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

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2006 Mara Mogensen Flaherty Memorial Lectureship

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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

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