

Sexual Dysfunction After Hematopoietic Stem Cell Transplantation

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Eighteen months after undergoing unrelated hematopoietic stem cell transplantation (HSCT) for acute myelogenous leukemia, 28-year-old E.M. was experiencing sexual difficulties. For E.M. and her husband, sexual intimacy had been an integral part of their relationship. However, since the transplantation, on the few occasions that she and her husband had attempted to reinitiate sexual intimacy, the physical discomfort E.M. experienced and her lack of desire resulted in dissatisfaction. This frustrated E.M. and her husband, neither of whom could understand this change. Although most other aspects of her life were returning to normal, E.M.'s sexual dysfunction persisted.

Prior to transplantation, E.M. had been informed that the treatment would result in premature ovarian failure, leaving her incapable of having children. Long-term side effects and complications of HSCT were discussed, but the possibility of sexual dysfunction was never addressed. The unexpected loss of her sexuality, of the intimacy that she shared with her husband, was negatively affecting her quality of life (QOL) and relationship. Upon questioning E.M., the nurse identified that a decreased libido combined with vaginal dryness and dyspareunia (pain with intercourse) were major challenges. Treatment options were discussed, and E.M. was started on hormone replacement therapy and the use of vaginal lubricants was suggested. Although these treatments were helpful, E.M.'s sexual responsiveness never returned to the level it was prior to HSCT. The nurse referred E.M. and her husband to couple-based therapy to facilitate behavior interventions. In therapy, E.M. and her husband were able to communicate openly with one another and discuss alternate ways for increasing sexual satisfaction. Those interventions helped E.M. and her husband to gradually return to sexual activity and, although different, they found their renewed intimacy to be rewarding.

Sexuality and Cancer

Sexuality is defined by the World Health Organization ([WHO], 2011) as a dynamic multidimensional construct involving physiologic, psychological, and social processes. Sexuality includes the concept of oneself as a sexual being; sexual expression is an integral part of self-identity and the human experience. Sexuality is a means by which personality is expressed, love is communicated, and emotions are experienced (Tierney, 2008; WHO, 2011). The innate desire to express and experience sexual and emotional closeness often is abruptly and irreversibly changed by the diagnosis of cancer and its subsequent treatment.

Survival rates for HSCT have increased significantly since the 1990s with the advent of better management of acute toxicities and advances in treatment. With improved survival rates, attention has shifted to the long-term effects of HSCT and QOL issues (Yi & Syrjala, 2009). Studies have concluded that sexual dysfunction is one of the most commonly reported QOL issues; many cancer survivors experience alterations in sexuality regardless of age, gender, or relationship status (Tierney, 2008).

Causes of Sexual Dysfunction

Sexual dysfunction is a group of disorders characterized by physiologic or psychological changes that adversely affect sexuality, leading to psychological and social distress (American Psychiatric Association, 2000). Sexual dysfunction in the HSCT survivor can be attributed to the type of treatment, side effects associated with treatment, the psychological distress of diagnosis or treatment, and alterations in relationships (Tierney, 2008; Yi & Syrjala, 2009).

Physiologic Changes

Physiologic issues regarding sexual dysfunction are caused by a disruption of the neurovasculature of the genitalia

or irreparable changes in hormonal milieu, often a direct result of cancer therapy (Tierney, 2008). Rigorous HSCT conditioning regimens include high-dose chemotherapy and radiation, causing direct injury to gonads. This may result in infertility in both genders and premature ovarian failure in women. Indirect effects of chemotherapy and radiation include irreversible damage to the hypothalamic-pituitary-gonadal axis, resulting in changes in the hormonal milieu (Syrjala, Kurland, Abrams, Sanders, & Heiman, 2008; Yi & Syrjala, 2009). Side effects of treatment, such as nausea and vomiting, diarrhea, pain, skin changes, weakness, fatigue, and chronic graft-versus-host-disease (cGVHD) also contribute to alterations in sexual function. High-dose corticosteroids commonly used to treat cGVHD not only suppress endogenous hypothalamic and adrenal hormones, but also have a major impact on physical features and body image. Corticosteroids also may cause emotional lability and depression (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Yi & Syrjala, 2009).

Psychological Impact

Psychological distress experienced by HSCT survivors begins at the time of diagnosis and persists throughout treatment and into survivorship. The psychological dimension encompasses anxiety, anger and depression, grieving the loss of fertility, fear of recurrence, vulnerability, decreased self-confidence, and changes in body image. This psychological distress has a significant impact and lingering effect on sexual functioning. Because sexuality is a complex interaction of physiologic, psychological, and social factors, alterations in sexuality cannot be confined to one aspect alone (Tierney, 2008).

Social Impact

In one study of cancer survivors, altered sexuality was one of the highest

factors for negative effect on social well-being (Tierney, 2008). For individuals in a relationship, the cancer survivor is not alone in the turmoil that accompanies the cancer experience. The fear and anxiety at diagnosis, emotional and physical toll of treatment, and uncertainty about the future affect the partner as much as the cancer survivor (Cooke, Gemmill, Kravits, & Grant, 2009; Tierney, Facione, Padilla, Blume, & Dodd, 2007). The lack of communication between partners about what has changed, what feels good and what does not, insecurities about appearance, and the fear of failing to become aroused are common barriers that inhibit couples from attempting to re-establish intimacy and sexual activity. These problems do not spontaneously resolve on their own but require active discussion and problem solving on the part of the couple (Yi & Syrjala, 2009).

For survivors not in a relationship, it may be a challenge to confide in potential partners the residual side effects of treatment. The fear of having to explain alterations in sexuality may be debilitating and can result in the avoidance of relationships altogether (Mosher et al., 2009; Yi & Syrjala, 2009).

Gender Differences

The duration and degree to which sexual dysfunction is experienced varies according to gender. Women generally tend to experience a higher number of sexual issues than men. When comparing sexual function at baseline (pre-HSCT) and one and three years post-HSCT, Humphreys, Tallman, Altmaier, and Barnette (2007) found that men reported consistent or decreased sexual problems over time, whereas women reported an increase in problems with sexuality over time. Yi & Syrjala (2009) found that, prior to HSCT, 42% of women reported one or more sexual problems; however, by three years post-HSCT, sexual dysfunction was reported by 80% of women. In comparison, only 19% of men reported sexual dysfunction pre-HSCT and 29% reported problems three years post-HSCT. In this five-year prospective longitudinal examination of sexual functioning, 20% of women consistently reported a lack of interest between six months and five years post-HSCT. For men, lack of interest decreased from 14% at six months to 6% after five years. At all times during this study, more than 40% of women were sexually inactive (Yi & Syrjala, 2009). Commonly reported reasons for sexual inactivity and sexual dysfunction

in women are vaginal dryness, pain during intercourse, difficulty achieving an orgasm, and a lack of self-perceived sexual attractiveness. Sexual dysfunction most commonly reported by men include difficulty obtaining and maintaining erection, premature ejaculation, and a lack of sexual interest (Tierney et al., 2007; Yi & Syrjala, 2009). For individuals, particularly women, whose sexual function has not returned by one year, the effects are likely to persist for several years and possibly indefinitely (Yi & Syrjala, 2009).

Interventions

The efficacy of treatments for sexual dysfunction in the HSCT population is not well known; however, certain medical and behavior therapies may benefit individuals experiencing sexual dysfunction. Hormone replacement therapy helps to alleviate symptoms of menopause and may possibly restore ovarian function. Lubricants and topical estrogen are helpful for vaginal dryness or constriction caused by treatment and genital cGVHD. Vaginal dilators also can be used to reduce vaginal constriction and sensitivity. In some extreme cases of vaginal stenosis, surgery also may be an option. Erectile dysfunction often is successfully treated medically with phosphodiesterase inhibitors such as sildenafil. Testosterone replacement has been suggested in treating erectile dysfunction and decreased libido; however, studies have shown men may continue having problems even when testosterone levels are within normal range. External vacuum devices or penile implants are additional treatment options that may be considered if necessary (Syrjala et al., 2008; Yi & Syrjala, 2009).

Addressing the physiologic, psychological, and social dimensions may be necessary to restore intimacy and sexual functioning in cancer survivors. The quality of the relationship and the response of a partner to changes post-HSCT can affect sexual functioning in a positive or negative manner (Yi & Syrjala, 2009). In this regard, interventions that focus on communication and intimacy may be beneficial for improving sexual activity and satisfaction among couples. Support groups educating participants about sexuality and cancer, teaching women about the use of lubricants and dilators, and encouraging patients to talk about their fears also may be beneficial in reducing the anxiety involved in resuming sexual activity (Tierney et al., 2007; Yi & Syrjala, 2009).

Nursing Implications

Sexual dysfunction has been identified as one of the most prevalent long-term issues that HSCT survivors face (Yi & Syrjala, 2009) and, yet, is one of the most inadequately addressed issues. Numerous studies indicate that discussions regarding potential and actual alterations in sexuality are not taking place between patients and members of the healthcare team and, when sexuality is discussed, it is not addressed thoroughly or in detail (Tierney, 2008). The single most important intervention for patients with or at risk for sexual dysfunction is to have an open discussion regarding sexuality and potential sexual changes. As providers of holistic care, nurses have a responsibility to the patient to assess sexuality and intervene as necessary. Not all nurses can be sex counselors; however, nurses should be able to assess all patients for potential sexual dysfunction and provide basic information, reassurance, and referral when necessary (Krebs, 2011).

Several models exist that nurses can use to assess sexuality. Two models that may be particularly helpful in assessing sexuality in patients with cancer are BETTER, which allows for assessment and intervention, and PLISSIT, which focuses purely on interventions (see Figure 1). Initiating a discussion prior to HSCT and before the patient experiences sexual changes allows the patient time to process the information and emotionally and physically prepare for the anticipated changes. It also enables the patient

BETTER

- Bring up sexuality.
- Explain role of sexuality in quality of life.
- Tell about and facilitate resources.
- Timing critical
- Educate patient and partner.
- Record in health record.

PLISSIT

- P**—Permission (to be sexually active)
- LI**—Limited information (about disease and treatment effects on sexuality)
- SS**—Specific suggestions (to manage dysfunction)
- IT**—Intensive therapy (psychological or sexual)

Figure 1. Models for Sexual Assessment and Intervention

Note. Based on information from Annon, 1976; Mick & Cohen, 2003; Mick et al., 2004.

and partner to discuss concerns and fears and establish realistic expectations for sexual functioning following treatment (Tierney et al., 2007). In addition, initiating a discussion prior to treatment makes it easier for the patient to discuss concerns with the healthcare team after treatment when these potential problems

have actualized and further intervention is needed (Tierney, 2008).

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Clinical Highlights: Sexual Dysfunction After Hematopoietic Stem Cell Transplantation

Definition

Sexuality is a broad concept that encompasses the physiologic, psychological, and social aspects of oneself as a sexual being (World Health Organization, 2011). It extends beyond the act of sexual intercourse to encompass the physical and emotional closeness shared with another individual, allowing for the expression of personality, love, and emotions (Anastasia, 2006; Tierney, 2008). Sexuality is an integral part of the lived experience that can be altered suddenly by a cancer diagnosis.

Psychosocial Issues

Alterations in sexuality can have a devastating effect on the hematopoietic stem cell transplantation (HSCT) survivor. Although the types of sexual issues experienced may differ by age, gender, and relationship status, most survivors experience some form of sexual dysfunction regardless of these differences (Tierney, 2008). These changes in sexuality do not resolve on their own but require active discussion and intervention on the part of the HSCT survivor and healthcare team. Sexual dysfunction is one of the most common long-term survivorship issues and can have a permanent and devastating effect on an individual's quality of life if not addressed early and thoroughly.

Interventions

The efficacy of treatments for sexual dysfunction in the HSCT population is not well known; however, certain medical and behavior therapies may benefit individuals experiencing sexual dysfunction. Hormone replacement therapy helps to alleviate symptoms of menopause and may possibly restore ovarian function. Lubricants and topical estrogen are helpful for

vaginal dryness or constriction caused by treatment and genital graft-versus-host disease. Vaginal dilators also can be used to reduce vaginal constriction and sensitivity. In some extreme cases of vaginal stenosis, surgery also may be an option. Erectile dysfunction often is successfully treated medically with phosphodiesterase inhibitors such as sildenafil. Testosterone replacement has been suggested in treating erectile dysfunction and decreased libido; however, studies have shown that men may continue having problems even when testosterone levels are within normal range. External vacuum devices or penile implants are additional treatment options that may be considered if necessary (Syrjala, Kurland, Abrams, Sanders, & Heiman, 2008; Yi & Syrjala, 2009).

Addressing the physiologic, psychological, and social dimensions may be necessary to restore intimacy and sexual functioning in cancer survivors. The quality of the relationship and the response of a partner to changes post-HSCT can affect sexual functioning in a positive or negative manner (Yi & Syrjala, 2009). In this regard, interventions that focus on communication and intimacy may be beneficial for improving sexual activity and satisfaction among couples. Support groups that educate participants about sexuality and cancer, teach women about the use of lubricants and dilators, and encourage patients to talk about their fears also may be beneficial in reducing the anxiety involved in resuming sexual activity (Tierney, Facione, Padilla, Blume, & Dodd, 2007; Yi & Syrjala, 2009).

Nursing Implications

Sexual dysfunction, reported as one of the most common long-term issues that HSCT survivors face (Yi & Syrjala, 2009), continues to go unaddressed

far too often. Several studies indicate that a lack of communication exists between patients and healthcare providers regarding sexuality (Tierney, 2008). Nurses are in a prime position to initiate a discussion regarding sexual changes and educate the patient early on in the course of treatment. Although initiating this discussion can be difficult for the nurse, it empowers patients to be open about sexual concerns and encourages implementation of interventions early on, improving their quality of life.

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