Sexual Health: Exploring Patient Needs and Healthcare Provider Comfort and Knowledge

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**Background:** Sexual health is an important quality-of-life issue for many cancer survivors; however, this issue remains inadequately discussed by healthcare providers (HCPs) and patients.

**Objectives:** The purpose of this study is to explore whether clinical oncology HCPs have adequate knowledge and are comfortable addressing sexual health issues, and to explore and describe patients’ attitudes, beliefs, and informational needs regarding sexual health.

**Methods:** A survey was completed by HCPs and three patient focus groups were conducted to learn more about sexual health. Survey data were analyzed using descriptive statistics, and qualitative responses were analyzed using content analysis.

**Findings:** The majority of survey respondents reported on the importance of discussing sexual concerns with patients, lacked sexual health training, and were uncomfortable discussing sexual health with patients. Focus group participants wanted access to timely information during treatment, online educational resources, and brochures and handouts; involvement of significant others; support from providers, peers, and survivors; and expert consultation.

**Background:** Many survivors experience physiological and/or psychological problems related to sexual health, including relationship changes, loss of libido, erectile dysfunction, and vaginal dryness (American Cancer Society, 2014). Particular chemotherapy regimens and radiation therapy often cause long-term sexual changes in men and women. Of these sexual changes, 30%–100% result in difficulties, depending on the cancer type and treatment (Galbraith, Fink, & Wilkins, 2011). Sexuality is important to people; however, sexual health concerns are frequently underassessed, underdiagnosed, underreported, and undertreated because of a variety of barriers, such as lack of healthcare provider (HCP) information and knowledge (Krebs, 2010; Sporn et al., 2014).

All components of the healthcare system should recognize psychosocial needs as an integral part of quality cancer care; sexual health issues are of considerable concern to cancer survivors (Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine, 2008, 2013; National Comprehensive Cancer Network [NCCN], 2015). The NCCN (2015) guidelines indicate that sexual dysfunction is common during and after cancer.

The Patient-Reported Outcomes Measurement Information System (PROMIS®) is a large collaborative effort between the National Institutes of Health (NIH) and several research institutions to develop tools to understand patient self-reported physical, psychological, and social well-being related to chronic disease (NIH, 2016). Flynn, Jeffery, et al. (2011) and Flynn, Reese, et al. (2011) used the PROMIS methodology in their focus group studies to assess patients’ sexual health experiences across the cancer continuum. Their studies not only reiterated previous research findings that sexual health issues occur in patients with cancer at
Multiple studies have documented the sexual health concerns of patients with cancer. Uscher, Perz, and Gilbert (2012) conducted an online survey of 1,956 Australian participants with breast cancer to inquire about their changes in sexuality and intimacy. The findings indicated that patients experienced a decreased number of sexual encounters (78%), diminished sexual arousal (74%), a loss of energy for sex (71%), and a lack of intimacy (60%). Abbott-Anderson and Kwekkeboom (2012) completed a systematic review of physical, psychological, and social sexual concerns of gynecological cancer survivors, and identified physical (n = 16), psychological (n = 11), and social (n = 7) sexual health concerns.

Rasmusson, Plantin, and Elmerstig (2013) found that patients with cancer received insufficient information regarding sexuality and fertility changes, with 48% stating that they had not received any information on treatment effects on sexual health. In a needs assessment of patients with cancer in the United Kingdom (N = 394), Catt, Fallowfield, Jenkins, Langridge, and Cox (2005) found that only 37% of respondents recalled having discussions or receiving information on sexual well-being. Similar results were found in a survivorship clinic population with low rates of communication on sexual health by HCPs (Sporn et al., 2014). In another study, nurses perceived that patients did not prioritize sexuality throughout the continuum of care, although nurses themselves believed that sexuality should be discussed (Olsson, Berglund, Larsson, & Athlin, 2012). In addition, conversations about sexual issues were not seen as part of nurses’ daily routine; in fact, the nurses hoped that someone else would take responsibility for addressing sexual health (Olsson et al., 2012).

Several studies have examined patient preferences for receiving sexual health information. McCallum et al. (2014) studied 113 women with gynecologic cancer and found that 64% desired no help for their sexual needs, 24% preferred discussions with their HCP, 17% preferred written information, and 2% preferred group-based interventions.

The needs of patients with cancer regarding sexual health are inadequately addressed clinically and practically. Locating resources and information can be time-consuming and burdensome for survivors. With cancer survival rates improving, understanding survivors’ sexual health needs is essential.

The current study’s purpose was twofold: (a) to understand if clinical oncology HCPs have adequate knowledge and are comfortable addressing sexual health issues with patients and (b) to explore and describe patients’ attitudes, beliefs, and informational needs about sexual health. The scope of this project was to explore sexual function and intimacy concerns. The findings can be used to inform the development and implementation of an educational module for oncology nurses and other HCPs.

Methods

Three oncology nurse residents on the inpatient oncology/bone marrow transplantation (BMT) unit at an academic medical center conducted an evidence-based literature review as part of their evidence-based practice project. CINAHL® and Ovid databases were searched for articles published from 2008–2012 using the key terms sexual health, oncology nurses, knowledge, attitudes, and beliefs. The reliable and valid surveys (Cronbach alpha = 0.91) Sexual Health Care Scale–Attitude and Sexual Health Care Scale–Practice were translated from Korean into English by a certified translator (Kim, Kang, & Kim, 2011). Survey items were adapted with permission from the original author for this project’s use. The survey consisted of three subscales: (a) attitudes, 17 items (related to discomfort, uncertainty, fear, environmental support); (b) practices, 21 items (related to sexual function, psychological factors, social problems, reproductive care); and (c) demographics, 5 items (gender, age, ethnicity, experience, and practice location). Cancer center interdisciplinary HCPs were surveyed using electronic methodology to understand sexual health attitudes and practice. Inpatient and ambulatory nurses, physicians, midlevel providers, social workers, pharmacists, psychologists, and others (n = 402) were invited to participate.

In addition, focus groups were used to expand the understanding of the sexual health attitudes, beliefs, and informational/resource needs of patients with cancer. Patients were recruited through flyers, emails to patients in the database, and self-referrals. Interested participants were contacted and provided with project details. Inclusion criteria for focus groups included adult patients with cancer who were 18 years or older, regardless of cancer diagnosis or stage. Three 90-minute focus groups were conducted from September 2013 to February 2014: a male focus group (n = 5), a female group (n = 4), and a BMT group (n = 2). All five participants in the male group were Caucasian, two had a bachelor’s degree, one had a master’s degree, and one had a doctorate. All five had prostate cancer; one was in treatment, one had finished treatment and was in follow up, and two had completed treatment. In addition, one had undergone surgery, four had undergone radiation, three

Can you share with us whether or not you have received sexual health information or education at any point during or after your cancer treatment? If so, please tell us about it.

Would you have liked to receive information? What would that have been?

As you are comfortable, would you please share examples of physical, psychological, or social sexual health issues that were not addressed but that you would like to have had information on? (Prompting participants about relationships, body image, sexual drive, and so forth may be needed.)

What do you feel are barriers to asking or receiving sexual health information or education? (Discussion prompts—embarrassment, fatigue, short appointment times, the stoic “It is normal, and I just have to deal!”)

How would you like to receive education on sexual health issues? (Remain open for discussion and participant ideas, and then get feedback on the following):

– One on one with a healthcare provider
– Group classes for education and support (on or off campus)
– Information sheet
– Web page information and resources

Is there anything else you want to share about your experience with sexual health and cancer that might help other patients?

FIGURE 1. Patient Focus-Group Questions
had received hormonal therapy, and one had received another type of treatment.

The female focus group consisted of one African American and three Caucasian women. Two had bachelor’s degrees, one had a master’s degree, and one had a doctorate. Two had breast cancer, one had ovarian cancer, and one had peritoneal cancer. At the time of the study, two participants were in treatment, one had received care for symptom management, and one had completed treatment. Four had undergone surgery; one, radiation; four, chemotherapy; and one, hormonal therapy.

The BMT focus group consisted of two Caucasians, one with a bachelor’s degree and one with a master’s degree. One participant had multiple myeloma, and one had non-Hodgkin lymphoma/prostate cancer. At the time of the study, one was in treatment and one had completed treatment. One BMT recipient had undergone radiation, and both had undergone chemotherapy and other treatment.

Although 16 participants registered, only 11 attended. Each participant was offered a $15 gift certificate for participation. Experienced oncology nursing facilitators guided the focus group discussions using a semistructured script with six open-ended qualitative questions (see Figure 1).

Results

Quantitative

Survey respondents’ (n = 95) demographic data are displayed in Table 1. A majority of HCPs reported no past education in sexual health training (n = 92, 73%); however, they stated that sexual health concerns were important to patients (n = 89, 84%). More than half of the respondents reported discomfort discussing sexual health issues/sex with patients (n = 86, 60%) and addressing specific sexual activities with patients (n = 86, 65%). Despite these issues, 61 (n = 86, 71%) indicated that they were ready to talk about sexual health issues, and 58 (n = 86, 67%) were not embarrassed to discuss sexual issues with patients. Views of patient perception were divided: 48 participants (n = 86, 56%) believed that patients would be uncomfortable discussing sexual issues with an HCP, whereas 38 (n = 86, 44%) believed patients would not be uncomfortable. The majority of HCPs feared that patient privacy would be invaded (n = 86, 56%) but not that they would offend patients (n = 85, 61%) or create distance between themselves and patients (n = 85, 84%) by addressing sexual health issues. The most prevalent reported barrier to addressing sexual health concerns with patients was lack of time (n = 85, 48%), but neither finding a private place to discuss this topic with patients (n = 86, 47%) nor concern for colleagues’ opinions (n = 84, 11%) was a significant barrier.

Table 2 displays HCPs’ experiences caring for specific patient sexual health issues. Most relevant findings suggest that HCPs have more experience managing stress and depression, body image changes, and communication with patients’ partners. HCPs were least experienced with referring patients to sexual health counseling experts, documenting sexual health concerns and education, and addressing impotence.

Qualitative Focus Group Findings

Six themes emerged from the discussion groups: timing, partners, loss, information, support, and expectations.

Timing: Both men and women wanted access to information when the disease stabilized. One patient explained,

I think the timing of when you are approached with this information is also kind of key. I think too early in diagnosis, you can’t even think about it. It’s kind of something that kicks in once you get to a point of stability [emotionally and physically].
**Partners:** All groups endorsed including partners in discussions because partners were also affected by the information. One woman noted, “This is not just our issue, it’s our partners’ issue as well. They need to be included too.” Participants suggested providing support for partners separately from patients. Some women did not want to discuss sexual concerns in front of their partners. Women wanted opportunities either to discuss sexual health with or without their partners, noting that it should be individualized based on patient and partner preference.

**Loss:** Several participants expressed a sense of loss of libido, identity, body image, and relationship changes. One male participant remarked, “I got divorced because I became . . . well, part of it was sexual, because I was impotent. You know, I didn’t know where to go for help.” One woman expressed, just as the other focus groups reported, “It’s not the way it was before.” She continued, “I’ve got scars and fake nipples and everything.” Some participants desired that relationships/sex return to the way they were before cancer. One man stated, “You cannot live without sex; it impacts your whole quality of life.” Another participant noted, What’s the purpose of all of this if I can’t lead a whole life. . . . I really feel like I was let down both times I’ve had cancer, in regards to being treated as a whole person. I feel like that’s why a lot of people give up hope a lot in their cancer battles—because they feel like they’re half a person instead of a whole person.

**Information:** All groups endorsed the importance of receiving online information, including information sheets, YouTube videos, or webinars. One participant noted, “The way to reach the most people . . . is over the Internet . . . because they just feel more comfortable.” Some men in the BMT group wanted to know how to assess a website’s quality and determine if it was a legitimate, accurate source of information. Other participants expressed the need for providers to use plain language while discussing issues of sexuality. Participants also believed that HCPs should take an individualized approach. Men vocalized a need for more help and information on deciding what the best treatment was for them, and perceived that they were on their own in managing sexual changes.

**Support:** The BMT group felt burdened when they could not discuss these sexual health issues with their providers, and expressed the need for more psychosocial support. They believed that “whole person care” would be helpful. The women also voiced concerns about support. They wanted HCPs to open the door for conversations and to provide resources. Others believed that they did not have any support to make decisions and felt let down by their providers. Multiple groups desired peer support. One participant shared, “It was very helpful for me to talk to someone who had the experience and not the doctor, but someone who walked in [my] shoes.” The participants in the women’s group did not just desire validation from peers but wanted concrete suggestions and ideas.

**Expectations:** A number of participants expressed the need to know what was ahead and what to expect. They wanted clarification about normal versus abnormal or unexpected changes, so they were prepared for recovery. “[You want] somebody to kind of prepare you for the changes that are coming.”

### TABLE 2. Healthcare Providers’ Experiences Caring for Patients’ Sexual Health (N = 84)*

<table>
<thead>
<tr>
<th>Issue or Experience</th>
<th>Experienced</th>
<th>Not Experienced</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body image changes</td>
<td>63</td>
<td>19</td>
<td>2</td>
</tr>
<tr>
<td>Communication with spouse or partner</td>
<td>60</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td>Contraception use during cancer treatment</td>
<td>40</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Decrease in sexual desire</td>
<td>30</td>
<td>51</td>
<td>3</td>
</tr>
<tr>
<td>Decrease in sexual satisfaction</td>
<td>25</td>
<td>57</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>69</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Documenting patient sexual concerns or sexual education</td>
<td>22</td>
<td>60</td>
<td>2</td>
</tr>
<tr>
<td>Feeling a sense of closeness with spouse or partner</td>
<td>38</td>
<td>44</td>
<td>2</td>
</tr>
<tr>
<td>Fertility/sterility issues related to treatment</td>
<td>42</td>
<td>39</td>
<td>3</td>
</tr>
<tr>
<td>Impotence</td>
<td>24</td>
<td>55</td>
<td>5</td>
</tr>
<tr>
<td>Menopausal symptoms induced by treatment</td>
<td>40</td>
<td>42</td>
<td>2</td>
</tr>
<tr>
<td>Referral to sexual health counseling experts</td>
<td>18</td>
<td>64</td>
<td>2</td>
</tr>
<tr>
<td>Sexual activity during treatment</td>
<td>42</td>
<td>39</td>
<td>3</td>
</tr>
<tr>
<td>Stress and managing stress</td>
<td>74</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Vaginal dryness</td>
<td>33</td>
<td>46</td>
<td>5</td>
</tr>
</tbody>
</table>

*Eleven participants skipped the question.
education on vaginal dryness, impotence, and decreased sexual satisfaction and desire.

Julien et al. (2010) found that HCPs with more years of experience reported less discomfort discussing sexual health. The HCPs in the current study were relatively inexperienced (X = 8.4 years). This inexperience, combined with discomfort, led to the conclusion that the HCPs were not sufficiently prepared to provide care in this area. Interestingly, HCPs denied feeling unready to pursue these discussions, recognized the importance of sexual health, and were not embarrassed to discuss sex with patients. Perhaps HCPs, reflecting on the importance of sexual health and their own lack of knowledge, were emotionally comfortable with the topic of sex but not professionally ready to provide care. Additional research on HCP focus groups should provide data to support or refute this interpretation and guide future interventions.

Patient Focus Groups

The patient focus groups provided a window into the human experience of cancer treatment and its impact on sexuality and relationships. Multiple themes emerged across focus groups, including timing, inclusion of partners, the importance of providing resources, feelings of loss, and lack of HCP support. Participants emphasized that holistic care is essential in cancer treatment and, although their initial focus is on survival, their focus shifts to larger issues, namely, quality of life. Across focus groups, the feelings of loss regarding sexual health, such as body image and intimacy, were significant for participants, who did not have many resources or interventions offered to them. Almost all participants noted that HCPs did not address much about sexual health, and many patients needed to gather information on their own. All three groups wanted HCPs to open the door to discussing sexual concerns and realistic expectations. The women’s and BMT group did not expect HCPs to solve the problem but would have liked to have been referred to experts. However, the men’s group (all prostate cancer survivors) expected HCPs to be well versed in sexual dysfunction and to provide treatment.

Limitations

The convenience sampling of staff resulted in high numbers of RN and advanced practice nurse respondents, and low numbers of physicians, social workers, and others who could engage patients in sexual health care. The sample was predominantly inpatient nurses who were more focused on acute rather than survivorship concerns, which could have skewed results. In addition, their subjective examination based on self-report knowledge could have hindered the assessment of staff preparedness to deliver sexual health care. Comfort or discomfort with the topic could also have skewed HCPs’ perception of their own experiences and knowledge.

Focus group limitations included a small number of participants, participant self-selection, lack of representation of all cancers, and predominantly female Caucasian participants. Despite the small sample size, numerous themes emerged across genders, age, and cancer diagnoses. Focus group participants strongly agreed that changes and improvements regarding sexual health treatment were needed. The participants were self-selected and were not representative of all patients with cancer, such as adolescents and young adults; patients concerned about reproductive health; and lesbian, gay, bisexual, and transgender patients. The facilitators did not specifically ask about the participants’ sexual orientation or gender identity. Future studies should explore the sexual health needs of these specific populations to gain a comprehensive understanding of diverse populations.

Implications for Practice

- Educate healthcare providers (HCPs) on sexual health, encouraging the incorporation of assessment and care into practice.
- Prepare HCPs to address sexual health with evidence-based interventions to help patients navigate difficult transitions along the cancer continuum.
- Provide patients with support regarding sexual health, such as what changes to expect, and interventions to help them maintain sexual health.

Implications for Nursing

Consistent with prior research, HCPs in this study lacked the specific training and comfort necessary to provide adequate sexual health care and education to patients and their partners (Hughes, 2009; Julien et al., 2010; Kotronoulas, Papadopoulou, & Patiraki, 2009). However, HCPs acknowledged the importance of sexual health and reported having experience with providing other aspects of psychosocial care related to depression, stress, body image disturbance, and communication with spouses and partners. A significant opportunity exists to educate HCPs so they are comfortable addressing sexual health care. Other studies have shown a correlation between experience and comfort in this domain; therefore, future work with HCPs should provide opportunities to address sexual health (Kotronoulas et al., 2009).

The focus groups of patients with cancer revealed that HCPs, including nurses, can provide more holistic care to patients by discussing and educating patients on sexual health. The groups demonstrated that sexual health is not distinct from the cancer experience and, for many, the cancer treatment resulted in feelings of loss. Overall, patients did not feel supported by HCPs. Preparing patients and partners for expectations and providing them with evidence-based interventions for sexual health and intimacy changes allows patients and partners to actively engage in holistic healing. By addressing these issues, HCPs can help patients navigate the difficult transitions along the cancer continuum.

Conclusion

The overall goal of oncology HCPs is to improve patient quality of life and outcomes, so they must address sexual health, body image, and intimacy issues. Patients have shared that sexuality is a key part of their identities and that it must be addressed to facilitate healing and a sense of wholeness during and after cancer care.
References


