

Experiences in Sexual Health Among Women After Hematopoietic Stem Cell Transplantation

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Purpose/Objectives: To explore the experiences in sexual health among women after hematopoietic stem cell transplantation (HSCT).

Research Approach: A qualitative phenomenologic approach was used to explore sexual health after HSCT.

Setting: The leukemia and bone marrow transplantation outpatient clinic at Massachusetts General Hospital in Boston.

Participants: This study included five women aged 18 years or older with a prior diagnosis of leukemia or lymphoma requiring HSCT who were at least three months post-HSCT and were sexually active prior to HSCT. Participants did not experience menopause pre-HSCT and did not show signs of relapsed disease or vaginal graft-versus-host disease.

Methodologic Approach: A semistructured interview was conducted and included one open-ended question regarding sexual health after participants' HSCT and several follow-up questions. The interviews were audio recorded without participant identifiers. Interviews were then transcribed and analyzed. Primary investigators and an expert reviewer analyzed data using content analysis to identify themes from the interviews.

Findings: Six themes emerged from the interviews: (a) relationship changes, (b) significant and concerning physical changes, (c) sense of loss and powerful emotional impact, (d) fatigue, (e) body image, and (f) educational needs.

Conclusions: Findings portray women's experiences in sexual health post-HSCT and demonstrate the emotional and physical consequences that arise from HSCT-related complications. A need exists for greater support and education for women regarding sexual health post-HSCT, as well as improved education among clinicians regarding sexual health complications experienced by this population. Women articulated their desire for same-sex providers to educate them on the sexual health side effects of HSCT.

Interpretation: Sexual health education is needed immediately prior to and following HSCT. Implications for practice include designating time for pre- and post-HSCT education, improving current sexual health education provided by HSCT clinicians, engaging same-sex providers to discuss sexual health with patients, and increasing nurses' expertise in this area.

Sexual dysfunction is one of the most common and persistent long-term complications following hematopoietic stem cell transplantation (HSCT) (Syrjala, Langer, Abrams, Storer, & Martin, 2005). Increased awareness is needed to improve quality of life (QOL) and to manage and alleviate long-term complications of sexual health in HSCT survivors (Heinonen et al., 2001). An estimated overall 44% decrease in QOL occurs after HSCT (Claessens, Beerendonk, & Schattenberg, 2006). Although significant quantitative data exist regarding sexual health among female recipients of HSCT, qualitative data regarding women's experiences are lacking.

Sexual health and sexuality contribute to a person's identity, self-esteem, and overall QOL. Sexual health is the state of emotional, physical, mental, and social well-being in relation to sexuality (World Health Organization [WHO], 2010). Sexuality provides a sense of self and encompasses sex, gender identity, sexual orientation, pleasure, intimacy, and reproduction (Barton-Burke & Gustason, 2007; WHO, 2010). Sexuality and intimacy reduce emotional distress and affects the psychosocial response to the cancer diagnosis and complications of cancer (Hordern & Currow, 2003). Diminished sexual functioning is significantly correlated with decreased emotional functioning and overall QOL (Watson et al., 1999). Therefore, sexual health plays a significant role in a person's well-being after HSCT.

Patients with leukemia and lymphoma may be cured of cancer through HSCT, which involves cytotoxic chemotherapy regimens as a conditioning procedure (Yi & Syrjala, 2009). Cytotoxic chemotherapy affects normal ovarian function, which can result in primary ovarian failure and subsequent changes to sexual health (Barton-Burke & Gustason, 2007). Quantitative research suggests that women experience sexual health changes post-HSCT, including amenorrhea, vaginal dryness, bleeding with penetrative intercourse, inability to achieve an orgasm, and vaginismus (Dizon, Suzin, & McIlvenna, 2014; Yi & Syrjala, 2009). Fatigue is also associated with sexual dysfunction because of decreased libido (Barton-Burke & Gustason, 2007). Women experience changes in body image post-HSCT related to hair loss, muscle loss, skin rashes, skin sensitivity or dryness, scars, weight change, and edema, all of which disrupt a woman's sense of self (Yi & Syrjala, 2009).

Women experience a greater number of sexual health complications compared to men (Heinonen et al., 2001; Humphreys, Tallman, Altmaier, & Barnette, 2007). For example, 80% of women reported at least one sexual health problem in the three years following HSCT compared to only 29% of men who reported a sexual health problem. In addition, women's sexual experiences declined over time, while men recovered from sexual dysfunctions more quickly than women following HSCT (Syrjala, Kurland, Abrams, Sanders, & Heiman, 2008).

Communication among providers and patients has been found to play a large role in the sexual health of HSCT recipients (Syrjala et al., 2008). Humphreys et al. (2007) found that 48% of participants reported that their provider did not discuss the sexual side effects of HSCT with them. In addition, at one and three years post-HSCT, about half of the respondents reported that sexuality was not discussed during visits with their providers. Patients who discussed the sexual effects of HSCT with their providers post-

transplantation had fewer sexual functioning problems at three years post-HSCT (Humphreys et al., 2007).

To enhance long-term QOL for women after HSCT, healthcare providers must understand how cytotoxic chemotherapy affects women's sexual health. Providers must assess and educate their patients about sexual health as part of their comprehensive care (Bober, Carter, & Falk, 2013). Research focused on women's sexual health experiences after HSCT can contribute to an enhanced understanding of the impact of HSCT and lead to improved long-term QOL and sexual health for female survivors.

Research Approach

A qualitative phenomenologic approach was used to explore women's sexual health after HSCT. The study took place at Massachusetts General Hospital's leukemia and bone marrow transplantation outpatient clinic. Participants were recruited through flyers posted in the outpatient setting and through physician and nurse practitioner colleagues who initially discussed the study with eligible participants. Informed consent was obtained by one of the two primary investigators once inclusion criteria were established.

Eligible women were aged 18 years or older, sexually active prior to diagnosis of leukemia or lymphoma, and were a minimum of three months post-HSCT with ablative conditioning chemotherapy. Eligible participants did not experience menopause pre-HSCT and did not show signs of relapsed disease or vaginal graft-versus-host disease. Women were excluded if they were unable to speak and read English.

Five women participated in the study. The average age of participants was 34 years (range = 24–45 years, median = 34.5 years). The range of time post-HSCT was 115–468 days, and average time post-HSCT was 250 days. Four of the five participants had undergone HSCT within six months of the study interview, and one participant had undergone HSCT over a year before the study interview. At the time of the study, four of five participants were either married or in a committed relationship. The other participant was single and not dating at the time of interview. Two of the five women resumed working in limited capacity based on their recovery stage, and the other women recovered at home. Two women had children, and three women hoped to maintain fertility for future pregnancies. All women were Caucasian and middle class, and had formal education with varying levels of employment prior to diagnosis.

Methodologic Approach

Approval was obtained prior to study. A semistructured interview (see Figure 1) was conducted by

two interviewers, which included an open-ended question regarding sexual health following HSCT. The two interviewers conducted each interview separately; however, they formally discussed techniques for consistency among interviews before and after each interview. No baseline assessment of sexual health was conducted prior to interviews, although the sexual health of women pre- and post-HSCT was integrated throughout the entirety of the interviews. The interviews were audio recorded with no identifiers and were guided by the question, “Can you tell me about your experiences with your sexual health since your stem cell transplantation?” Investigators explored participants’ thoughts, perceptions, and feelings by inquiring into responses.

During the recruitment and consent process, the interviewers discussed the nature of the interview with the participants, describing the sensitivity of the content. Participants were given the choice to be interviewed privately or with a person of their choice. Two of the five women were interviewed with their significant other, and one participant was interviewed with a friend.

The phenomenologic approach has been outlined with the following six basic activities: (a) turning to a phenomenon of great interest, (b) focusing on the lived experience of the phenomenon, (c) reflecting on essential themes of the phenomenon, (d) describing the phenomenon through writing, (e) maintaining a strong pedagogical relationship to the phenomenon, and (f) considering the whole and the parts of the phenomenon (van Manen, 1990). Investigators individually analyzed the transcripts line by line and identified initial themes that captured the participants’ experience. To establish reliability, the interviewers shared the themes with an expert reviewer and a clinical nurse specialist who works closely with

recipients of HSCT. The two nurse researchers and expert reviewer refined and combined their collective synthesis, and data were analyzed and coded after the participant interviews. The two investigators and expert reviewer agreed on the individually identified themes captured by the shared experiences of the participants.

Findings

The following six themes were identified and portray women’s sexual health experience following HSCT: relationship changes, significant and concerning physical changes, a sense of loss and powerful emotional impact, fatigue, body image, and educational needs. The primary investigators and expert reviewer found saturation of these themes after conducting the five interviews.

Relationship Changes

Participants described changes in their relationships with present or past partners. The women shared how their relationships were transformed as a result of HSCT and subsequent sexual health changes. The interviews evoked emotions of concern, anxiety, anger, and sadness. One participant stated, “Seven years in, and we still had a great sex life; it’s just not how it used to be.” Another reported, “They think they know how you feel, but they don’t. So that, to me, is frustrating, and it’s a turnoff too.” Despite not being in a relationship at the time of the interview, one participant described her decision to end a relationship during the HSCT because “he could not emotionally deal with it.” Overall, all five participants experienced a sense of change. Four of five women shared that their ability to have pleasurable sex changed because of cumulative side effects following HSCT. Only one of five participants shared positive changes in her relationship with her husband, stating, “It made us stronger.”

In addition to the changes that occurred within relationships, participants described concerns that arose regarding their partners. One participant stated, “It makes me worry if he thinks about someone else instead of me because he’s not getting what he’s hoping for.” Another participant said, “I feel bad for him, and I feel bad for me because it’s hard.” Another woman shared, “I feel bad a little that things have changed so much.” Participants appeared concerned about their partner’s sexual satisfaction.

Significant and Concerning Physical Changes

The women interviewed articulated the significant physical changes they experienced, and those changes were devastating and profound. They used words

FIGURE 1. Structured Focus Group Questions

RESEARCH QUESTION

- Can you tell me about your experiences with your sexual health since your stem cell transplantation?

QUESTIONS FOR CLARIFICATION AND EXPANSION

- Can you tell me more about that?
- How does that make you feel?
- What did that mean to you?
- Is there anything I have not asked you that you would like to share?
- What kind of information related to sexual health would you want to know about?
- Who would you want this information from?
- How were your relationships affected?

such as *horrible*, *uncomfortable*, and *terrible* when describing the changes they endured. One woman described her physical symptoms this way: “When we do [have sex], it’s very painful, it’s dry, everything’s dry, it’s just horrible.” Another participant said, “Particularly after the transplant, it’s kind of uncomfortable. It didn’t really feel too good afterward; it hurts, and it’s uncomfortable.” One woman commented, “In the first couple months, I noticed I had really terrible vaginal dryness, and it was very, very uncomfortable.”

Apart from the physical symptoms of dyspareunia, vaginal dryness, and vaginismus, the participants reported altered menstrual bleeding or a complete loss of periods. One participant shared the difficulties related to amenorrhea. “It’s like slightly tender breasts, it’s like, oh, are we pregnant? But we don’t know my fertility status.” The physical changes described by all five women portray the biologic changes likely caused by reduced estrogen levels that can occur after ablative chemotherapy is used for conditioning prior to HSCT.

Sense of Loss and Powerful Emotional Impact

All five women described profound and at times painful loss. Loss was most consistently identified as the loss of some aspect of a relationship, the loss of sexual desire, or the loss of fertility. One woman stated, “It’s a loss of a part of a relationship.” Another participant shared, “It’s more of me wishing we had our old life, you know? Have it like it was before.” Another woman similarly stated, “I had a lot of interest [sexual drive]. It’s quite different now I would say. I have no interest because it just doesn’t feel the same.” Referring to fertility, one participant confessed, “It all stems back from me at least being 29 and . . . being able to have kids. It’s something I always wanted.” All five women articulated a profound sense of loss and emotional impact in the interviews.

Fatigue

The participants conveyed the burden of post-HSCT fatigue, which interfered with activities of daily living. The fatigue was portrayed as debilitating, altering, and disruptive of normal routines. One participant recounted, “I’m tired all the time.” Another said,

If I did have someone that I was having sex with, I don’t think I could a lot of times, unless I napped all day, because a lot of times, you’re just physically so exhausted, especially the first eight months post-transplant.

The fatigue was so profound that one participant said, “Right out of the hospital and past day 100, you get really tired. And sometimes I’ll try to walk up the stairs, and I’ll get to the top and think, ‘Oh my God,

I’m so tired.’” The interviews of the participants revealed that fatigue greatly affected their ability to engage in sex and their overall QOL.

Body Image

Women focused on body image in different degrees. Some women were forthright about their feelings on their bodies, confessing that they no longer felt attractive. One woman said she felt OK with her body image but still described the many physical changes she observed. Four of five women experienced changes in body image, which affected their sense of sexuality. One participant described her body image this way: “I just don’t feel attractive . . . I’m bald and, for me, underweight and kind of skinny and just not feeling like myself.” Weight was a common denominator, with participants expressing statements like “I’m trying to gain weight”; “I lost a lot of weight, so everything’s sagging and it’s not there”; “I lost a lot of weight, which, in some ways, was good for me because I always had excess weight that I needed to get rid of”; and “I get upset about it because my clothes don’t fit; I don’t look the same as I did.” Changes in body image affected how most participants viewed themselves as sexual beings.

Educational Needs

All participants described a great need for further education about sexual changes and sexual health pre- and post-HSCT. These women did not feel prepared for the sexual side effects they endured. One woman said,

I didn’t know . . . I mean, it says it in your paperwork when they give you the side effects of chemo and that sort of thing, and it says the fertility and sexual intercourse you can have still, but you have to use protection . . . but you don’t realize that it’s going to put you in full menopause.

Another woman stated, “Maybe we could talk about this and that type of thing [referring to sexual health] because they don’t educate you at all about that.” Overall, they felt unprepared for the changes they experienced and wished they had received more education on how their sexual health would be affected following HSCT.

When asked who should provide this education, four of the five women said they would prefer a same-sex practitioner. One woman shared, “From a woman’s standpoint . . . I think a female should explain that because then you’re more apt to ask more questions.” All five participants agreed that they would prefer to hear the information from a primary nurse or a nurse practitioner as opposed to an oncologist, regardless of gender. One woman said, “I would say either a nurse that you know well [or] someone that you know already or try to know. Maybe a nurse practitioner.”

Discussion

Study participants consistently shared the six identified themes that women experience regarding sexual health following HSCT. Although sexual health was not their first priority when recovering from HSCT, all five women agreed that sexuality played an important role in their identity and relationships, which they desperately hoped to regain. Three of the study participants discussed the impact of feared infertility, but this was considered a separate experience from sexuality.

Women who learned about sexual health through talking with their gynecologists, chatting online with female survivors, or through reading information on sexual health felt additionally supported. Two of the five women were obtaining support and guidance from their gynecologists. One participant was working with a fertility specialist in hopes of getting pregnant. Some women reported using vaginal creams or lubricants during sex to reduce dryness. One participant stated, "I thought it was me, but my [gynecologist] said, 'You're in full menopause right now, and this is what happens from the chemo, but we can stimulate that hormone.'" Seeking help made women feel supported, more knowledgeable about their sexual health changes, and less responsible for the changes they experienced. However, women wished they had more information on sexual health prior to and following HSCT.

Limitations

The participants all were recruited from one hospital setting, limiting generalizability. In addition, the researchers faced barriers to recruitment because of the study's strict criteria.

Implications for Nursing Practice and Research

The authors' findings suggest the need for further research and support and education for women following HSCT. Physician colleagues, nurse practitioners, and nurses can create a curriculum educating women on sexual health following HSCT. Nurses should schedule time dedicated to discussing sexual health during their patients' pre- and post-HSCT visits. This education could be provided by same-sex nurses or nurse practitioners. Although gynecologic examinations are unsafe immediately after HSCT because of neutropenia, nurses should encourage women to arrange time with their gynecologists to discuss the implications of chemotherapy on sexual health.

A barrier to open dialogue about sexual health following HSCT is the length of time of a scheduled

Knowledge Translation

- Relationship changes occur when a women's sexual health is impaired following hematopoietic stem cell transplantation.
- Patients experience feelings of loss and emotional distress related to impaired sexual health.
- Women desire increased sexual health education and prefer to receive sexual health education from same-sex providers.

outpatient clinic visit. This research demonstrated that some women preferred to start the conversation and education on sexual health prior to HSCT and suggested that this topic be further discussed during HSCT recovery. Insurance companies should also designate the standards for the time frame of outpatient clinician appointments and either pay for longer appointments, so all aspects of a patients' recovery can be discussed, or reimburse patients for education visits regarding sexual health education. Healthcare providers can lobby and advocate to have insurance companies recognize this demand and make a change.

Literature review revealed a gap between qualitative and quantitative studies on women's sexual health after HSCT, with lack of qualitative data. This gap could be related to the sensitive nature of the topic. Although quantitative literature clearly outlines the physiologic changes that occur following HSCT, it is unclear which specific changes create the loss of desire for sex. Further research is needed in this area and should include more participants to extend the findings and further validate these experiences. In addition, future qualitative studies should examine the sexual health of other women, including older women and women of other sexual orientations.

To best serve these women, nurses must be comfortable providing competent sexual health care to patients. Providing workshops to educate nurses and nurse practitioners on the sexual side effects women experience post-HSCT can help them feel more comfortable discussing sexual health.

One topic that is not discussed in the literature is the effect HSCT has on patients' relationships. Nurses should be aware of the relationship changes patients experience after HSCT that may warrant follow-up and potential intervention with counseling. In addition, the emotional impact and loss related to impaired sexual health after HSCT also has not been discussed in the literature, and the psychosocial assessment of patients and their partners must be recognized following HSCT.

Conclusion

The researchers discovered the need for increased sexual health education following HSCT and identified implications for education and more resources. Women in this study preferred same-sex nurses or nurse practitioners to provide education on sexual health. Education regarding sexual health during HSCT is inconsistent among nurses and providers.

This study described the physical and emotional side effects women experienced after HSCT. To improve patients' QOL following HSCT, healthcare providers within hematology-oncology and HSCT, gynecology, and primary care must provide care for women's sexual health. Men and women should be included in further qualitative studies to improve overall education and access to interventions for sexual health pre- and post-HSCT.

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