Guide* in diverse cultures and to address sexuality needs in men.

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