Learning Themes

- Introduction to sexuality and the human experience
- An interprofessional lens to healthcare providers and sexuality

Introduction

Sexuality is an integral and essential component of being human. It is influenced by physical function, relational quality, self concept, body image, cultural, religious, social and other values and beliefs, as well as, childhood experiences and learning. A diagnosis of and treatment for cancer may have a dramatic impact on a person's sexuality. The way an individual views themselves, and their ability to connect with others at sexual and intimate levels, irrespective of their age, gender, culture, partnership status or cancer site may be altered (Hordern, 2008, Krebs, 2008).

Sexuality often is not accurately portrayed; many think only of the act of intercourse or a physical act that leads to an orgasm or an erection, rather than including body image, reproduction, intimacy, closeness, touching, numerous ways of communicating with others, and a myriad of activities to show affection. Historically, references to sexuality in cancer care have been predominantly focused on this narrow relationship of sexual function as it intersects with cancer treatments. This is inconsistent with an increasingly evident array of holistic and patient-centred definitions of sexuality that expand beyond sexual function (Ganz, 1997; Hordern, 2008; Krebs, 2008; Rice, 2000; Watkins, Bruner & Boyd, 1998). The differences between sexual function, sex, and sexuality are often not easily articulated and the concept of human sexuality becomes muddied and not easily defined. For our use we defer to the Pan American Health Organization (2003) who define sex as "the sum of biological characteristics that define the spectrum of humans as females and males" and sexuality as "a core dimension of being human which includes sex, gender, sexual and gender identity, sexual orientation, eroticism, emotional attachment/love, and reproduction" (p. 6). This is corroborated by the World Health Organization (2004) definition of sexuality as one of the "central aspects of being human," (p. 4) that is "the result of the interplay of biological, psychological, socioeconomic, cultural, ethical, and religious/spiritual factors" (Nusbaum, Hamilton, & Lenahan, 2003, p. 6).

People who have experienced cancer often search for ways to deal with altered self-perceptions and body image, negotiating relationship and roles with partners, and desire information regarding practical ways to adjust to living with sexual and intimate changes after a cancer experience. A cancer experience may result in questioning how others have coped in similar situations, what is normal or not, and to search out ways to adapt to the many side effects of cancer treatment that impact upon sexuality and intimacy (Krebs, 2008).

Sexual Health Needs of Persons with Cancer

Patients with all kinds of cancer, not just those with cancers affecting fertility and sexual performance, want open communication about intimacy and sexuality (Hordern, 2008; Robinson & Lounsberry, 2010). What information however are persons looking for? While it is difficult, if not erroneous, to make blanket assumptions regarding the sexual health needs of persons with cancer the literature reveals certain commonalities. In a recent study Baker, Denniston, Smith, and West (2005) found that more than 41% of persons with cancer identified concerns regarding their sexuality. Persons in research studies expressed concerns around body image, diminished self-esteem and self-confidence, and having difficulty in adapting to altered self-perception and fear (Gamel, Hengeveld & Davis, 2000; Holmberg, Scott, Alexy, & Fife, 2001; Lemieux, Kaiser, Pereira, & Meadows, 2004). Persons who experience a diagnosis of cancer have also indicated they wished practical information from a healthcare professional. Seeking information could thus be seen as a way of coping with a new cancer diagnosis (Chamberlain Wilmoth, 2001; Davison, Gleave, Goldenberg, Degner, Hoffart, & Berkowitz, 2002). Feldman et al. (2000) examined what questions men with prostate cancer want answered. Participant responses included a desire for information regarding whether treatment will affect sexual functioning, and for how long, if left untreated, will sexual functioning be affected; could having sex make the cancer worse; could having sex with cancer adversely affect a partner; and can a man have sex during the treatment. Similarly, Chamberlain Wilmoth (2001) in examining what sexuality meant to women with breast cancer, revealed participants wished information regarding details about how their treatment would specifically affect their sexual function, as well as psychological support from health professionals to assist them to deal with sexual losses, which had a direct impact on their sexual adjustment.

The way information is received, as well as the type of information given is also important. A multinational European study found that 23% of men with prostate cancer had received written material related to sexuality, but 46% stated that sexuality counseling would have been helpful (Kirby, Watson, & Newling, 1998). In a study of an education intervention with women diagnosed with gynecologic cancer participants were given a book about sexuality and cancer and were encouraged to discuss their concerns with one of the investigators. A number of measures were completed post intervention including a knowledge test. Ninety-four percent of the participants stated they now had a clearer understanding of sexuality and cancer, however 17% wanted even more information (Robinson, Scott, & Faris, 1994).

This need for more information is not unique. Corney et al. (1993) studied women who had radical pelvic surgery for cancer of the cervix and vulva. Twenty-six percent of those interviewed stated that they needed more information about sexual matters related to the surgery, and 22% stated that their partners needed additional information. A needs assessment of 73

women with gynecologic cancer attending follow-up care found that almost half the participants had received little or no information on sexuality and cancer, while 60% wanted more information (Bourgeois-Law, & Lotocki, 1999).

Overwhelming, patients report that few health professionals are willing to engage in open and honest discussions about sexual health issues throughout their trajectory of care. Additionally, more often than not healthcare professionals do not routinely address sexual health concerns (Bartlik, Rosenfeld, & Beaton, 2005; Guthrie 1999, Hordern, 2008). In one recent study, 96% of healthcare professionals identified that sexual health concerns were part of their scope of practice. Despite this, only 2% reported regularly asking patients about their concerns (Hautamaki et al., 2007). Other studies have identified that if the health professional does not ask, less than 10% of patients will raise the issue (Driscoll, Garner, & House, 1986) even though many patients identify that they think it is appropriate to ask them about this area of their lives (Waterhouse, 1996).

Patient issues **Intimacy and sexuality after cancer**
Survival is more important than my sexuality He told me "no more erections" and . . . I am a little bit disappointed as it's an important part of your life . . . Better to be alive than dead. I don't look at myself any more.
Trust in the expert If it were that important they would have told me. I don't want to make them [health professionals] to feel uncomfortable . . .
Search for options Can you have sex after chemotherapy? . . . I was looking for the option of discussing these concerns with a health professional. Now I will never know. I was searching for the right person who would understand how I was feeling. I want to be viewed as a person rather than my disease.
Am I normal? Has something gone wrong with my treatment? . . . Was there something they had not told me? My body has changed, my mind has changed, everything has changed . . . Is this normal to feel so ugly? Is that normal to lose interest in sex? . . . it's a big worry for me
Tell it to me straight I want to enter a partnership between the medical professional and the patient . . .which would see me as part owner of everything that is being done to me. My relationship is the most important part of my life . . . not just physically . . . mentally . . . nobody seems to understand that around here. You're brought up in an environment of trusting a doctor and believing them . . . But today . . . if something is diagnosed, I'll go home to the Internet and check it out so I know what they are talking about.
Selected participant responses, grouped by cluster theme (adapted from Hordern & Street, 2007)

Healthcare Professionals and Sexuality

The literature reveals that relatively few health care professionals feel comfortable or confident in raising the topic of sexuality following a cancer diagnosis or discussions the sexual and intimate changes that may occur after treatment. The reasons for this hesitancy and discomfort in attending to sexual health are multipronged and complex. Hordern and her colleagues have published work on why the topic of sexuality and intimacy after cancer remains taboo in clinical settings (Hordern, 1999; Hordern & Currow, 2003; Hordern & Street, 2007). The attitudes and barriers that prevent these discussions occurring include a lack of time, the belief that the cancer patient is too ill or is not interested in sex, the belief that disfigured bodies are not sexually attractive, the fear of opening a Pandora's Box or of transgressing medico-legal boundaries as well as third parties being present at the consultation (Hordern, 1999; Hordern & Currow, 2003; Hordern & Street, 2007; Schwartz, & Plawecki, 2002; Sunquist & Yee, 2003). Healthcare professionals may also believe their discussions may be construed as disrespectful and inappropriate. Research also suggests that gender, age, culture, socioeconomic factors, and religion all contribute to healthcare professionals avoidance of the topic (Bello & McIntire, 1995; Schwartz, & Plawecki, 2002; Sunquist & Yee, 2003).

In their research Hordern and Street (2007 a & b), found that Oncology and palliative care healthcare professionals worried about what their patients or colleagues would think of them if they raised the topic of sexuality. This concern was magnified if the healthcare professional believed they were personally sexually inexperienced or if they struggled to talk about sexual topics in their own lives. This highlights the importance of healthcare professionals reflecting on their own feelings of discomfort, embarrassment, or awkwardness when raising the topic of sexuality and examining the personal barriers they may bringing to the communication process (Monturo, Rogers, Coleman, Robinson, & Pickett, 2001; Roberts, 1992). Psychosocial guidelines in cancer care advocate the need to overcome personal attitudes and beliefs related to sexuality in order to promote patient centred communication. Substantial evidence exists that persons experiencing cancer have a better quality of life and are more satisfied with their care when the healthcare professional caring for them are effective communicators (Fitch, 1994, 2000; Hordern, 2007; Robinson & Lounsberry, 2010).

The timing of engaging in questions regarding sexual health is seen to be important. Healthcare professionals who perceived a person was not ready to engage in the discussion may also influence the decision to ask questions or to offer information (Herson et al., 1999; Katz, 2005). Katz (2005, 2007) indicated that a lack of sexuality education in healthcare professional curricula might also play a role. Questioning persons about their sexual health may be ignored in course of study focused on cure and alleviation of symptoms. Whatever the reason for the barriers, the end result is that the topic is not routinely included and ultimately patients do not receive holistic care focused on all aspects of human functioning (Katz, 2005).

Enhancing Skills, Knowledge, and Comfort

In 1974, the World Health Organization held a conference focused on the training needs of health professionals working in the area of sexual health. Their generated report noted that a "growing body of knowledge indicates that problems in human sexuality are more pervasive and more important to the well-being and health of individuals in many cultures than has previously been recognized". This watershed report emphasized the importance of taking a positive approach to human sexuality and the enhancement of relationships.

Twenty years later the World Association of Sexology, meeting in Hong Kong, adopted a Declaration of Sexual Rights to assure that all humans and societies develop healthy approaches to sexuality. The Declaration declared the following sexual rights must be recognized, promoted, respected, and defended:

- The right to sexual freedom, excluding all forms of sexual coercion, exploitation and abuse.
- The right to sexual autonomy and safety of the sexual body.
- The right to sexual pleasure, which is a source of physical, psychological, intellectual and spiritual wellbeing.
- The right to sexual information...generated through unencumbered yet scientifically ethical inquiry.
- The right to comprehensive sexuality education.
- The right to sexual health care, which should be available for prevention and treatment of all sexual concerns, problems, and disorders.

This declaration highlights that addressing sexual health concerns with people affected by cancer is as important as addressing other aspects of their health. Rather than deferring sexual concerns to "others", healthcare professionals in cancer care need to work at overcoming their discomfort with sexual health and to breakdown the silence that causes many people so much distress. While some concerns do require help from healthcare professionals trained in sexual counseling or therapy, those working in cancer care need to develop some level of comfort and skill in exploring sexual health concerns and in understanding the impact of these concerns on distress and quality of life.

Talking about sexuality may be perceived as a huge barrier that is difficult to overcome. However there are some relatively simple strategies to begin to mitigate these barriers and include sexual health as part of clinical care. Proficiency in communicating about sexuality with the persons experiencing cancer requires little more than knowledge of sexual sequalae of the cancer in question and a willingness to initiate the conversation. The majority of information needs can be met through normalization of thoughts and feelings, presentation of accurate information and the provision of appropriate suggestions (Robinson & Lounsberry, 2010). The

beginning juncture for conversation is to address personal attitudes that may be preventing the inclusion of sexual health into assessment and care. It is essential that healthcare professionals understand their own sexual identities and those sexual patterns and practices that they deem personally acceptable or unacceptable. Additionally, feeling comfortable with one's own sexuality will aid in entering these conversations and conducting assessments with a caring and non-judgmental approach (Katz, 2005: Krebs, 2008).

Wilmoth (2006) has suggested four key factors that will assist persons working in cancer care to address sexual health concerns. The suggestions included: increasing personal comfort and decreasing embarrassment when talking about sex and sexual functioning; expanding one's knowledge of sexual issues, including potential dysfunctions and possible interventions; enhancing communication skills; and being able to identify and help the person obtain and use attain and use appropriate resources for their identified sexual health needs. In addition, Katz (2005) stressed the critical need for healthcare professionals to understand their own sexual attitudes, values, and beliefs. In particular, attention needed to be paid to attitudes, values, and beliefs that might hinder the opening of conversations of sexual issues. Awareness and knowledge of one's own beliefs, values, and attitudes will allow appropriate consideration of any personal attitudes, beliefs, or discomforts with topics such as sexual practices or preferences that differ from one's own, which may affect the healthcare professional's ability to address sexuality.

Mick (2007) identified ten strategies to help oncology healthcare professional enter into conversations regarding sexual health. Specific strategies include: developing an understanding of sexual health as it relates to cancer care; wholistic assessment from a quality of life perspective; use of broad open ended questions; reflective listening; avoidance of assumptions about the value of sexuality and intimacy in the face of a cancer diagnosis and treatment; encouraging the person/partner to ask questions and explore sexual concerns; and using identified practice standards to ensure sexual health assessment and management needs are met.

Wholistic comprehensive care to all persons experiencing cancer is the primary goal. We have already touched on the fact that assessments and intervention for sexual health, while important are frequently omitted or only cursorily discussed. Reasons for this have been postulated in the literature and exist for both healthcare professionals and persons with cancer. Persons/partners may fear embarrassment or are not certain if addressing sexuality is acceptable when faced with the more emergent issue of having cancer and undergoing treatment. Healthcare professionals also have fears of embarrassment (for themselves or for causing embarrassment in the persons they are working with), but more commonly cite lack of knowledge and skill in addressing sexual health, lack of time, and the belief that addressing sexual issues is not required or expected of them as common reasons for not broaching this topic. However, it has been found that once a discussion of sexual health issues is begun, most persons and partners react with

relief, knowing that discussing this sensitive topic is not only acceptable, but encouraged (Krebs, 2005).

Using pertinent assessment and intervention models and armed with a willingness to initiate conversations, we as healthcare professionals can provide some level of sexual health care at the time of initial patient interactions, throughout treatment, and during follow-up. The assessment should be conducted using sensitivity, caring, knowledge, skill, and appropriate timing. Sexual health care assessments need to be conducted with consideration of the person's age, level of illness, sexual orientation, and with questions and educational information focused on their specific needs. It is essential that all healthcare professionals "give patients the opportunity to discuss the issues of sexuality and sexual functioning associated with their specific disease and treatment." (Penson et al., 2000, p.336). This does not mean that all of us as healthcare professionals need to be, or wish to be, sexual counselors. However, being able to broach sexuality and sexual health topics, cancer, and treatment in an open non-judgmental manner, listening, providing appropriate resources, including referrals can and must be included in a model of integrated wholistic care that is an expectation of practice (Krebs, 2008).

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