A cancer diagnosis can have an overwhelming effect on patients’ sexuality. Patients can suffer physically and emotionally from the side effects of cancer treatments. Nurses and physicians often fail to recognize the importance of the sexuality assessment to patients. The purpose of this article is to discuss sexuality from the perspectives of patients with cancer. Fifty-two patients were asked to define sexuality and its meaning to them. The results demonstrated that patients’ definitions of sexuality can take on many different meanings. Only a small number of patients stated that sexuality was addressed by their nurse or physician. Many patients wished someone had asked them about or brought up the topic of sexuality. The results support the value and importance of performing a sexuality assessment in patients with cancer.

At a Glance

- Nurses and physicians often fail to recognize the importance of sexuality assessments to patients.
- The definition of sexuality differs greatly among patients.
- Surveyed patients wished someone had either asked about or addressed sexuality with them.

Defining Sexuality and Sexual Health

Sexuality or sexual functioning are broad terms that include social, emotional, and physical components. Partner issues such as the couple’s sexual history, the partner’s ability to function sexually, communication issues, and marital stresses are important factors to consider (Barton, Wilwerding, Carpenter, & Loprinzi, 2004). The World Health Organization’s (WHO’s) definition of sexuality is: “A central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, and social well-being that relates to one’s sexuality” (WHO, 2002). The way people experience and express sexuality is different for each individual and can be influenced by biologic, psychological, social, cultural, and religious factors. WHO defined sexual health as: ‘Physical,
emotional, and social well-being that relates to one’s sexuality.” Each patient defines their sexuality and sexual health differently and uniquely according to gender, age, personal attitudes, and religious and cultural beliefs (National Cancer Institute, 2006). Consideration of how patients view sexuality is important when making this assessment and will ensure that the appropriate information is given.

Patients’ Sexual Health

Sexual health may initially be a low priority for newly diagnosed patients with cancer (American Cancer Society, 2006). As treatments are completed and patients survive their disease, sexual health again becomes important. Although many cancer survivors may return to a normal state of sexual functioning, others do not. A patient’s sexuality and sexual health can be temporarily or permanently altered (Krebs, 2006). Structural changes to the body, temporary or permanent hair loss, issues with erectile dysfunction, vaginal dryness, and loss of sensation can cause distress. In addition, patients often suffer in silence. Many issues patients face regarding their sexuality can be avoided or addressed by simply letting patients know that they can discuss sexuality with their healthcare providers.

Focus of the Research

Much sexuality assessment research focuses on the personal and professional barriers nurses face in their ability to assess and educate patients on issues pertaining to sexuality. Although nurses generally agree that sexuality assessment is part of the holistic care of the patient, they are unlikely to discuss the issue in their practice (Haboubi & Lincoln, 2003). The lack of a sexuality assessment occurs despite knowledge of how the disease or treatment affects patients’ sexual health (Magnan, Reynolds, & Galvin, 2005). Magnan and Reynolds (2006) identified the top barrier in sexuality assessment as the nurses’ perception that patients do not expect them to address their sexuality concerns. However, most patients feel that receiving information regarding potential changes in sexual activity because of their disease is important (Henson, 2002). In a study by Stead, Fallowfield, Brown, and Selby (2001), patients with ovarian cancer thought the healthcare provider should have supplied written information or discussed sexual issues with them (Hautamaki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007).

Research that explores patients’ experiences during their cancer journey helps nurses understand their needs and provides a better understanding of why certain assessments should be made. In a study identifying personal issues and concerns of female African American breast cancer survivors, universal concerns such as body image, menopause, and sexuality exist along with concerns about prosthetics that match skin tone and wigs matching hair consistency (Wilmoth & Sanders, 2001). A study of sexuality after early prostate cancer treatment identified erectile dysfunction as having a significant impact on patients’ quality of life. Men may find themselves reevaluating their sexuality and challenging their identity after a cancer diagnosis (Bokhour, Clark, Inui, Silliman, & Talcott, 2001).

Sexuality Survey

The study was conducted to determine the need for sexuality assessments in patients with cancer and was a graduate capstone project approved by the nursing graduate department of a major university. A written survey consisting of five questions was conducted to assess the perspectives of patients with cancer regarding sexuality. The questions were developed by two graduate oncology certified nurses with a focus on whether sexuality assessments were being done, by whom, and if the assessment had importance to the patient. Three questions were designed for narrative response and two questions were “yes” or “no” choices. No time limit existed for completing the survey, but most participants finished within 20 minutes.

A convenience sample was obtained from two community-based oncology outpatient clinics and two hospital-based support groups. All respondents remained anonymous, but age, gender, and diagnosis were obtained. Fifty-five patients were approached about the survey, and 52 verbally consented to participate. The three that declined cited lack of interest. The sample consisted of patients with cancer who were either currently in or had recently completed chemotherapy, radiation therapy, or hormonal treatment. Of the surveys returned, 46 were women and 6 were men. Respondents were aged 23–84 years with varying cancer diagnoses and a mean age of 57 years.

An oncology certified nurse reviewed the survey and its purpose with each participant, and questions were encouraged. After participants verbalized willingness to participate and an understanding of the questions, they each completed the survey independently. An oncology certified nurse was available if participants needed additional clarification. Participants were asked to define sexuality and its importance, if the subject was addressed by their nurse or physician, and, if not, what the patient would have liked to discuss.

The responses were read by two master’s-educated oncology certified nurses. No predetermined categories or themes existed before reading the narrative answers. Ideas expressed within the narrative answers were noted and common categories were then identified. The categories were discussed and agreed upon by the reviewers.

Patients’ Definitions of Sexuality

Patients were asked to define what sexuality meant to them. Responses included passion, feeling desirable, sharing, and the ability to be sexy (see Figure 1). The themes that evolved for women participants were based on body image, remaining appealing to their partners, the ability to be a woman, maintaining femininity, love, sex, and intimacy. Sexuality themes for men included maintaining normal relationships, physical touch, and arousal.

Body image was an important component of sexuality for many women responders. The ability to look good and be appealing or desirable to their partners regardless of changes to their appearance was a high priority in defining sexuality. A 62-year-old patient’s definition included trying to still be a woman throughout treatment and remembering that, although the outside appearance had changed, the inside remained the same. Mastectomies affected the way women defined their sexuality. One woman
stated that her sexuality was defined by how she continued to feel as a woman, particularly after a mastectomy. Another said she used to feel sexy in her own skin but has felt broken and unattractive since she lost her breast. Hair loss from chemotherapy was another concern that affected self-esteem and the ability to feel attractive. Men also felt that body image was important, with significant concern placed on erectile dysfunction.

For women, the ability to continue to feel like a woman and be feminine was associated with a spiritual and mindful aspect. Being a woman was described as having physical, emotional, and sexual components. What had defined each woman as an individual was changed by chemotherapy or surgery. It became challenging for the women to find new ways to redefine their sexuality and, ultimately, who they were.

Both men and women felt that love was an integral part of their sexuality. Being able to love themselves for who they were was instrumental in feeling attractive to others. Love was associated with being close with someone or being in a relationship. A 41-year-old woman defined sexuality as the intimate act of love between two people; a 56-year-old man defined it as being in love with his spouse and loving himself.

Intimacy and sexual intercourse were other ways men and women defined sexuality. Both sexes described touching, holding hands, cuddling, kissing, and hugging as components of intimacy. Sexual desire also was important, along with the ability to be aroused and achieve orgasm, although many patients stated that chemotherapy had impaired that ability. Another patient felt sexuality meant having all the parts in proper work.

Addressing Patients’ Concerns

Patients were asked if sexuality concerns or issues were addressed with them during treatment or at the time of follow-up. Only 9 of 52 (17%) patients answered “yes” regarding their nurse addressing sexuality. That number increased to 12 (23%) when patients were asked if their physician discussed sexuality with them (see Table 1). Only one patient in the study brought up the subject with her physician because she wanted to discuss side effects of hormonal therapy. Another patient stated that she would have been more comfortable bringing up the subject with a female nurse than her male doctor if given the opportunity.

Importance to Patients

Twenty-two of 52 (42%) patients said that discussing sexuality with their nurse was important. Patients expressed a desire to be able to ask questions regarding their sex life and the emotional changes experienced during treatment. Fertility concerns, sex drive, body image, and physical and mental well-being were areas patients felt nurses should have expertise in to properly guide them. Sexuality was recognized as a sensitive subject that should be addressed in a private, confidential, and nonjudgmental way. It also was important to the patients that nurses be knowledgeable, empathetic, and non-patronizing. A 63-year-old woman felt that issues concerning sexuality were an important part of a holistic, all-encompassing approach to oncology treatment.

Twenty of 40 patients aged 50–84 stated that a sexuality assessment was not important to them. Seven patients defined sexuality as the physical act of intercourse, which was the most common reason given for why an assessment was unimportant. Older women who were widowed said they had stopped sexual activity prior to their diagnosis because their partner had died. Other patients felt that a sexuality assessment was unimportant to them because the cancer diagnosis and its treatment did not impact their sexuality, the cancer did not change who they were sexually, or because they felt sexuality was a concern for younger patients. Naturally occurring or chemically or surgically induced menopause also was attributed to decreased libido and lack of interest in sex. One patient who rated sexuality as unimportant said that it would have been interesting to be aware of common effects cancer treatment had on his sexuality.

Various reasons existed as to why patients felt unsure about the importance of discussing sexuality (see Table 2). One 42-year-old woman thought she would not mind having the conversation but felt her oncology nurses were too busy to sit and talk. Some did not consider the importance of sexuality prior to the survey, and others were more concerned about getting through chemotherapy. One patient was celibate by choice and stated that the expression of intimacy through sex was not a part of her life. Although the importance was unknown, some women felt they would be more comfortable talking with their nurse if needed.
What Patients Would Have Discussed

Patients were asked what they wished nurses had discussed with them regarding their sexuality. A majority of responses were associated with the physical changes of chemotherapy and surgery. Information regarding what happens to the body during cancer treatment, hair loss, infertility and decrease in sperm count, sexual dysfunction, lack of libido, resuming sexual activity, early menopause, and the impact fatigue has on sexuality would have been appreciated. Psychological concerns included how to prepare for the loss of a breast, coping with sexual desires, changes in emotions about self and others, concerns about partner relationships, and self-esteem. Several patients requested referrals to community programs that dealt with sexual health and others inquired about educational books for patients with cancer having difficulties with sexuality.

Several patients stated that they wished they had simply been asked about their sexuality by their nurse. One patient said she had nothing to discuss but would have been interested in what her nurse may have felt was important to help her out physically and mentally. Others wanted to know that it would have been okay to ask their nurse questions about sexuality. A 67-year-old woman said that “if my nurse had brought up the topic of sexuality, it is possible I would have found it interesting.”

Implications for Nursing

The wide variation in responses identified the need for oncology nurses to discuss sexual health with their patients and provide education, guidance, and referral as needed. Patient responses supported research, demonstrating that nurses are not assessing sexuality although patients have an interest in discussing it. Patients do notice when nurses appear too busy to be approached or uncomfortable with the subject. A lack of information on changes that can occur affects patients and their ability to successfully return to normal functioning.

Nurses should be aware that each patient will have his or her own unique definition of sexuality. Many will include emotional and physical components in their definition. The physical changes patients may encounter with treatments and the impact the changes may have on their definition of sexuality should be considered. Partners should be included in discussions when appropriate. Nurses should listen with compassion to patients’ thoughts on sexuality and educate them on broader definitions, if necessary.

Nurses should never assume that increasing age means loss of interest in sexuality. Nurses should find their own comfort zone for making this assessment in their patients. Providing holistic care to patients includes taking the time to listen to patients’ concerns and offer the proper information they need.

For nurses who want to develop a better understanding on how to perform a sexuality assessment, two models exist that are similar in approach: the BETTER Model (Mick, Hughes, & Cohen, 2003) and the PLISSIT Model (Annon, 1974) (see Figure 2).

The BETTER Model involves nurses addressing the topic with patients, explaining that sex is a part of quality of life, and advising patients to discuss sexuality concerns with nurses. Nurses should then inform patients about available resources. If the timing is not appropriate, patients may ask for information for future use. In addition, nurses should note in patients’ information that a discussion on sexuality has occurred (Katz, 2007).

In the PLISSIT Model, after nurses let patients know that discussing sexuality concerns is okay, nurses should provide factual information regarding patients’ questions. This requires nurses to have some knowledge of the potential sexual consequences of medications and treatment. In addition, a referral to a sex therapist or counselor for severe sexual issues out of the scope of practice or expertise of nurses may be necessary (Katz, 2007).

These models can provide nurses with a guide for discussing the topic of sexual health with their patients. Nurses should review each of the models to decide which one they are more comfortable using.

### Table 2. Importance of Discussing Sexuality

<table>
<thead>
<tr>
<th>IMPORTANCE OF DISCUSSING SEXUALITY</th>
<th>NUMBER OF PATIENTS</th>
<th>AVERAGE AGE (YEARS)</th>
<th>MEN (%)(N = 6)</th>
<th>WOMEN (%)(N = 46)</th>
</tr>
</thead>
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<tr>
<td>Very important</td>
<td>7</td>
<td>39</td>
<td>33.3</td>
<td>10.9</td>
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<tr>
<td>Important</td>
<td>11</td>
<td>56</td>
<td>–</td>
<td>23.9</td>
</tr>
<tr>
<td>Somewhat important</td>
<td>4</td>
<td>50</td>
<td>33.3</td>
<td>4.3</td>
</tr>
<tr>
<td>Not important</td>
<td>20</td>
<td>65</td>
<td>33.3</td>
<td>39.1</td>
</tr>
<tr>
<td>Unsure of importance</td>
<td>9</td>
<td>54</td>
<td>–</td>
<td>19.6</td>
</tr>
<tr>
<td>Celibate by choice</td>
<td>1</td>
<td>60</td>
<td>–</td>
<td>2.2</td>
</tr>
</tbody>
</table>

N = 52

### BETTER Model
- Bring up the topic.
- Explain that you are concerned with quality-of-life issues, including sexuality. Although you may not be able to answer all questions, you will want to convey that patients can talk about their concerns.
- Tell patients that you will find appropriate resources to address their concerns.
- Timing might not seem appropriate, but acknowledge that patients can ask for information at any time.
- Educate patients about the side effects of their cancer treatments.
- Record your assessment and interventions in patient medical records.

### PLISSIT Model
- P—Permission-giving
- LI—Limited information
- SS—Specific suggestions
- IT—Intensive therapy

**Figure 2. BETTER and PLISSIT Models**

*Note. Based on information from Annon, 1974; Mick et al., 2003.*

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Conclusion

Additional research should identify the impact of sexuality assessment in patients with cancer. Many treatments, including radiation therapy and surgical procedures, can have a lasting effect on patient sexuality. Patients who are unprepared for the consequences may experience difficulty in attaining a normal lifestyle after completion of disease treatment. This study has identified that sexual health continues to be a concern for many patients with cancer.

Education has been identified in the research as an important factor for nurses to successfully gain the confidence and ability to assess patient sexuality (Haboubi & Lincoln 2003; Magnan et al., 2005). Nurses should identify reasons that negatively affect the ability to discuss sexuality with patients, what they can do to change those reasons, and resources available to help (see Figure 3). Nurses who are able to partner with their patients and develop a relationship can empower patients in the healing process.

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References


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