



SEXUALITY AND GYNECOLOGIC CANCER: SUPPORTING WOMEN ON THE JOURNEY TO HEALING

By

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Abstract

New cases of gynecologic cancer in the United States affect more than 70,000 women and their partners annually. Due to the nature of the disease, women report being negatively affected both physically and psychosocially following diagnosis and treatment. By far the most common complaint relates to sexual dysfunction, with more than 50% of gynecologic cancer survivors reporting mild to severe sexual dysfunction following treatment. The purpose of this literature review was to determine how women and their partners are affected by sexual dysfunction related to treatment modalities and how well their nurses and healthcare providers addressed these concerns. Eighty-four relevant articles were identified using OVID Medline, of which ten were chosen for analysis. Results of the literature review showed that gynecologic cancer greatly affects women's sexual functioning, body image, sexual self-concept and intimate relationships negatively. The results of the review further revealed that nurses and other providers experienced multiple barriers to initiating patient discussions related to sexual dysfunction.

Keywords: Gynecologic cancer, sexuality, body image and nursing.

Many would likely agree that 'cancer' is perhaps the most feared diagnosis to receive from a healthcare provider. Using the word cancer can evoke deep fears to the point that when one consoles another for having a bad day, it is not uncommon to hear, "well, at least you don't have cancer." Yet, each year, approximately 1.5 million Americans are diagnosed with cancer and must face these fears head on (American Cancer Society, 2015). Of these new cases, over 70,000 are women diagnosed with gynecologic cancer. Gynecologic cancer is a broad term that describes cancers of the female reproductive system, which include ovarian, uterine, cervical, vaginal, vulvar and fallopian tube cancers (Centers for Disease Control and Prevention, 2012). While this number is relatively small in terms of cancers diagnosed annually, the psychosocial effects are significant to the affected women and their partners. Due to the nature of gynecologic cancer, it seems understandable that the area of most concern to women and their partners would be in relation to body image and sexuality.

Nursing has long been associated with holistic health and healing practices. Florence Nightingale, universally considered the founder of modern nursing, advocated that nurses must attend to the whole person and not simply endeavor to cure disease. When discussing the nature of nursing, Nightingale stated: “the art is that of nursing the sick. Please mark: nursing *the sick*; not nursing sickness” (Arnstein, 1956, p. 542). Unfortunately, nurses often do not feel that they are sufficiently prepared to discuss sexuality concerns with their patients. This reticence leads to sexual health concerns being frequently overlooked by health care providers (Stilos, Doyle, & Daines, 2008). Due to the nature of the profession, nurses are ideally placed to address sexuality and body image concerns with patients and identify methods to aid in coping for both women and their partners. The purpose of this author is to determine the extent women and their partners are adversely affected by gynecologic cancer and how well healthcare providers respond to the unique sexuality concerns they face.

Method

A search of OVID Medline using keywords: “gynecologic cancer” and “body image or sexuality” yielded ten useful articles for this review. Search limitations included articles published since 2005, and English language only. Article titles, abstracts, and reference lists were manually searched to determine articles that pertained to sexuality and gynecologic cancer. Additionally, articles relevant to the field of nursing were preferred. Additional information was obtained from governmental and organizational websites.

Results

Analyzing the evidence presented in each article determined that common threads ran through many but two predominant themes emerged. The most prevalent theme was the physiologic and psychosocial changes related to gynecologic cancer for patients and their intimate partners (Carpenter, Anderson, Fowler, & Maxwell, 2009; Cleary, Hegarty, & McCarthy, 2011; De Groot, et al., 2005; Tierney, 2008; Vaidakis et al., 2014). The second theme sought to determine the barriers that exist among nurses and providers for addressing sexuality concerns with gynecologic cancer patients (Hordern & Street, 2006; Katz, 2005; Krebs, 2006; Magnan & Reynolds, 2006; Stilos, Doyle, & Daines, 2007).

Effects of Gynecologic Cancer on Patients and Intimate Partners

Five authors focused on the physical, psychosocial and quality of life effects of gynecologic cancer. Their articles differed by subject, either focusing on the perspectives of patients alone or that of patients and their intimate partners together. Overall, the content of these articles reflected the complications of gynecologic cancer and its impact on sexuality and how these repercussions were perceived by the subjects. Of particular concern was the idea of sexual self-schema, also referred to as sexual self-concept. This theory relates to the cognitive perception a person has about their sexuality and is determined through past experiences and affects current and future sexual beliefs and practices (National Cancer Institute, 2010).

Gynecologic cancer and treatment modalities change the physical and physiological characteristics of a woman’s body. The most reported physiologic complaints included pain and sexual dysfunction such as vaginal dryness and inability to achieve orgasm (Cleary, Hegarty, & McCarthy, 2011; Vaidakis et al., 2014). These complaints alone understandably can have a large

impact on the quality of sexual encounters but overall the largest area of complaint related mostly to the psychosocial effects reported by women and their partners (De Groot, et al., 2005; Carpenter, Anderson, Fowler, & Maxwell, 2009; Cleary, Hegarty & McCarthy, 2011; Vaidakis et al., 2014; Tierney, 2008). Over half of women affected by gynecologic cancer reported a loss of femininity, feelings of being less sexually attractive and decreased sexual functioning following diagnosis and treatment (Cleary, Hegarty, & McCarthy, 2011). Interpersonal relationship quality between patients and partners also appeared strained with women and their partners both reporting decreased sexual desire, enjoyment, arousal, relationship quality, and ability to orgasm (Vaidakis et al., 2014). Consequently, women and their partners reported the frequency of sexual intercourse with their partners had decreased since diagnosis (Cleary, Hegarty, & McCarthy, 2011; Vaidakis, et al, 2014). According to Tierney (2008), sexuality is multifactorial and is a basic human need on par with breathing, eating and sleeping. Tierney stated that altered sexuality can be influenced by the type of gynecologic cancer, the psychological distress of diagnosis, the cancer treatment and side effects, the psychological distress following treatment, and the changes in relationships throughout the spectrum of illness and recovery. Conversely, DeGroot, et al. (2005) determined that the intensity and range of psychosocial distress related with the stage of disease at diagnosis. This study determined the lower stage of disease at diagnosis, the fewer concerns each partner had related to sexual dysfunction. An increased level of concern correlated with an increasing stage of disease progression. Protective factors such as this can safeguard women and their partners from the adverse psychosocial effects of gynecologic cancer. Closely related, Carpenter, Andersen, Fowler, and Maxwell (2008), studied whether or not sexual self-schema was a moderator for psychosocial perseverance among gynecologic cancer survivors. Based on the data gathered, the authors determined that a higher score a participant had for sexual self-schema, the less likely were their chances of experiencing negative psychological and depressive symptoms when sexual satisfaction was low. This study reported statistical significance for determining a positive method for measuring risk among gynecologic cancer survivors.

Barriers and Recommendations Related to Addressing Sexuality Concerns

The remaining five authors focused on barriers that nurses, providers and patients feel exist that deter discussions regarding sexuality concerns from being addressed. Additionally, these authors offered recommendations that can be utilized to overcome these barriers.

The vast majority of nurses across the spectrums of age and practice specialty reported that they did not feel that patients expected their nurses to initiate conversations about sexuality concerns. Furthermore, nurses reported a lack of comfort and confidence in initiating conversations of an intimate nature with their patients (Magnan & Reynolds, 2006). Similarly, Katz (2005) suggested that nurses may fear initiating discussions related to sexuality based on the belief that such inquiries would be seen as an invasion of privacy, and could result in legal ramifications if deemed inappropriate by the patient. Data collected by Hordern and Street (2007) showed that providers struggled with communication strategies for initiating sexuality conversations with lack of time being a major factor in whether or not sexuality concerns were discussed. Lack of communication between healthcare providers and patients exists even when providers profess to practice a holistic approach to care. In particular, nurses expressed insecurity reporting they felt they were not adequately furnished with the knowledge and skills necessary to

address sexuality concerns with their patients (Stilos, Doyle and Daines, 2008). While the majority of nurses report receiving sexuality education during nursing school, only 16.2% reported receiving continued education or supportive training during their subsequent nursing practice (Magnan & Reynolds, 2006). Lack of knowledge and confidence play a large role particularly for nurses when one considers that a majority of providers admitted to believing that more in-depth discussions regarding sexuality concerns were the responsibility of other members on their team (Hordern & Street, 2007). Compounding these concerns, patients were shown to have a desire to discuss sexuality concerns but felt that if these concerns were not raised by their providers that the issues must not be deemed important. Providers in turn, felt that patients should be more concerned with prognosis, treatment and survival rather than quality of life concerns such as sexuality. Providers were shown to feel that if patients felt the need to address their concerns that they would raise these concerns themselves (Hordern & Street, 2007).

Katz (2005) stated that while sexuality education is often set forth as a key responsibility of nursing, this often does not correlate with practice. The PLISSIT model, explained below, may be used to aid reticent nurses in initiating and normalizing sexuality discussions (Katz, 2005; Krebs, 2006). This model provides a framework for conversations by: directing nurses to give *permission* for the patient to discuss sexuality, allowing for *limited information* to be conveyed, requiring the nurse to provide *specific suggestions* by anticipating sexual consequences of prescribed medications or treatments, and lastly suggesting that *intensive therapy* should be referred to a sexuality specialist if patients have further concerns (Katz, 2005). Understanding the influence of cancer treatments such as surgery, chemotherapy and radiotherapy can also guide sexuality conversations among nurses and patients. Explaining exactly how treatments function and effect physiologic functioning may lead to further understanding among patients on why certain sexuality concerns arise (Krebs, 2006). Perhaps it is this knowledge which in turn could lead to normalizing the sexual side effects of the treatments. In addition to utilizing the PLISSIT model to guide discussion, Krebs (2006) recommended that individualizing patient education was integral to successful and meaningful patient and practitioner interaction.

Summary

Overall, the evidence from all ten studies support the conclusion that women and their partners suffer greatly with sexuality problems after treatment for gynecologic cancer. The literature also suggests that multiple barriers exist for both patients, providers and nurses that appear to prevent these concerns from being addressed.

Discussion

From reviewing the literature it appears evident that gynecologic cancer affects women and their partners adversely. A major element of a woman's sexuality is influenced by her connection to her reproductive organs. Gynecologic cancer not only alters a woman's body physically, but also affects her body image and her sexual identity adversely (Vaidakis, et al., 2014). According to Stilos, Doyle & Daines (2008), "sexuality encompasses feelings about one's body, the need for touch, interest in sexual activity, communication of one's sexual needs to a partner and the ability to engage in satisfying sexual activities" (p. 461). By taking this into

consideration, it is easier to understand how gynecologic cancer can have such a profound effect on a woman's sexuality and body image. Complicating the issue is that sexual dysfunction appears to be the most common side effect of gynecologic cancer treatment. In fact, more than 50% of survivors of gynecologic cancer report experiencing sexual dysfunction after treatment (Cleary, Hegarty, & McCarthy, 2011). Adjusting to the new realities imposed upon the woman due to the nature of her cancer and the psychological effects it generates can be highly difficult for couples to cope with (Vaidakis, et al., 2014). Patients have identified issues relating to sexuality as having a high level of importance as other quality of life issues (Stilos, Doyle, & Daines, 2008). The idea of self-concept is understood to be multifactorial (McLeod, 2008). Thus it is possible that a disruption in one area, such as the physiological changes brought on by surgery, chemotherapy and radiotherapy, probably has significant repercussions on the other areas that comprise an individual's self-concept and sexual identity.

Generally, nursing includes holistic practice. Nurse typically recognize that treating a patient cannot be done in a sterile environment devoid of external factors (Arnstein, 1956). Florence Nightingale stated that the backbone of nursing practice relies on the belief that one cannot simply treat a disease without treating the whole person. This, and an analysis of available literature seems to indicate that many nurses and providers understand this in theory, but struggle to integrate this into practice in regards to sexuality (Carpenter, Anderson, Fowler & Maxwell, 2009). Sexuality, especially as it relates to women, has long been a forbidden subject among many societies. Stilos, Doyle, and Daines (2008), discussed that sexuality concerns are often taboo subjects. The authors further related that many societies not only discourage discussion of the topic of women's sexuality, many often encourage misinformation. The authors further stated that among women who have gynecologic cancer, many do not appear to fully understand the effects of treatment on sexuality, and report believing that bringing up their concerns is inappropriate.

So how does this affect nursing practice? Understanding the concept that sexuality is not often considered a topic freely open for discussion seems important for nurses to recognize. Every nurse may need to enter into practice with an awareness that the burden to initiate conversations on sexuality rests almost exclusively with them (Katz, 2005). Hordern and Street (2007) demonstrated that women with gynecologic cancer do not feel it is their place to bring up concerns about sexuality. Additionally, healthcare providers reported believing that patients would value survival higher than quality of life concerns such as sexuality. Even with training that emphasizes holism, nurses were also found to believe that patients do not want them to initiate sexuality discussions (Magnan & Reynolds, 2006). However, these beliefs were not supported by the literature, or the patients the data represented. While survival was viewed as the ultimate goal of most patients, they also felt that quality of life issues were of equal importance to survival (Stilos, Doyle, & Daines, 2008). Thus, possibly inaccurate assumptions by nurses and healthcare providers may have contributed to patients stating they feel that their sexual concerns are largely ignored by their health professionals (Hordern & Street, 2007).

The literature has shown that nurses cannot solely rely on women affected by gynecologic cancer to address their sexuality concerns. Women and their partners seemingly want their nurses to understand and anticipate their need to discuss sexuality concerns. The annual Gallup poll, related to professional honesty and ethics, has continually found nurses to be

the most trusted profession in America (Riffkin, 2014). Gynecologic cancer patients and their partners trust their nurses to care for all of their concerns and as the literature proves, these concerns definitely include sexuality.

Summary, Conclusions and Recommendations

Summary

A literature review was conducted to answer the question of how greatly gynecologic cancer affects women and their partners, and how well healthcare providers respond to the unique issues they face. Published articles from 2005 to 2015 were analyzed and ten were reviewed related to the topic under consideration. A review of available literature proved valuable in understanding that the extent of the effects of gynecologic cancer on women and their partners appears vast and multifaceted. Furthermore, the literature review determined that while nurses and providers understand that sexuality is an important topic to address, they struggle with fully meeting the needs of this population related to sexuality education.

Conclusions

Women and their partners are adversely affected by the diagnosis and treatment of gynecologic cancer. Additionally, although nursing claims to be a holistic practice and thus seems to be ideally placed to address these adverse effects, barriers exist deter nurses from incorporating discussions related to sexual dysfunction into their practice.

Recommendations for Research and Practice

Future research likely needs to be conducted which supports the effects of sexuality education on limiting the deleterious effects of gynecologic cancer on affected patients and partners. Much of existing research seemingly proves that gynecologic cancer adversely affects this population but little research exists on how effective education programs are at addressing sexuality concerns.

Future nursing education should better prepare nurses to recognize and address patients who are at risk for adverse sexual effects of gynecologic cancer treatment. Nursing continuing education can provide nurses with techniques they can use to initiate conversations related to sexuality and appropriate methods for discussing the concerns of patients and their partners.

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