Sex talk and cancer: Who is asking?

by Deborah L. McLeod and Joan Hamilton

Abstract

Estimates of sexual health problems after cancer treatment range from 40% to 100% across cancers, with almost half of cancer survivors reporting problems with sexual functioning. While many side effects of cancer treatment gradually resolve within the first year or two, many sexual health issues do not. These problems can remain severe and constant and can even become worse over time causing considerable distress. Although sexual health issues are common, they are not addressed often enough in cancer settings. There are a variety of barriers to addressing sexual health concerns. In this lecture, we discuss those challenges and offer some possible approaches nurses could use to improve sexual health care, including the BATHE and the PLISIT models. Case examples highlighting the models are included.

Addressing sexual health concerns

Although sexual health issues are common, they are not addressed often enough in cancer settings. In two studies (Magnan & Reynolds, 2006, 2005) of nurses from five different specialty areas, including oncology, nurses identified that sexual assessment and counselling was part of the nursing role and responsibilities, but most did not routinely include it as part of their assessment, teaching or counselling. Confirming this, Hautamaki and colleagues (2007) revealed that 96% of oncology health care professionals reported that the discussion of sexuality-related issues with patients was part of their job. However only 2% of nurses reported this regularly taking place. In one literature review (Kotronoulas et al., 2009) examining nurses’ knowledge, attitudes and practices of sexual health care, the authors concluded that nurses never, rarely or only occasionally offered to listen to patient sexual health problems. Flynn and colleagues (2012) wrote “for nearly three decades, researchers have documented barriers and opportunities for patient-provider communication about sexual matters in oncology... yet, discussions about sexuality rarely occur” (p. 595). Sexual health is gaining recognition as an essential area requiring attention in practice (Kim et al., 2011) and according to many, oncology nurses should have the knowledge, skill and sensitivity to address the varied sexual health needs of cancer patients (Julien et al., 2010; Kim et al., 2011; Kotronoulas et al., 2009).

There is limited Canadian data to identify how well oncology systems address the sexual health needs of patients. However, the Ambulatory Oncology Patient Satisfaction Survey (NRCC) is revealing. Almost all provinces have had at least one survey completed in the last 10 years. In 2009, patients who reported being satisfied in response to the question, “Did I get enough information about sexual changes”, on average, in Canada was 44.5%. From the data available, the highest score in provinces that participated from 2009–2011 was 59.6% and the lowest score was 40% (J. Petrella, Manager of Quality, Cancer Care Nova Scotia, personal communication, September 17, 2012). These data confirm what the literature reveals, that this is an area that deserves more attention.

What sexual health care do patients want from health care professionals?

A number of studies have identified that oncology patients want health care professionals to take the lead in initiating conversations about sexual health (Cox et al., 2006; Flynn et al., 2012; Julien et al., 2010) and will not bring up the topic if the health professional does not (Flynn et al., 2012). Patients describe wanting open, honest, reflective communication about sexual health concerns (Cox et al., 2006; Hordern & Street, 2007b), permission to openly discuss their issues, and to be asked how changes with treatment have affected their sexual function and relationship (Park et al., 2009). Further, they want nurses to normalize the changes and the concerns they are experiencing, and to know that their issues are not unique (Hordern & Street, 2007b; Stead et al., 2003). In one study (Flynn et al., 2012), 78% of patients wanted to have the sexual health discussion and be informed about common sexual side effects before treatment began, including basic practical information about sexual functioning and the intimacy changes caused by disease treatment (Horden & Street 2007a; Stead et al., 2003). Stead et al. (2003) found that patients did not expect the nurse to have sexual health expertise, but wanted a supportive space with the nurse to rehearse their experience, ideas, concerns and hopes.

Barriers to addressing sexual health needs

Given the strong evidence of need in this area and the relative simplicity of what patients are asking from nurses, how is it that sexual health concerns are not being addressed more frequently?

We found a range of barriers to sexual health care identified in the literature.

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Not part of nursing role: In a large study by Magnan and Reynolds (2005), the major barrier for oncology nurses to discussing sexual health with their patients was that they did not believe that patients expected them to address sexual issues. Hautamaki and colleagues (2007) reported that 92% of nurses felt it was primarily the treating physician’s responsibility to discuss sexual issues, although 78% of these nurses also reported that it was a responsibility they shared with the physician and the patient.

Lack of knowledge and skill: Nurses and other health care professionals often report feeling inadequately prepared and uncomfortable about initiating the conversation and lacked confidence because they did not feel properly prepared or trained (Flynn et al., 2012; Hautamaki et al., 2007; Kotronoulas et al., 2009; Lavin & Hyde, 2005; Stead et al., 2003). In the Hautamaki study, lack of education was the main barrier to addressing sexual health with patients, a view shared by others (Kotronoulas et al., 2009). Although many nurses felt this was an important aspect of care, nurses worried about making mistakes and did not want to show their vulnerability to patients, nor provide incorrect information (Cox et al., 2006; Haboubi & Lincoln, 2003; Hordern & Street, 2007b; Stead et al., 2003). Kotronoulas et al., (2009) concluded that nurses’ inadequate knowledge was divided into three categories: inability to provide explicit information on specific sexual concerns, inadequate communication skills, and lack of experience.

Environment and system issues: Heavy workloads and time constraints are also reported as factors preventing nurses from addressing sexual health, though some speculate that failure to prioritize and address these concerns might reflect some avoidance because sexual health was not valued or because the nurses did not feel knowledgeable or skilled (Hautamaki et al., 2007; Kim et al., 2011; Kotronoulas et al., 2009). Some nurses reported that the lack of written education materials for both the patient and themselves, and lack of sexual health resources to refer patients to, prevented them from initiating conversations (Kotronoulas et al., 2009; Stead et al., 2003). Others avoid sexual health discussions because there was no privacy, or they did not see patients alone (Hordern & Street, 2007b; Kotronoulas et al., 2009; Stead et al., 2003). Two studies (Hordern & Street, 2007b; Magnan & Reynolds, 2005) described barriers relating to team members. For example, health care professionals sometimes worried that team members may feel that this aspect of care was totally inappropriate to discuss because of the life-threatening nature of the situation (Hordern & Street, 2007b). Nurses also reported concerns related to pressure and criticisms from co-workers, cited lack of support from managers and other leaders and absence of role models as barriers to addressing sexual health issues (Magnan & Reynolds, 2006).

Attitudes, values and beliefs of nurse: In a variety of ways, the attitudes, values and beliefs of nurses have an effect on how, or if sexual health concerns are addressed. Some nurses worry about offending or upsetting patients (Hordern & Street, 2007a; Kim et al., 2011; Lavin & Hyde, 2005) and believe that patients would not be willing to have sexual health discussions (Nakopoulou et al.; 2009). In contrast, one large study found that it was the nurses who did not feel comfortable talking about sex (Magnan & Reynolds, 2006). Embarrassment has been found to be a factor and can outweigh the patient’s need (Cox et al., 2006; Kotronoulas et al., 2009, Magnan & Reynolds, 2006; Stead et al., 2003). Ironically, findings from studies examining patient views have indicated that patients avoid raising their concerns because they are worried about embarrassing health care professionals (Stead et al., 2003). It would appear their worry is well founded.

Many health care professionals did not want to address sexual health issues because of patient age (too young or too old), gender, culture, religion, or because they lacked an awareness of customs and beliefs and were worried that the conversation could be misinterpreted (Hordern & Street, 2007b; Kotronoulas et al., 2009). Some health care professionals do not discuss sexual health because patients reminded them of their parents (Hordern & Street, 2007b), while others report that talking about sexual health is an invasion of privacy (Kim et al., 2011; Magnan & Reynolds, 2005). Hautamaki et al. (2007) concluded that the health professional’s own comfort level was a key predictor of whether sexual health issues would be addressed.

What can nurses do differently?

It is clear from the foregoing that there is a need and a desire on the part of patients for health care professionals to address sexual- ity. While it is true that several health care professionals might be in a position to do so, nurses are arguably in the best position given their access to most patients and skill in patient education. Two models that we have found helpful in increasing confidence and skill with sexual health concerns are the BATHE model (Stuart & Lieberman, 2008) and the PLISSIT model (Annon, 1976) (see Table 1). There is evidence that 80% of oncology-related sexual concerns can be managed through the first three levels of the PLISSIT model (Schover et al., 1987).

The BATHE model (Stuart & Lieberman, 2008) and its adaptation to BATHE-RS have been used successfully as a framework to guide nurses in addressing distress screening results (McLeod, Morck, & Curran, in press). Once a topic of concern has been identified, and it is clear it is something the patient wants to discuss (I see that you have checked off “intimacy/sexuality” on the problem checklist; is that something you would like to talk about today?), the nurse follows the BATHE framework. The process of the BATHE conversation implicitly addresses the permission (P) step of the PLISSIT model. For many patients, this is sufficient. However, others will want some limited information (LI), the second step of the PLISSIT model. When neither of these two are sufficient, experienced oncology nurses can provide more specific suggestions (SS) for common sexual concerns. The approach to using the PLISSIT model is less one of directing and more one of coaching and providing normalization, validation and information along the way, as needed. When couples have relationship challenges in addition to sexual concerns, referral to someone with more specialized skill in sexual health counselling and/or couples counselling may be needed; this is the intensive therapy (IT) step of the PLISSIT. Each of these steps is discussed in more detail below and illustrated by the case examples.

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their treatments (see Table 2), it is not appropriate for the nurse to choose who to ask based on age, gender or assumptions about who is, or is not concerned. We have often been surprised by which patient is most concerned about sexuality—and those surprises point to our own biases! Simply saying, “Many patients affected by X cancer are concerned about the impact on how they feel about themselves, as a man or a woman or their sexual function. Has this been a concern for you?” both normalizes the concern and gives someone permission to talk about it, if they wish, whether or not sexuality is a concern. If it is not a concern at that particular point in the illness trajectory, it could be later. In our experience of almost 70 collective years of practice in this area, we have found it to be exceptionally rare for patients to be offended by the question. Occasionally this does happen, but responding that sexual health is an aspect of health like all others is usually sufficient. If it is a concern to the patient, using the BATHE is helpful in shaping a useful conversation about the concern, one in which patients typically will experience support to discuss the concern.

While health care professionals are much more likely to address sexual health when the cancer affects the sexual organs, Robinson and Lounsberry (2010) make the point that many aspects of illness, cancer and treatment can affect how one sees oneself and one’s sexual appeal, including things like fatigue, nausea, incontinence, and feeling dependent, as well as changes to one’s body and appearance. This suggests that all cancer patients should be given an opportunity to discuss sexual health concerns, and the decision about whether to or not should be theirs.

Limited information: Once the patient has had an opportunity to discuss their concerns, it is generally evident what kind of limited information they might need. There are some excellent resources available to guide the nurse and patients, in this area (see Box 1). If the nurse understands the information in these resources, she or he has sufficient knowledge to offer limited information and can often shape the information, or reinforce it, before or after the patient has read some information for him or herself. This helps with understanding and retention. Regardless of the situation, and whether or not the nurse is completely confident about what might help, it is very important that patients are advised that their sex lives are not over. In some cases sexual function may be dramatically altered, but there are always possibilities for maintaining sexual intimacy.

Specific suggestions: Most health care professionals who wish to offer specific suggestions will need to review recommendations for the particular cancer populations with whom they practise. However, there are some very common concerns that require simple, but specific suggestions. In all cases, if patients have difficulty following through on suggestions, particularly after repeated coaching to address barriers, referring on to other professionals may be in order.

Loss of desire: Sexual desire is the least understood aspect of sexual response and loss of desire is very common for both men and women experiencing cancer. There are a variety of reasons, including fatigue and other cancer- and treatment-related symptoms, as well as changes in body image, all of which can affect sexual desire and interest. In addition, changes in hormone levels following ovarian failure with chemotherapy or surgical intervention, androgen deprivation therapies affect desire, sometimes dramatically. Psychosocial factors have been implicated in the experience of sexual desire perhaps even more than physical factors (Robinson & Lounsberry, 2010; Walker & Robinson, 2010). For women particularly, the role of the relationship quality has been found to be as important as hormonal changes (Demeristein, Lehert & Burger, 2005) in desire, and some men at least report full sexual responsiveness, including desire, even in the presence of castrate levels of testosterone (Warkeinten, Gray & Wassersug, 2006; Wassersug, 2009). Thus, specific suggestions about strengthening the relational bond (e.g., when have you felt closest? What gives you a good feeling about your relationship with one another? Is there room to do more of that these days?) might be appropriate. Similarly, specific suggestions on how to improve satisfaction with sexual touch, both as the giver and the receiver, can be accomplished by suggesting the sensate focus exercises (see e.g. Katz, 2007).

Female dyspareunia: Women can experience pain with penetration for different reasons post treatment. Physical/mechanical alterations to the vagina can be at fault. This can be caused by narrowing, shortening or changes in the vagina (e.g., with pelvic surgery, graft versus host disease (GVHD), pelvic radiation), lack of lubrication (e.g., with treatment-induced menopause, side effect of medication such as aromatase inhibitors), tissue breakdown and skin changes (inflammation, blistering) or skin conditions that may or may not be related to a malignancy. A second cause of pain is infection, either yeast or bacterial, and inflammation caused by acute effects of pelvic radiation to local tissue and mucositis from chemotherapy. A third area that can contribute to dyspareunia is neurological changes. Nerve pain from nerve damage can occur months to years post pelvic radiation. Pain with chronic GVHD of the vagina and abnormal pain sensation at the opening of the vagina (allodynia) can be an issue.

It is important to normalize the fear of pain and discuss how fear of pain can cause a lack of interest, avoidance and tension with an intimate partner. There may be simple interventions that can help women feel more comfortable, but before interventions are recommended, women with perineal pain should have a pelvic exam to determine the likely cause of the pain. For a woman with a known shortened vagina, putting a donut-like ring on a partner’s penis shortens the penis so it does not hit the top of the vagina. For vaginal dryness, a vaginal lubricant may be recommended with sexual activity to ease penetration. There are several types of lubricants: water-based—with and without glycerine, all natural, silicone-based, oil-based and each with their own pros and cons. For day-to-day discomfort, burning and irritation, a vaginal moisturizer could be suggested. Vaginal dilation is recommended for women who have had pelvic radiation to prevent or manage vaginal stenosis (Briere et al., 2012; Johnson, Miles & Cornelis, 2010; Katz, 2007; Murthy & Chamberlain, 2012; Shani et al., 2012; Woods, 2012).

Erectile dysfunction: Erectile dysfunction certainly occurs in the context of cancer-related fatigue and decreased desire. Also, it is very common after pelvic surgeries, including radical prostatectomy, and pelvic radiation. There are a variety of treatments for erectile dysfunction, though couples are often disappointed with these. It is important for nurses who work with men receiving these treatments to have a working knowledge of these aids (e.g., phosphodiesterase-5 inhibitor medications, vacuum erection devices and intracavernosal injections), even if they are not responsible for teaching men

| Table 2: Factors that increase the risk for sexual difficulties (Krebs, 2006) |
|-------------------------|-------------------------|
| **Women**               | Age > 30                |
|                         | Gynecologic surgery: hysterectomy, oophorectomy, vaginectomy, vulvectomy |
| **Men**                 | Any age beyond puberty  |
|                         | Testicular or prostate surgery |
| **Both**                | Chemotherapy: alkylating agents, antimetabolites |
|                         | Radiation to the pelvis  |
|                         | Surgery: abdominal-perineal resection, pelvic exenteration |
|                         | Medications: antidepressants, antiinflammatories, antihistamines, antihypertensives, narcotics, sedatives, steroids, tranquillizers |
|                         | Psychological issues: alterations in body image and self-esteem and reactions related to amputation, alopecia, head and neck surgery, mastectomy, weight loss or gain |
|                         | Treatment side effects: fatigue, mucositis, pain |
and treatment there is a pause and she responds that they are not having sex. They have experienced changes in their sex life as a result of her cancer and treatment there is a pause and they respond that they are not having sex. With some further inquiry (Is this a concern for you? What was the performance of intercourse? Ted acknowledges he misses the performance of intercourse and discovers that it is the touch and closeness she misses, not so much the performance of intercourse. He felt pressured and exhausted.

The nurse offered the following information. First, she reassured Ted that many people who are recovering from cancer treatment experience a decline in their sexual interest and their ability to perform sexually, and that fatigue and medications can affect sexual interest, too. Sexual interest commonly returns with time and usually after the fatigue abates. Ted found it helpful to learn that he was not “abnormal”, that many men experienced a lack of sexual response and that this improves gradually through recovery. He had his hunch that this would gradually get better validated. He was relieved to know that six months is still relatively early in recovery, given the treatment. He left the clinic planning on talking to Charlene.

Case example 3: Specific Suggestions
Ted and Charlene return to clinic together a few months later. Ted reports that the fatigue has continued and that they are still not having sexual activity of any kind. The nurse, asking who is most concerned about that, discovers that Charlene is feeling disconnected from her husband and is quite upset. Ted is only upset because Charlene is and states that he doesn’t feel like initiating sex when he cannot be sure he can “follow through”.

The nurse asks what it is about sex that is important to Charlene and discovers that it is the touch and closeness she misses, not so much the performance of intercourse. Ted acknowledges he misses that, too. The nurse offers the idea that people can manage well without sexual intercourse, but need touch for well-being. She also introduces the metaphor of sex as a meal—when one is not hungry, a four-course meal can seem daunting, but an appetizer might be manageable. While their usual sexual practice might be too much right now, a small amount of touch might be manageable. After getting agreement from both that this might be possible and their willingness to try something new, she suggests the sensate focus level 1 as a beginning exercise.

Box 1: Resources

Pamphlets for Patients and Partners


Support
Cancer Chat Canada www.cancerchatcanada.ca
Canadian Cancer Society www.cancerconnection.ca

Courses for Health Professionals
“Sexual Health in Cancer” and “Sexual Counseling and Cancer” offered by the Canadian Association of Psychosocial Oncology, Interprofessional Psychosocial Oncology Distance Education (IPODE) Project www.ipode.ca

to use an aid. There is emerging evidence that use of such aids soon after prostatectomy and cryoablation can improve erectile recovery (Ellis, Manny, & Rewcastle, 2007; Kohler et al., 2007; Raina, Pahlajani, Agarwal, & Zippe, 2007; Zippe & Pahlajani, 2007) and preserve penile length after prostatectomy (Kohler et al., 2007). Specific suggestions about trying these aids are appropriate, but may require referral to other services. Many couples need help learning to incorporate these aids into their sexual repertoire, as the difficulty of this, even after men have learned the mechanics, is a factor that has been shown to limit their use (Neese, Schover, Klein, Zippe, & Kupelian, 2003).

Intensive Therapy: Some couples will not find the psycho-educational approach of the first three levels of the PLISSIT model enough to solve the challenges they are experiencing. This is most common when the issues are very complex or the couple is struggling with effective communication or conflict. Typically this will be outside of the scope of most nurses, save advanced practice with training in couple/marital therapy, and couples should be referred to whichever health care professional has training in this area.

Thoughts about obligations in practice
Nurses are typically responsive to the needs that patients present and endeavour to do their best to assist. In the case of sexual health concerns, however, patients are often silent and do not ask for help. Unfortunately, all too often nurses collude in that silence. Given that the needs are real, well supported by the evidence, nurses have an obligation to break the silence and directly address sexual health. The vast majority of sexual concerns will be addressed by the first three levels of the PLISSIT, while the BATHE model provides a framework to discuss concerns, even when nurses have limited knowledge themselves. Patients have a right to expect more from us.

Case examples
Case example 1: Giving Permission
June Harper is a 56-year-old woman who had a lumpectomy for breast cancer. She is seen for follow-up along with her husband, Tim, who is 60 years old. It has been three months since the surgery and it is determined that chemotherapy is not needed. When the nurse asks if they have experienced changes in their sex life as a result of her cancer and treatment there is a pause and she responds that they are not having sex. With some further inquiry (Is this a concern for you? What was your relationship like before cancer?), the nurse determines that they previously enjoyed a very active sex life and this is a major change for them. When the nurse asks who initiated sex in the past and if either has attempted to initiate sex lately she discovers the following: in the past, their sexual interest was fairly matched and that both initiated and most often the other responded. However, June says she is afraid to initiate now because she is afraid that Tim is no longer attracted to her. This belief is further reinforced by the fact that Tim has not initiated sex. For his part, Tim is astonished to hear his wife’s thoughts. He was attempting to be respectful of her need for healing and was waiting for her to initiate. After some tears and laughter both said that understanding what the other was thinking was enough for them to make some changes and they expressed confidence that they would not need any further help.

Case example 2: Limited Information
Ted Smith attended a routine clinic visit alone following a related allogeneic stem cell transplant for AML six months ago. He is struggling with considerable fatigue. The nurse asks about sexual health changes and if he has any questions or concerns. He pauses and then tells the nurse that he has absolutely no interest in sex. On further exploration, he says that he and his wife, Charlene, had a good sex life before his diagnosis, and while he was waiting for transplant they were having some sexual activity with intercourse. Lately, Charlene has been asking when they are going to begin having sexual activity again. They tried a couple of times, but he wasn’t able to maintain an erection. He felt pressured and exhausted.

Ted does have spontaneous erections a couple of mornings each week. He reports wanting to please Charlene, but that sex “just wasn’t on my radar screen”. Ted is beginning to feel a bit anxious, “but only because Charlene is bringing it up”. It is her questioning that is troubling him the most. He wonders if his lack of sexual interest is due to treatment and recovery, and believes that when he is feeling better, he will become interested again. He is handling this situation now by trying to distract Charlene, so they don’t have to talk about it.

The nurse offered the following information. First, she reassured Ted that many people who are recovering from cancer treatment experience a decline in their sexual interest and their ability to perform sexually, and that fatigue and medications can affect sexual interest, too. Sexual interest commonly returns with time and usually after the fatigue abates. Ted found it helpful to learn that he was not “abnormal”, that many men experienced a lack of sexual response and that this improves gradually through recovery. He had his hunch that this would gradually get better validated. He was relieved to know that six months is still relatively early in recovery, given the treatment. He left the clinic planning on talking to Charlene.

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