Life After Cancer: What Does Sexuality Have to Do With It?

Margaret Chamberlain Wilmoth, PhD, MSS, RN
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When I started my career, I had no idea that sexuality would be a major focus of my work as an educator and researcher. I am not sure how the effects of illness and medical treatments on sexuality became a focus of much of my work, but I am sure that an elective I took in college started me down this path. As a senior, I had a choice of taking a course on death and dying or a course on human sexuality. I chose the latter. That one decision shaped the future course of my nursing career, although I did not know it at the time.

Peggy and Rudy—two patients with head and neck cancer for whom I cared in the mid-1970s—are the reason that I began to ask myself, “Just what does sexuality have to do with life after cancer?” and “Why should I, as their nurse, care about their sexuality?” Peggy stamped her feet one morning while I was making her bed and helping her with her morning care. She was obviously upset and said that she could no longer kiss her husband since having part of her jaw bone and tongue removed. Her nasogastric tube kept getting in her way when she tried. She was not even sure her husband still found her attractive. I did not know what to say and I went away, confused and concerned, asking myself, “Was it my responsibility as her nurse to help her deal with these issues? Do these concerns fall under the label of sexuality? When should we, the nursing staff, become involved in addressing sexuality?” Unfortunately, there was no one on our staff to go to with my questions.

Many patients whose treatments have permanently altered the way that they are able to express their sexuality might say that there is no such thing as sexuality after cancer. Others might say that cancer treatment had little to no effect on their sexuality and that life really has not changed too much.

What is sexuality? The “S” word means different things to different people. It is a highly complex construct that permeates our entire beings as men or women. Sexuality encompasses all that we are as male or female—our gender identities and roles, our sexual orientations, our feelings of pleasure and intimacy, and our reproductive processes. We express our sexuality in many ways, including our thoughts, dress, attitudes, values, roles, and relationships. I have talked with patients diagnosed with breast cancer who have defined sexuality as “everything that makes us women.” Men with cancer, while not as expressive with their words, are concerned about their ability to have satisfactory erections and ejaculations (Canada, Neese, Sui, & Schover, 2005; Schover et al., 2002; Smith et al., 2000).

A person’s views of sexuality often are framed by his or her gender identity, culture, religion, and life experiences. Many times, we confuse sexuality with sex—one is very broad and encompasses all that makes us male or female, whereas the other is shorthand for a specific sexual activity. In many ways, sexuality is like pain or fatigue: It is what a person says it is. Our attitudes about sexuality often are defined by age. We consider someone to be too young or too old to have sexuality or to be sexual. But does a person stop having sexual thoughts and feelings just because he or she turns a certain age?

When I was collecting data for my master’s capstone project, a physician said to me, “Peggy, just why are you asking our head and neck patients about sexuality? They are all over 60 and are too old for that.” I wonder how many times we let our preconceived ideas, attitudes, and values interfere with the care we provide to our patients.

My project focused on body image and sexuality in patients with head and neck cancer. I wanted to find out how their treatments had affected them in those areas. When I interviewed Rudy for my project, he told me that he had lost his girlfriend, that he could no longer please her. He said he did not know whether his problems were related to the treatment we had given him two years earlier. He asked me what had caused him to stop being able to be a man. By that time, we were both in tears; he was relieved that someone had finally shown an interest in him and the issue of sexuality, and I was in tears because I had been one of the nurses who had cared for him two years earlier and had failed to talk with him about his cancer, his alcoholism, his cancer treatments, and his sexual health. I also realized how important it is for partners to...
discuss their concerns about their sexuality with one another and how nurses can help facilitate such discussions.

Nurses, particularly oncology nurses, like to say that we provide holistic care, and our standards of practice (see Figure 1) speak to that. Yet many of us fail to address all of the standards, including the one on sexuality. I know I did when I was a staff nurse, even though I had taken that elective on sexuality, until I met Peggy and Rudy. Practice standards address the need to assess patients’ sexuality, as well as the outcomes nurses can help patients and their partners achieve. Thus, the standards of practice put discussions of sexuality squarely in the area of nursing responsibility. Many of us still say, “Talking about sex with my patients is not part of my job”; “It’s too personal, and it has nothing to do with the nursing care they need”; “I never learned about this in school”; or “I’ll offend my patients if I start talking about sex.” Yet it is important to realize that many patients want to know about the sexual consequences of treatments and medications. We cannot count on their doctors to have discussed such issues with them. Unless nurses signal their willingness to discuss such topics, most patients will hesitate to bring them up and will continue to wonder, and perhaps worry, about the effects their illnesses and treatments will have on their own sexuality and their relationships with their significant others.

Of course, it is equally important to provide patients with the answers they are seeking. One woman I interviewed explained,

I was having trouble with hot flashes and vaginal dryness after my chemotherapy, so I decided I’d ask the female intern about how to deal with this. When I told her my problem, she said she would order some eye drops for my dry eyes.

### Implementing Standards of Care

Why should nurses care about their patients’ sexuality? Our standards of care (Brant & Wickham, 2004) promote the notion of holistic care, and that includes ensuring that our patients have the knowledge they need about the side effects of cancer treatments on their sexuality. How then do we go about implementing this standard? There are four key processes that nurses must address first: (a) achieving comfort with your own sexuality and with talking about sexuality; (b) gaining sufficient knowledge about sexuality, illnesses, and treatments that affect sexuality; (c) honing effective communication skills; and (d) identifying practitioners who can help you incorporate sexual healthcare into your practice.

**Achieving comfort** with your own sexuality and, more importantly, comfort when talking about sexuality is a process of self-exploration. One way to achieve a comfort level is to attend a Sexual Attitude Reassessment Seminar. Universities (see Figure 2) usually hold such seminars over a period of two or three days. They are intense sessions designed to assist attendees in examining their own attitudes, values, and beliefs about sexuality. Attendees often identify areas of conflict in attitudes and values. The programs usually combine lectures and media presentations with small group discussions on multiple sexuality-related topics, including childhood and adolescent sexuality, sexual myths, masturbation, fantasy, relationships, communication, intimacy, sexual variations, sexual lifestyles and values, sexual identity, sexual abuse, sexual dysfunction, sexuality and disability, and aging.

Another option for increasing comfort with sexuality is to engage in a program of reading. This can be done on your own or, even better, with several colleagues in the form of a book club. You and your colleagues can discuss readings about sexuality in a quiet and safe environment. This would allow you to learn from one another and to have your values and attitudes challenged by those you respect and trust. Consider forming a book club, journal club, or some other type of discussion group with your colleagues at work. You may experience some resistance and embarrassment at first, but I think that you will find it to be a very rewarding and informative endeavor.

The next phase of the process is to **increase your knowledge base** about sexuality and the impact of cancer and cancer treatments on sexuality, as well as the effects of other diseases on sexuality. Again, a unit-based journal club is a good way to ensure that everyone on the unit is engaged in the process. You can use one of several excellent cancer nursing textbooks available—they each contain a chapter on sexuality, body image, and related topics—as a starting point. Invite the physicians with whom you work to share their knowledge on the sexual implications of the diseases, procedures, treatments, and medications that most of their patients experience. The clinical nurse specialists, social workers, and pharmacists who work with you could do the same. You also can use a journal club as an opportunity to decide what patients need and come to a group decision with your coworkers about how you want to approach sexuality with your patients. Remember, too, that patients often have other chronic health problems, such as diabetes or multiple sclerosis, each of which has its own implications for sexuality and sexual functioning.

### Assessment

The oncology nurse

- Identifies past and present sexual patterns and expressions.
- Discusses the effects of disease and treatment on body image.
- Describes the effects of disease and treatment on sexual function.
- Discerns the psychological response of patient and partner to disease and treatment.

**Outcome Identification**

The patient and/or family

- Identifies potential and actual changes in sexuality, sexual functioning, and intimacy related to disease and treatment.
- Expresses feelings about alopecia, body image changes, and altered sexual functioning.
- Engages in open communication with his or her partner regarding changes in sexual functioning or desire, within a cultural framework.
- Identifies personal and community resources to assist with changes in body image and sexuality.

**Figure 1. Statement on the Scope and Standards of Oncology Nursing Practice Related to Sexuality**

*Note. Based on information from Brant & Wickham, 2004.*

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dyspareunia, whereas intensive therapy is indicated for those with serious sexual issues and is conducted by certified sexual therapists (Wilmoth, 2006).

Sexual assessment ensures that patients receive the care to which they are entitled, provides a baseline of their knowledge and understanding of their disease and treatment side effects, and, most importantly, serves as a way for us to “give permission” to our patients to discuss their concerns about sexuality with us. It is also important to understand the differences between a screening sexual history, a sexual assessment, and a problem-focussed sexual history and when each of them is indicated.

A screening sexual history can be taken by medical or nursing staff and should be done for most patients in the context of the general history and admission assessment. A sexual assessment is similar to a screening sexual history but is performed more frequently by nurses in the context of educating patients about their illness and treatment implications for sexuality (Lion, 1982). A problem-focused sexual history usually is done when a patient presents with a specific sexual problem or sexual dysfunction and includes a medication history. This is not the type of history that most nurses conduct and is not indicated in most nursing situations (Carpenito-Moyet, 2004; Siemans & Brandzel, 1982).

Most nurses are skilled at communicating: communication and critical thinking are two of our essential professional skills. Communicating about sexuality is not much different from talking about any other sensitive topics that we discuss with our patients, such as bowel and bladder habits or death and dying. Remember that communication is both process and content and comprises verbal and nonverbal components. The nonverbal part of communication is at least as important, if not more so, than the verbal part. For instance, if you tell a patient who just had disfiguring surgery that he or she “looks great” while grimacing at his or her appearance, your patient will focus on your negative reaction. Similarly, some patients may have made lifestyle choices that differ from our own; it may be difficult to be fully present and open to seeing their points of view or respond nonjudgmentally to how they express their choices. As professionals, nurses need to be alert to unconsciously disqualifying or dismissing patients’ rights, opinions, and experiences that are keys to their behavior and its impact on health.

A technique I use to help students achieve a comfort level with sexuality is to ask them to do a sexual assessment with an individual of their choosing. I challenge them to identify an area of sexuality with which they might have a high level of comfort—for example, homosexuality—and to interview someone who might test their preconceived values. Building on some sample questions, students are required to develop their own assessment questions, conduct the interview, and provide a confidential write-up and analysis of data from the assessment. They also have to describe what they learned about themselves from the assignment. Most students have found it to be an extremely beneficial learning experience. Although it may produce anxiety, it also results in a great deal of self-exploration and growth.

The principles associated with discussing sexuality are really no different than those associated with any sensitive discussions with patients. They include providing privacy as much as possible; ensuring confidentiality, as appropriate; setting judgments aside, assuming that everyone has some degree of sexual experience; and granting patients the right to refuse to answer any questions you ask. As with any interview, ask only what is necessary, letting patients know that discussions about treatment and sexuality may occur multiple times over the course of their treatments. Start with less intrusive questions and move to those that are more direct, using open-ended questioning (see Figure 3). Clarify terms, and use the simplest words possible. For example, I once asked a patient about menopause after her cancer treatment. As she answered, I realized that she did not understand the term—she confused the word “menopause” with “menstruation.” I should have validated that she understood me and, if needed, explained further using vernacular terms such as “the change” or “after your months.” Use open-ended questions, and move from less sensitive questions to those that are more sensitive. Strive to be warm, open, unembarrassed, and reassuring—and don’t apologize for interjecting a little humor into the conversation to cut the tension.

Two other communication techniques commonly used when talking about sexuality are “unloading” and “bridge” statements. Unloading lets patients know that others have similar concerns and that any questions they might have are within the “norm.” Examples of unloading questions are

• Many women and men after being treated for cancer have concerns about their sexual functioning. What are some of your concerns?
• Some women find they have vaginal dryness when they try to have intercourse after finishing chemotherapy. What has your experience been with vaginal dryness since finishing chemotherapy?

Bridge statements facilitate the transition from easy to more uncomfortable topics, assist in incorporating sensitive topics into interviews, help interviewers gain valuable information, and legitimize inquiries. Examples of bridge statements include

• Many active people like yourself want to continue having a close sexual relationship but don’t feel that it’s a perfectly normal thing to do. How do you feel?
What has your surgeon told you about the effects of your surgery on having sex?

Now that you are aware, comfortable, and knowledgeable, what comes next? I believe that the presence of nurses who consistently incorporate sexuality into their practice is critical to ensuring that patients have their sexual concerns addressed. Role models (i.e., staff members who routinely include sexuality in their practice) can be very helpful to nurses just beginning to broach such topics with patients. Role models are comfortable and secure and consider discussing sexuality to be an important part of their nursing role. Such nurses can serve as consultants for others on the unit and may be identified through informal or more formal recognition designations. Role models—or expert nurses—can role-play conversations involving sexual history taking and assessments, model educational discussions with patients and partners, and champion the standards of practice.

I was teaching some medics one summer, and one of them was taking care of two gentlemen who had had transurethral resections of the prostate for benign disease. I asked the student how he had assessed the gentlemen’s knowledge about the effects of their surgery on their sexuality. He looked at me like I was from another planet and was quite anxious about having to talk about “sex” with his patients. I offered to role-play how to go about it, and we went into the patients’ room. I pulled the curtain closed between the beds and sat down. I asked the gentleman what his surgeon had told him about how the surgery might affect his sexuality. He popped up in bed. At the same time, the other guy pulled back the curtain, and they both said, in unison, “He told me nothing, but my wife is dying to know!” We proceeded to talk about how the procedure affects ejaculation but not potency; both men were quite relieved and seemed much less anxious, and their wives thanked us for talking with their husbands.

Increasing Knowledge About Sexuality in Health and Illness

The first requirement to being knowledgeable about sexuality is to have a solid biophysiological knowledge base about sexual functioning and the anatomy and physiology related to sexuality. Unfortunately, gaining the necessary depth of knowledge that nurses need in the area of anatomy, physiology, and pathophysiology is not as easy as picking up a single textbook. Nurses need to have an understanding of anatomy and relevant neuromediators and hormonal mediators, as well as the nervous and vascular system pathways required for sexual functioning. The information can be found in any anatomy and physiology text, but because of the variety of systems that affect sexual physiology, the information is not found in any one chapter but across several chapters. Clinical nurse specialists can be very helpful by pulling the information together for discussion. Another source of consolidated information on sexual anatomy and physiology is textbooks on sexuality that are geared toward college-level students. Although the texts do not provide the depth of information needed by nurses, they do provide a general overview, which might be helpful initially to reduce staff discomfort in talking about sexuality.

One way to introduce the topic is through use of the sexual response cycle as Kaplan (1979) envisioned it. In her model, the sexual response cycle consists of three phases: desire, arousal, and orgasm. Desire, or libido, is interest in sexual activity and is the most complex of the phases and probably the least understood. It is mediated by luteinizing hormone and testosterone and either enhanced or modulated by dopamine or serotonin. This explains why the serotonin reuptake inhibitors commonly prescribed for depression have a negative effect on sexual interest. Arousal, or excitement, is mediated by the parasympathetic nervous system, with key centers located at T11/L12 for psychic arousal or S2-4 for somatic response. Physiologic signs of arousal are exhibited by the muscular and vascular systems; muscle tension increases, as does arousal; and vasocongestion is seen in the target organs as arousal continues. Thus, the swelling in the labia and clitoris in women and the swelling of the penis in men are manifestations of arousal and are key events that must occur for orgasm to take place. Orgasm is the release of the buildup of muscle tension and vascular congestion and is mediated by the sympathetic nervous system.

Nurses also must have a solid knowledge base about the effects of cancer and its related treatments on sexual functioning. All of the available cancer nursing texts are excellent sources of information. However, drugs and other treatments used to fight cancer change frequently; thus, it is important to regularly ask pharmaceutical representatives about the effects of new drugs on sexual physiology or to discuss with surgeons the effects of new techniques on the nerve innervation responsible for arousal and orgasm. For example, knowing what effect a gynecologic surgical technique has on the area where the G-spot is located and being able to incorporate that into the information you share with patients can have a profound effect on women’s ability to adjust to changes in sexual arousal, in their relationships with their partners, and in their quality of life. I remember the time I spoke with a woman who had had a vaginal reconstruction about her struggles to adjust to the new part of her body. A key to her recovery was the nurses who provided her with the education and information she needed to adjust and the validation that she received from them that her sexuality was an important part of her recovery.

One important caveat to talking about sexuality with your patients is that most of the conversations will happen serendipitously, in an informal, unexpected manner. You should be sensitive to hidden clues in conversations with your patients that may mask sexual concerns and follow up with open-ended questions.

Conducting Research

When I embarked on my program of research in the area of sexuality, I was fortunate to have two mentors who provided me with the encouragement I needed to stay focused. Dr. Susan Hetherington Fischman encouraged me as I worked on my master’s degree project and was a coauthor on my first manuscript on sexuality in patients with head and neck cancer. I think the article is still one of the few addressing such concerns in that patient population. Later, as junior faculty members at the University of Delaware, Dr. Julie Waterhouse and I were fortunate to have Dr. Rosalyn Watts from the University of Pennsylvania encourage us as we continued our work. We were searching for a sexuality tool to use and had heard about Dr. Watts’ work; we were quite amazed and honored at her willingness to share her tool after a short phone conversation. As two neophyte researchers who had not yet started our doctoral work, we were overwhelmed.
Despite Dr. Watts' generous offer, we decided to develop our own questionnaire, the Sexual Adjustment Questionnaire (SAQ) (Metcalf, 1990; Waterhouse & Metcalf, 1986), for our study of patients with head and neck cancer. To determine the psychometric properties of the SAQ, we administered it to healthy individuals and patients. We quickly learned that many people found cancer and sexuality to be unacceptable topics for research. We received notes from the healthy subjects who were insulted that we would send them a questionnaire that involved cancer and sexuality. Appreciative comments from the patients with cancer were very heartwarming and negated any thoughts we might have had about giving up. Our hard work and perseverance eventually paid off when the SAQ was revised by Dr. Deborah Watkins-Bruner (Watkins-Bruner et al., 1995) and adopted for use by the Radiation Therapy Oncology Group in its clinical trials.

Conducting research in this arena requires a determination of which dimension of sexuality is of interest: psychological, relationship, or physiologic. Perhaps you are more interested in sexuality from the perspective of satisfaction. Defining the dimension you want to study and the question you want to answer will lead you to the related concepts and variables. With those in mind, you are ready to review existing tools. It is always better to use an existing tool, even though I did not take this excellent advice. I have learned that tool development becomes a lifelong endeavor that never answers your original question. It is important to be sure that the tool you select is consistent with your definitions, has reasonable psychometric properties, and is sensitive in the population you wish to study. Instrument development is painstaking but critical work; otherwise, you may end up having spent a lot of time and money collecting data that cannot be analyzed to answer your research question. An excellent source that contains a compilation of sexuality questionnaires is Frank-Stromborg and Olsen's (2004) book *Instruments for Clinical Health-Care Research*.

When I did my doctoral work, I wanted to develop a sexuality measurement that was grounded in a nursing theory. I owe Dr. Jacqueline Fawcett and Dr. Florence Downs my gratitude for guiding me through the process as I developed a tool grounded in the Johnson Behavioral Systems Model. The Sexual Behaviors Questionnaire development and psychometric testing became my doctoral dissertation. Once again, I was reminded that sexuality is a sensitive topic when I began to collect data. Doors that I thought were open for subject recruitment suddenly closed, and unexpected others were surprisingly opened. During that time, I moved to the Kansas City, MO, area, where the commander of my Army Reserve hospital was a prominent physician. Thanks to Dr. Charles Van Way, I was successful in recruiting the subjects I needed for my research. Comments that subjects added to the end of the questionnaire reminded me again of how rarely we address the sexual implications of cancer treatments with patients. One woman wrote, "After a radical and phenylalnine mustard chemo, I have no sexual desire. I have consulted my surgeon, gynecologist, and internist—no answer and not much interest."

"Just Do It"

You are now armed with comfort, the necessary communication skills, and sufficient knowledge to include sexuality in your nursing practice. Now comes the hard part—"doing it." Research has shown that nurses are hesitant to discuss sexuality for fear of offending their patients, but patients expect us to educate them about the sexual implications of medications and treatments (Matocha & Waterhouse, 1993; Waterhouse & Metcalf, 1991; Wilson & Williams, 1988). I am continuously reminded of this as I continue my research.

A small article that was written about my research in my local newspaper ended with an invitation for breast cancer survivors who wanted to be interviewed for my latest project to call me. I had 40 calls in two days. The majority of the callers said, "I thought I was the only one who was having these (sexual) side effects from treatment."

I have a friend who is a 16-year survivor of breast cancer with three recurrences. She amazes me with her resiliency and continues to challenge me to stay the course in this area of study. We recently talked about the deep effects her treatment has had on her sexuality, her decision to take testosterone injections to give her some semblance of desire, and the deep aching and fatigue that she continues to experience for which no one has any answers. The conversations continue to raise questions for my research and reinforce the findings of the Institute of Medicine's report that survivors are "Lost in Transition" (Hewitt, Greenfield, & Stovall, 2006).

Two mentors were key in guiding me down this path and encouraging me to stay the course: Susan Hetherington Fischman, who supported my initial work, both as a master's student and as a peer educator in the Intimate Human Behavior course she coordinated at the University of Maryland, and Dr. Rosalyn Watts at the University of Pennsylvania, where I did my doctoral work. I also need to thank the many students whom I have taught over the years. I hope I opened some "closed" doors in their lives and that they have gone on to consider their patients' sexual concerns as they provide nursing care. There are numerous others who have supported my work, including my parents, but I owe my deepest gratitude to the male and female patients and research subjects who have shared such an intimate part of their lives with me. I hope that our conversations and my research have had a positive impact on their quality of life as they have learned to live and love with cancer.

Author Contact: Margaret Chamberlain Wilmoth, PhD, MSS, RN, can be reached at mcwilmot@unc.edu, with copy to editor at ONFEditor@ons.org.

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